Healthcare Improvement Scotland | Evidence
Advice, guidance and intelligence

Pregnancy screening:

- Down's syndrome, Edwards' syndrome and Patau's syndrome
- Mid-pregnancy ultrasound

Standards

NHS SCOTLAND

We are committed to advancing equality, promoting diversity and championing human rights. These standards are intended to enhance improvements in health and social care for everyone, regardless of their age, disability, gender identity, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation, socioeconomic status or any other status. Suggested aspects to consider and recommended practice throughout these standards should be interpreted as being inclusive of everyone living in Scotland.

We carried out an equality impact assessment (EQIA) to help us consider if everyone accessing health and social care services will experience the intended benefits of these standards in a fair and equitable way. A copy of the EQIA is available on request.

Healthcare Improvement Scotland is committed to ensuring that our standards are up-to-date, fit for purpose and informed by high-quality evidence and best practice. We consistently assess the validity of our standards, working with partners across health and social care, the third sector and those with lived and living experience. We encourage you to contact the standards and indicators team at his.screeningstandards@nhs.scot to notify us of any updates that might require consideration.

Healthcare Improvement Scotland

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Introduction

Healthcare Improvement Scotland published the pregnancy screening: fetal anomaly standards in 2019. In Autumn 2023, these standards were prioritised by the National Screening Oversight Board for review in 2024/25. The standards review incorporates recent changes to the screening programme[1] and terminology. This includes the:

- expansion of first line screening for Down's syndrome to include screening for Edwards' syndrome and Patau's syndrome
- implementation of non-invasive prenatal testing (NIPT) as second line screening for pregnancies with a higher chance result from primary (known as first line) screening
- inclusion of twin pregnancies for specific screening tests.

During pregnancy, women are offered a range of screening tests, ultrasound scans and health checks.[2-4] The term women is used in this document and includes any person who is pregnant including transgender and non-binary people.

The aim of pregnancy screening is to enable:

- early identification of screened conditions and to offer care options
- informed decisions about pregnancy
- pregnant women, and where appropriate their care partners, to plan care and support if this is required.

The national pregnancy and newborn screening programme covers a range of screening tests for specific conditions.[4] These standards relate to pregnancy screening for:

- Down's syndrome, Edwards' syndrome and Patau's syndrome
- the eleven conditions screened for during the mid-pregnancy screening scan (also known as fetal anomaly scan) including spina bifida and cardiac conditions.

The screening tests covered in these standards are for singleton and twin pregnancies. Multiple pregnancies greater than twins are not part of the national screening programme move. However, staff should discuss the options available for screening, in line with clinical guidance for triplet and higher pregnancies.[5, 6]

Table 1 below provides an overview of the type of test and eligibility criteria.

Table 1: National pregnancy screening tests covered by these standards

What conditions does the screen look for*	Type of test	Eligibility – who is offered the screening test and when
Combined - First line screening (also known as first trimester combined screening test or primary screening test)		
• Down's syndrome • Edwards' syndrome • Patau's syndrome	Maternal blood test and ultrasound scan to measure nuchal translucency (NT)	Pregnant women with singleton and twin pregnancies between 11^{+2} weeks to 14^{+1} weeks of pregnancy
Quadruple - First line screening (also known as second trimester quadruple screening or primary screening test)		
• Down's syndrome	Maternal blood test	Pregnant women with singleton and twin pregnancies between 14^{+2} week to 20^{+0} weeks of pregnancy.
Second line screening (also known as non-invasive prenatal testing (NIPT) or secondary screening test)		
• Down's syndrome • Edwards' syndrome • Patau's syndrome	Maternal blood test	Pregnant women with singleton and twin pregnancies with a higher chance result from the primary screen up to 21^{+6} weeks of pregnancy.
Mid-pregnancy screening ultrasound scan (also known as fetal anomaly scan)		
• Anencephaly • Open spina bifida • Cleft lip • Diaphragmatic hernia • Gastroschisis • Exomphalos • Serious cardiac anomalies • Bilateral renal agenesis • Lethal skeletal dysplasia • Edwards' syndrome • Patau's syndrome	Ultrasound scan	• Pregnant women with singleton and twin pregnancies between 18^{+0} weeks to 20^{+6} weeks of pregnancy. • A further ultrasound examination (up to 23^{+0} weeks of pregnancy) may be performed, if required to complete screen.

*In line with the national screening programme[4]

To note, changes to any national screening programme may be made after the publication of the standards. NHS boards and staff involved in screening should ensure they are following the correct eligibility criteria.

Information and resources

To support women to make informed decisions about screening tests and their care options, information should be provided in a format and language that suits their needs. Support should be provided, with opportunities for questions, to enable informed decisions. Where appropriate, information and support should be provided to the women's care partner. Care and communication should be compassionate, understanding and non-judgemental. Women should always be respected and supported in their choices and decisions.[6]

The following resources and organisations are available to support women, their care partners and staff:

- You're pregnant! Scans and tests
- Ready steady baby
- NHS Inform: Pregnancy screening
- Antenatal results and choices
- Down's Syndrome Scotland
- SOFT UK.

Scottish pregnancy and newborn screening programme: governance

The Scottish pregnancy and newborn screening programme board is:

- accountable for the pregnancy screening pathway, screening assessment, diagnosis and referral
- responsible for monitoring the effectiveness of the programme, including the offer of gestationally appropriate screening options and performance against key performance indicators (KPIs).[4, 7, 8, 9]

The national pregnancy screening programme collects data on the performance of the programme, including coverage and outcomes.[8, 9] The KPIs are available from the pregnancy and newborn screening programme board. NHS boards should ensure regular reporting through appropriate national databases and forums.

NHS boards deliver pregnancy screening services for women within their locality including:

- managing the care of women
- coordinating and booking screening appointments
- undertaking maternal blood tests and ultrasound scans
- informing women of the results from the screening tests
- provision of diagnostic testing

- provision of specialist referral or counselling including support.

Local NHS board laboratories and the nationally commissioned laboratory undertake all screening test analysis.[7]

These standards apply to NHSScotland services and staff delivering the relevant pregnancy screening services.

Related guidance and policy

All Healthcare Improvement Scotland standards are mapped to key national legislation, policy and standards.[10-12] They are also aligned to the principles of person-centred and trauma informed care, human rights and equality.[13-15]

These standards should also be read alongside the following:

- Healthcare Improvement Scotland: Congenital heart disease standards
- Healthcare Improvement Scotland: Core screening standards
- Healthcare Improvement Scotland: Pregnancy and newborn screening standards
- National Services Scotland: A guide to national population screening in Scotland
- NICE Antenatal Care guideline
- Public Health Scotland: Pregnancy screening for Down's syndrome, Edwards' syndrome and Patau's syndrome in Scotland
- Scottish Equity in Screening Strategy 2023-26.

Scope of the standards

These standards apply to all women who are eligible to take part in the national pregnancy screening programme.

These standards ensure a consistent and equitable approach to the provision and monitoring of the screening tests for Down's syndrome, Edwards' syndrome and Patau's syndrome, and the mid-pregnancy screening ultrasound in Scotland.[7]

The standards cover:

- pregnancy screening: information provision and informed consent
- first line screening in pregnancy
- second line screening: non-invasive prenatal testing (NIPT)
- mid-pregnancy ultrasound scan
- prenatal diagnostic testing and reporting
- specialist support and care planning
- laboratory processes.

Format of the standards

Healthcare Improvement Scotland standards follow the same format. Each standard includes:

- an overarching standard statement
- a rationale explaining why the standard is important
- a list of criteria describing what is needed to meet the standard
- what the standard means if you are a woman taking part in pregnancy screening
- what the standard means if you are a member of staff
- what the standard means for NHS boards
- examples of what meeting the standard looks like in practice.

Implementation

These standards have been developed by key stakeholders from across the pregnancy screening pathway. The standards support and inform organisational self-evaluation and improvement.

Implementation of these standards by the Scottish pregnancy and newborn screening programme and NHS boards will ensure the delivery of safe, effective and person-centred services across the pregnancy screening pathway.

These standards are a key component in supporting the Scottish pregnancy and newborn screening programme's approach to quality assurance. Monitoring performance against these standards, at a local and national level, aims to improve the quality of the programme.

External quality assurance (EQA) of screening programmes will be delivered using the Healthcare Improvement Scotland quality of care approach and the quality framework. This approach specifies how Healthcare Improvement Scotland will design and deliver EQA activity to support improvement in healthcare.

The approach emphasises the importance of regular, open and honest self-evaluation of programmes using the quality framework as a basis, combined with other relevant data and intelligence, including performance against these standards.

Terminology

Wherever possible, we have used generic terminology which can be applied across all health and social care settings. All terminology is included in the glossary.

Summary of standards

Standard 1: Pregnancy screening: information provision and informed consent

All eligible women are supported to make informed choices about pregnancy screening for fetal chromosomal and health conditions.

Standard 2: First line screening in pregnancy

NHS boards ensure first line screening is safe, effective and person-centred, with timely reporting of results.

Standard 3: Second line screening: non-invasive prenatal testing

NHS boards ensure non-invasive prenatal testing is safe, effective and person-centred, with timely reporting of results.

Standard 4: Mid-pregnancy ultrasound scan

NHS boards ensure the mid-pregnancy ultrasound scan is safe, effective and person-centred, with timely reporting of results.

Standard 5: Prenatal diagnostic testing and reporting

NHS boards ensure prenatal diagnostic testing is safe, effective and person-centred, with timely reporting of results.

Standard 6: Specialist support and care planning

NHS boards provide multidisciplinary specialist support and care planning as part of the pregnancy screening pathway.

Standard 7: Laboratory processes

Laboratory services and processes for pregnancy screening are carried out in line with nationally recognised standards.

Standard 1: Pregnancy screening: information provision and informed consent

Standard statement

All eligible women are supported to make informed choices about pregnancy screening for fetal chromosomal and health conditions.

Rationale

As part of the pregnancy screening programme, NHS boards offer all eligible women gestationally appropriate screening[4] for:

- first line screening for Down's syndrome, Edwards' syndrome and Patau's syndrome
- the eleven conditions screened as part of the mid-pregnancy screening ultrasound scan.

Throughout pregnancy screening it is important that women (and their care partners, where appropriate) are provided with sufficient information and time to understand and discuss their needs and ongoing care. Women should be informed about the time limitations for each screening test and given opportunities to discuss their options. The principles of informed consent and shared decision making are central to supporting women who take part in screening. Consent for screening should be obtained in line with national guidance and local protocols.[16]

The first antenatal appointment should identify the woman's preferred communication method for receiving information, support and results.[6, 17] Information should be provided at the first antenatal appointment and throughout the screening pathway. Information should be tailored to the person's needs, preferences and circumstances. This may include information in alternative formats, languages and easy read guides. Communication tools and services should be made available, including face to face, interpreters and virtual options, as appropriate. It is good practice to review a woman's understanding of screening and her communication needs throughout the pathway, as this may change.[3]

NHS boards should ensure that staff are supported and appropriately trained in communicating the benefits and implications of screening, eligibility for screening, potential results and care options available. Training should support staff to share results of screening using a person-centred and trauma informed approach.[18-21] Women should be respected and supported in their decisions. Referral to counselling and specialist support organisations should be made as appropriate.

Criteria

1.1 To support informed decision making, women are provided with evidence-informed, accessible and timely information, which covers:

- the conditions being screened for
- the aim, benefits and limitations of screening including possible incidental findings
- consent, that all screening tests are optional, and they can withdraw at any point in the pathway
- how to opt into screening if the woman initially declines
- the timeframes and time limitations of screening
- options for women who are not eligible for pregnancy screening
- when results will be received and what they mean
- what happens if a repeat blood test or diagnostic testing is required.

1.2 NHS boards offer screening appointments to all eligible women at the appropriate stage of pregnancy in line with national guidance.

1.3 Where an early pregnancy scan shows the woman is at a later stage of pregnancy and first trimester screening is not possible, the healthcare professional will provide information on which tests are available.

1.4 NHS boards ensure systems and processes are in place for the recording and sharing of information including:

- the woman's decision to accept or decline the offer of chromosomal or health conditions screening
- the woman's preference for communication, including receiving results
- timely reporting and sharing of results with the woman and relevant healthcare professionals.

1.5 Staff, relevant to their role and workplace setting:

- are trained and knowledgeable in the screening tests offered and eligibility criteria
- provide women with evidence-informed, accessible and timely information
- support women to understand what the screening results mean and their options
- signpost women (and where appropriate their care partners) to counselling and support including specialist support organisations.

What does the standard mean for women taking part in pregnancy screening?

- You will be offered screening tests to help find out if your baby may have a health or chromosomal condition.
- Some tests can only be done at certain times during pregnancy. Your midwife will explain what tests are available and when they can be carried out.
- Staff will provide information about the tests including how they are carried out and what the results can mean.
- You can decide at any time that you do not want to be tested or if you only want some of the tests.
- If you change your mind and decide you do want to be tested, you will be informed about what tests are available.
- You will be given the time you need to discuss what screening means to you. You will be able to discuss your decision with the people who matter to you.
- Whatever decision you make, you can agree a pregnancy plan with your midwife that feels right for you.

What does the standard mean for staff?

Staff, in line with their roles, responsibilities and workplace setting:

- support women (and their care partners, where appropriate) in informed decision making through providing compassionate, person-centred and trauma informed care
- signpost women (and their care partners, where appropriate) to information, specialist support organisations and other healthcare teams, where required
- are appropriately trained and knowledgeable in pregnancy screening including benefits and limitations, consent and eligibility criteria
- undertake regular training and continued professional development including mentoring and supervision.

What does the standard mean for the NHS board?
NHS boards: • have systems and processes to offer and provide timely, person-centred and trauma informed screening in line with national guidance and protocols • have arrangements for the consent process and supporting informed choice for pregnancy screening • ensure the availability of appropriate, easily accessible and timely information and support • have clear pathways of communication between the woman and multidisciplinary teams • ensure staff have time, resources and training to support and care for women (and their care partners, where appropriate).
Examples of what meeting this standard might look like
• Evidence of the woman's involvement in decision making. • Evidence of information provided in alternative formats and languages. • Evidence of support for people with additional communication needs, for example people with sensory impairments. • Signposting of women (and their care partners where appropriate) in accessing information and support services including specialist support organisations. • Documented evidence of staff training including personal development plans, mentoring and peer support. • Evidence of training related to screening including communication.[20, 22] • Local protocols for provision of pregnancy screening in line with national guidance.

Standard 2: First line screening in pregnancy

Standard statement

NHS boards ensure first line screening is safe, effective and person-centred, with timely reporting of results.

Rationale

First line screening for Down's syndrome, Edwards' syndrome or Patau's syndrome is offered to eligible women, in line with national guidance.[4, 7, 23] Depending on gestational eligibility criteria (see table 1), the tests offered are:

- combined screening (maternal blood test and measurement of the baby's nuchal translucency (NT), usually performed on the same day)
- quadruple testing.

Where there is a higher chance result from either the combined or quadruple testing, women are offered non-invasive prenatal testing (NIPT) or diagnostic testing. As with all screening tests, women may decline further testing and should be supported in their choice.

Equipment and peripherals used for first line screening including ultrasound should comply with agreed standards (see further criteria in standard 4).[24] To process a blood sample effectively, staff should ensure the laboratory request form is complete, accurate and legible. Laboratory processes are covered in standard 7.

NHS boards should ensure systems and processes are in place for the monitoring of first line screening and reporting of results. This includes, for example, screening outcomes review or failsafe protocols. Rapid and reliable reporting minimises anxiety and allows follow up testing to be performed at the earliest opportunity, where appropriate.

Criteria

2.1 NHS boards offer high-quality, safe and timely first line screening to eligible women in line with national timeframes and protocols.

2.2 NHS boards have systems and processes in place for first line screening, which includes:

- timeframes and methods for the communication of results
- opportunities for women to discuss their results
- referral to second line screening, diagnostic testing, specialist support and care planning
- monitoring and review of screening outcomes for example, failsafe protocols.

2.3 Staff delivering first line screening undertake training, which covers:

- eligibility criteria in line with national guidance and protocols
- information about the tests available and the conditions screened for
- interpretation of results
- person-centred communication of the results
- the options for further testing and referral.

2.4 The maternal blood sample taken for the combined or quadruple test is:

- undertaken by appropriately trained and experienced staff
- accompanied by a complete and accurate laboratory request form in line with agreed protocols
- carried out in an appropriate clinical environment and using equipment that complies with national guidance and protocols.

2.5 Where a result has not been achieved from the sample, local protocols are in place which covers:

- timely communication from the laboratory to the appropriate team
- communication with the woman, in the format requested, to discuss next steps
- the offer and timely provision of a repeat test, where appropriate.

2.6 Staff undertaking a NT ultrasound scan:

- have relevant qualifications and continued professional development in line with national pregnancy screening protocols
- are trained in person-centred and trauma informed communication[25]
- can explain the purpose of the test and factors which may affect the scan
- check for understanding of the purpose of the scan, consent and document accordingly.

2.7 Where NT measurement has not been obtained, women are offered a further opportunity to undertake an appropriate test in line with national protocols.

2.8 Women with a higher chance result from first line screening are:

- informed of the result in line with national timeframes
- provided with an opportunity to discuss the result with appropriately trained staff
- provided with support and information in a language and format that is appropriate for their needs.

2.9 Women with a higher chance result from first line screening are:

- supported to make an informed decision about participating in further testing including declining
- offered non-invasive prenatal testing or diagnostic testing.

2.10 All results from first line screening are recorded electronically as part of national and local data collection and review.

2.11 Women with a lower chance result will be provided with the outcome of the screening before, or at, their next appointment.

What does the standard mean for women taking part in pregnancy screening?
• You will be offered a screening test for Down's syndrome, Edwards' syndrome or Patau's syndrome to help you make decisions about the care for you and your baby. • You will be able to discuss why the test has been offered and what the results may mean. • You will be supported to make decisions and be able to ask questions. • You may choose to have a NT (nuchal translucency) measurement and blood test or not, and your decision will not affect any part of your care. • You will be contacted as soon as possible if the test shows you have a higher chance result. • You will be given information and support that is right for you. • Information about available specialist support organisations and further referral will be provided.
What does the standard mean for staff?
Staff, in line with their roles, responsibilities and workplace setting: • understand and follow local and national protocols for first line screening including further testing or referral • demonstrate knowledge and skills required to undertake screening in line with national protocols • can provide and signpost to accurate information and support that is compassionate, respectful and non-judgemental to the choices of women.
What does the standard mean for NHS boards?
NHS boards: • have systems and processes in place to provide first line screening including the timely communication of results in line with national guidance • meet standards and requirements for safe and effective first line screening procedures • have failsafe mechanisms in place to ensure that the results of first line screening are received in a timely manner by all participating women.

Examples of what meeting this standard might look like
• Evidence of staff training in person-centred communication of results and incidental findings, where appropriate.[25] • Audit of NT outcomes including incidental findings. • Audit demonstrating adherence to national guidelines, standards and protocols. • Regular data collection and audit of chromosomal screening procedures. • Demonstration of learning at national, local and regional levels of screening incidents and adverse events. • National protocols for the selection of appropriate tests depending on the screening results.

Standard 3: Second line screening: non-invasive prenatal testing

Standard statement

NHS boards ensure non-invasive prenatal testing is safe, effective and person-centred, with timely reporting of results.

Rationale

Non-invasive prenatal testing (NIPT) is a maternal blood test which is offered to women who received a higher chance result from earlier screening for Down's syndrome, Edwards' syndrome or Patau's syndrome.[23]

Staff should be trained and knowledgeable in providing NIPT, eligibility criteria, results and options available.[22]

Women should be provided with information at the time of screening on the possible NIPT results along with eligibility for further or repeat testing.[26]

NHS boards should ensure systems and processes are in place for the monitoring of NIPT and the reporting of results.

Laboratory processes are covered in standard 7.

Criteria

3.1 NHS boards ensure eligible women are offered NIPT in line with nationally agreed timeframes and protocols.

3.2 Women who opt for NIPT:

- are informed of the purpose of the test including the benefits and limitations
- provide consent for the test, which is recorded and shared appropriately
- are given information on possible results, outcomes and further options
- are informed of when to expect the result
- are provided with time to consider their decision within the gestational time frame for the test.

3.3 Staff are appropriately trained and knowledgeable[22] in:

- the benefits and limitations of NIPT
- when NIPT should be offered
- providing accurate information about NIPT, results and options for further testing
- how to accurately complete a laboratory request form to ensure all essential information is included.

3.4 NHS boards have systems and processes in place to monitor and review the screening test, which covers:

- NIPT sample taking including request for referral
- transportation of samples to the national laboratory
- the reporting of high chance results and outcomes to the local clinical lead
- accurate completion of laboratory forms
- adverse events and incidents.

3.5 Women who receive an NIPT high chance result are:

- given time and opportunities to make decisions about their options
- provided with information about the gestational timeframes for any further testing
- supported to make informed decisions about diagnostic testing or no further testing
- provided with information about specialist support organisations.

3.6 Where no result has been obtained from NIPT, women are offered further testing in line with national protocols.

What does the standard mean for women taking part in pregnancy screening?

- You will be offered a blood test (known as NIPT) where earlier screening indicates a higher chance of your baby having Down's syndrome, Edwards' syndrome or Patau's syndrome.
- Staff will give you information about NIPT, what the results may mean and what happens following the results. You will be able to ask questions.
- You will be given the choice to have the blood test or not, and staff will support you in your decision.
- If you get a high chance result NIPT, you will be given information and support about diagnostic testing that is right for you.
- You will be offered details of specialist support organisations.

What does the standard mean for staff?

Staff, in line with their roles, responsibilities and workplace setting:

- understand and follow local and national protocols for NIPT
- understand the possible NIPT results and respective care pathways including further testing or referral
- demonstrate knowledge and skills required for NIPT screening[22]
- ensure accurate completion of laboratory request forms
- can provide support that is compassionate, respectful and non-judgemental
- can signpost women to information and specialist support organisations.

What does the standard mean for NHS boards?

NHS boards:

- have processes and care pathways in place to ensure timely referral and management of women following a high chance result, including access to diagnostic testing or specialist support and care planning
- demonstrate systems and processes are in place for monitoring the quality of NIPT and identify issues or adverse events in a timely manner
- have failsafe mechanisms in place to ensure that the results of NIPT are received in a timely manner by all participating women.

Examples of what meeting this standard might look like
• Completion of staff training on NIPT.[22] • Audit of laboratory forms to monitor completion of relevant information. • Evidence of information offered to women and signposting to specialist support organisations. • Regular data collection and audit of NIPT outcomes and referral for diagnostic testing.

Standard 4: Mid-pregnancy ultrasound scan

Standard statement

NHS boards ensure the mid-pregnancy ultrasound scan is safe, effective and person-centred, with timely reporting of results.

Rationale

A mid-pregnancy ultrasound scan (also known as a fetal anomaly scan) is offered to eligible women between 18^{+0} and 20^{+6} weeks of pregnancy. The scan checks the baby's overall structural health and development and screens for eleven specific conditions.[2, 4] Women should be informed of the benefits and limitations of the scan.

NHS boards should provide safe and timely ultrasound services undertaken by appropriately trained staff. Ultrasound services should be provided in suitable facilities and using equipment that complies with national standards and guidance.[24, 27] Staff undertaking mid-pregnancy ultrasound should be trained in line with national protocols and guidance. This includes being skilled and experienced in using person-centred and trauma informed language to communicate the purpose of the scan and results.[22, 25]

When a condition is detected or suspected during the scan, a second opinion is sought from another healthcare professional, where appropriate. The findings should be documented and shared appropriately with relevant staff. Information from the scan supports care planning of pregnancy and timely onward referral, where required.

Women should be offered a further ultrasound examination (up to 23 weeks of pregnancy) to complete the screening examination if the image quality of the first examination is compromised. The quality of the first scan may be impacted by factors including increased maternal body mass index, uterine fibroids or position of the baby. Where another scan is required, this should be carried out on the same day where possible.

Where a repeat scan is incomplete, the women should be informed of the outcome. The outcome of the scan should be documented.

Criteria

4.1 NHS boards ensure all eligible women are offered a mid-pregnancy ultrasound scan that is person-centred and trauma informed.

4.2 Women who opt for a mid-pregnancy ultrasound scan:

- are informed of the purpose of the scan
- are informed about the benefits and limitations of the scan including factors that may impact the completion of the scan
- provide consent for the scan, which is recorded and shared appropriately
- are informed of the result on the same day, where possible
- are provided with an opportunity to discuss the result with appropriately trained staff.

4.3 Performance of the mid-pregnancy ultrasound scan complies with national guidance and protocols, including:

- assessment of the main fetal structures
- identification and image capture of pre-defined fetal anatomical sections
- measurement to assess fetal growth.

4.4 Staff undertaking a mid-pregnancy ultrasound scan:

- have relevant qualifications and continued professional development in line with national pregnancy screening protocols[24]
- are trained in person-centred and trauma informed communication[25]
- participate in relevant local or national professional forums to share learning.

4.5 Where the scan indicates a possible health or chromosomal condition, staff, where appropriate:

- seek a second opinion from another appropriately trained staff member
- document the results and share with relevant staff.

4.6 Where the mid-pregnancy ultrasound scan is incomplete or inconclusive, staff:

- offer a repeat ultrasound on the same day or at a later date before 23 weeks of pregnancy
- ensure relevant details and data are recorded.

4.7 Where a repeat scan is incomplete, staff should inform the woman and document the outcome.

4.8 Where the mid-pregnancy ultrasound scan either detects a condition, or there is a suspected condition, women are:

- referred to a relevant specialist team for diagnostic testing in line with national protocols, where eligible
- provided with time and opportunity to make decisions about the next stage in the management of the condition
- provided with information to access specialist support organisations.

4.9 Ultrasound services provide a safe and trauma informed environment and maintain privacy during consultation.

4.10 NHS boards ensure that equipment and peripherals used for the mid-pregnancy ultrasound screening comply with national or regulatory equipment specification and infection prevention control.

4.11 NHS boards have processes in place to support quality assurance and improvement of ultrasound screening services, which includes:

- local protocols for the storage, access and archiving of images and correspondence on an electronic system
- peer review of ultrasound scans
- regular monitoring of data and images for trends
- adverse events and incidents monitoring and review.

4.12 Data on ultrasound outcomes are recorded, reviewed and monitored in line with national guidance.

What does the standard mean for women taking part in pregnancy screening?

- You will be offered a mid-pregnancy ultrasound scan between 18 and 21 weeks. It is sometimes called a fetal anomaly scan.
- Staff will give you information about the scan including what to expect. You will be able to ask questions.
- You will be told the results of your scan at your appointment. If needed, you may be offered a follow up scan or a prenatal diagnostic test.
- If the sonographer has not been able to see your baby clearly, you may be asked to come back for a repeat scan.

What does the standard mean for staff?
Staff, in line with their roles, responsibilities and workplace setting: • demonstrate the knowledge and skills required to deliver safe, effective and person-centred mid-pregnancy ultrasound scans • are aware of the importance of timely reporting of results • can communicate in a person-centred way the purpose of the scan, findings and outcomes • can provide person-centred information and support to women • respect the choices made by women.
What does the standard mean for NHS boards?
NHS boards: • have processes and protocols in place to ensure mid-pregnancy scans are performed in line with national guidance and protocols • ensure that mid-pregnancy scans are undertaken by appropriately trained and knowledgeable staff • have planned preventative maintenance, quality assurance and a rolling replacement schedule in place for all ultrasound equipment and peripherals • monitor, report and review data on performance of the mid-pregnancy screening scan • have systems and processes in place for the appropriate communication of the ultrasound screening results to other staff.
Examples of what meeting this standard might look like
• Audit of outcomes and quality assurance of mid-pregnancy scans in line with national protocols. • Evidence of training and continued professional development for staff undertaking mid-pregnancy scans. • Demonstrate use of electronic reporting systems for the storage images and mid-pregnancy scan reports, in line with national guidance. • Evidence of appropriate information sharing between healthcare teams.

Standard 5: Prenatal diagnostic testing and reporting

Standard statement

NHS boards ensure prenatal diagnostic testing is safe, effective and person-centred, with timely reporting of results.

Rationale

NHS boards have responsibility for the provision of prenatal diagnostic testing. All diagnostic testing should be offered in line with national pregnancy screening eligibility and timeframes.[4, 7]

The tests offered include chorionic villus sampling (CVS) (from 11 weeks of pregnancy) and amniocentesis (after 15 weeks of pregnancy). Information on diagnostic testing should include the purpose of the test and any implications for the women and the pregnancy, including the chance of miscarriage. Information should be person-centred and available in a range of formats and languages. Results of diagnostic testing should be shared with the women in line with national timeframes.

NHS boards should ensure women receive timely referral and access to specialist support and care planning.

Staff should be appropriately trained in all aspects and outcomes of diagnostic testing.[28]

NHS boards should monitor and review outcomes following prenatal diagnostic testing and communicate these appropriately with relevant staff or teams.

Criteria

5.1 NHS boards ensure timely appointments for diagnostic testing are arranged and carried out at a local maternity unit or other appropriate services.

5.2 NHS boards have systems and processes in place for diagnostic testing, which includes:

- timescales and methods for communication of results
- opportunities for women to discuss their results
- specialist support and care planning
- monitoring and review of testing results and outcomes.

5.3 Women referred for prenatal diagnostic testing:

- provide consent for the diagnostic testing, which is recorded and shared appropriately
- are referred to a specialist team for further discussion, assessment, counselling and support, where appropriate
- are given time and support to consider their decision
- are provided with information about specialist support organisations.

5.4 Results of diagnostic testing are reported to women using an agreed method of communication and in line with agreed national timeframes.

5.5 Data on diagnostic testing outcomes are recorded, reviewed and monitored in line with national guidance.

5.6 Staff are appropriately trained and knowledgeable in diagnostic testing and reporting.

What does the standard mean for women taking part in pregnancy screening?
• You will be offered a prenatal diagnostic test if your baby has a higher chance of having a chromosomal or health condition. • You will be supported to make decisions and you will be able to ask questions. • You will be given information and support that is right for you. This includes information about available specialist support organisations. • You may be referred to a specialist team who may offer further tests and will give information and advice. • It is your choice to have the test or not. You will be supported by staff in your decision.

What does the standard mean for staff?
Staff, in line with their roles, responsibilities and workplace setting: • understand the diagnostic pathway including outcomes and specialist referral • are trained and knowledgeable in prenatal diagnostic testing in line with national guidance and protocols • can communicate results in a compassionate and person-centred way • provide person-centred information and support to women, and respect their choices • understand the importance of timely reporting of results following prenatal diagnostic testing.
What does the standard mean for NHS boards?
NHS boards: • have systems and processes to support safe, effective and high-quality diagnostic pathways including specialist referral • ensure staff are appropriately trained and supported to take part in local and national learning forums • collect, monitor and review outcomes of prenatal diagnostic testing • have processes and care pathways in place to ensure timely reporting of results and referral for specialist assessment, if appropriate.
Examples of what meeting this standard might look like
• Audit of outcomes from prenatal diagnostic testing. • Evidence of timely referral to specialist appointments within agreed timeframes. • Evidence of signposting to specialist support organisations and further resources. • Evidence of completion of diagnostic pathways within agreed reporting timeframes.

Standard 6: Specialist support and care planning

Standard statement

NHS boards provide multidisciplinary specialist support and care planning as part of the pregnancy screening pathway.

Rationale

Referral for specialist support and care planning is offered when pregnancy screening confirms the baby has a chromosomal or health condition. Women are informed about their baby's prognosis and options available to enable informed decision making, effective planning and any further referral that may be required.

NHS boards should have referral pathways which includes access to specialist fetal medicine, specialist support organisations, counselling and bereavement services. Multidisciplinary and multiagency care planning should be available for women (and their care partners, where appropriate).

Staff involved across the pregnancy screening pathway are appropriately trained and knowledgeable to provide women (and their care partners, where appropriate) with person-centred and trauma informed support. This should include all treatment and care options including if they chose to continue or end the pregnancy.[18, 20, 29] Communication should be at a time and pace that is right for the woman and always compassionate, respectful and non-judgemental.

Criteria

6.1 NHS boards have processes and protocols in place for timely referral to specialist support and care following identification that the baby may have one of the conditions screened for, in line with national guidance and protocols.

6.2 NHS boards have a designated multidisciplinary team with relevant training and expertise, including neonatology, fetal medicine and palliative care.

6.3 Women, and where appropriate their care partners, are signposted to specialist support organisations including peer support groups.

6.4 NHS boards provide person-centred and trauma informed support to women (and their care partners, where appropriate). Support should be responsive to the woman's needs and include, where appropriate:

- the options for care and management of the condition during pregnancy
- onward referral for counselling
- planning for birth and ongoing care
- assessment for referral to appropriate services including perinatal mental health, clinical or practitioner in psychology or wellbeing support
- referral for genetic counselling.

6.5 Women are supported by empathic staff to make informed decisions about continuing or ending a pregnancy and referral to appropriate support services including counselling.

6.6 NHS boards provide person-centred bereavement care for women (and their care partners, where appropriate) in line with national guidance and standards.[20, 29]

6.7 Staff provide support and information in a range of formats and languages on anticipatory grief, grief and bereavement support.

What does the standard mean for women taking part in pregnancy screening?
• You will be able to access specialist staff and services to support you. • You will be supported by compassionate, respectful and non-judgemental staff and given the time to make your decision. • You (and your care partner, where appropriate) will receive the support that you need, including emotional wellbeing support. • Staff will signpost you to specialist support organisations.

What does the standard mean for staff?
Staff, in line with their roles, responsibilities and workplace setting: • are appropriately trained and knowledgeable in care pathways following a diagnosis of a health or chromosomal condition • provide empathic and compassionate support for the woman in her decision making • undertake training and continued professional development in the provision of person-centred and trauma informed care and communication • signpost women (and their care partners, where appropriate) to information, specialist support organisations and other healthcare teams, where required.
What does the standard mean for NHS boards?
NHS boards: • have systems and processes to offer and provide timely, person-centred and trauma informed specialist support and care planning, in line with national guidance and protocols • ensure access to the appropriately trained multidisciplinary teams and local care pathways for specialist referral and support are clear and accessible.
Examples of what meeting this standard might look like
• Local referral pathways to specialist multidisciplinary teams and services including fetal medicine. • Signposting and referral to specialist support organisations. • Standardised referral documentation with evidence of appropriate referrals. • Demonstration of a person-centred and trauma informed approach to services delivery and design.[19] • Provision of specialist evidence based training including bereavement care.[20, 29]

Standard 7: Laboratory processes

Standard statement

Laboratory services and processes for pregnancy screening are carried out in line with nationally recognised standards.

Rationale

The laboratory processes and analyses maternal blood samples collected from first and second line screening.

Robust clinical governance ensures that pregnancy screening tests are processed within an environment that can deliver high reliability and accuracy. Laboratories must comply with national and local guidance and be accredited with the relevant national accreditation body to perform tests.[30]

NHS boards should ensure laboratory staff have access to ongoing training, supervision and assessment to ensure all staff maintain professional accreditation, in line with national guidance.[30]

Criteria

7.1 Laboratories involved in processing and analysing samples for the pregnancy screening programme maintain relevant national accreditations.

7.2 Laboratories have a designated clinical lead and service manager with responsibility for pregnancy screening laboratory processes.

7.3 Screening samples are processed using equipment and techniques which meet national protocols and guidelines.

7.4 All laboratory staff are trained to the required standards of competence and undertake regular training, continued professional development, supervision and assessment appropriate to their roles and responsibilities.

7.5 Laboratory request form completion is monitored in line with agreed protocols.

7.6 Results from first or second line screening are issued by the laboratory in line with national timeframes.

7.7 Where no result has been obtained for NIPT, the laboratory will inform staff to offer a repeat blood test.

7.8 Laboratories involved in processing samples from pregnancy screening pathways demonstrate:

- participation in the relevant quality assurance and regulatory frameworks
- adherence to national standards and procedures for results reporting and monitoring quality, including adverse events management
- reporting against screening KPIs and result turnaround times
- learning from the detection, review and reporting of any issues relating to laboratory processes.

7.9 Laboratory services work collaboratively with national screening governance groups, local maternity units and other relevant clinical departments to participate in learning at multidisciplinary meetings and forums.

What does the standard mean for women taking part in pregnancy screening?
• You can be confident that your screening test sample will be analysed by appropriately trained staff. • The laboratory will process your results in line with national timeframes.
What does the standard mean for staff?
Staff, in line with their roles, responsibilities and workplace setting: • understand and work within the relevant national standards, protocols and guidance • work collaboratively as part of the wider multidisciplinary team • are supported to attended regular training, continued professional development and education.
What does the standard mean for NHS boards?
NHS boards: • ensure standards and requirements for safe and effective laboratory services are in place • ensure laboratories maintain the relevant accreditation • provide data monitoring in line with national and relevant audit returns • review internal and external monitoring and quality reports to ensure quality and identify issues in a timely manner.
Examples of what meeting this standard might look like
• Evidence of timely laboratory processes. • Evidence of relevant laboratory accreditation. • Evidence of laboratory staff qualifications and continued professional development. • Evidence of regular data collection, audit and review of laboratory processes to monitor and implement service improvement. • Protocols for laboratory staff to request confirmation of relevant information required for screen in cases where the information is missing or illegible. • Demonstrate lessons learned from any incidents or adverse events. • Regular reporting to screening programme board on quality measures to monitor laboratory processes.

Appendix 1: Development of the standards

Healthcare Improvement Scotland has established a robust process for developing standards which is informed by international standards development methodology.[31] This ensures they:

- are fit for purpose and informed by current evidence and practice
- set out clearly what people accessing services can expect
- are an effective quality assurance tool.

The standards have been informed by current evidence, best practice recommendations and developed by expert group consensus.

Evidence base

A review of the literature was carried out using an explicit search strategy devised by an information scientist in Healthcare Improvement Scotland. Additional searching was done through citation chaining and identified websites, grey literature and stakeholder knowledge. Searches included Scottish Government, Public Health Scotland, NICE, SIGN, NHS Evidence and Department of Health websites. This evidence was also informed by an equalities impact assessment.

Standards are mapped to a number of information sources to support statements and criteria. This includes, but is not limited to:

- government healthcare policy
- approaches to healthcare delivery and design, such as person-centred care
- clinical guidelines, protocols or standards
- professional or regulatory guidance, best practice or position statements.

Standards development

A standards development group, chaired by Dr Lorna Rashid, Consultant Clinical Scientist, NHS Lothian, was convened in April 2024 to consider the evidence and to review the 2019 pregnancy screening: fetal anomaly standards.

Membership of the development group is outlined in Appendix 2.

Each standard is underpinned by the views and expectations of healthcare staff, third sector representatives, people participating in screening and the public. Information has been gathered from several sources and activities, including:

- four development group meetings between April and June 2024
- a six-week consultation period including a survey and stakeholder workshops
- a final development group meeting held on 3 October 2024
- two editorial panel meetings on 27 June and 28 November 2024.

Consultation feedback and finalisation of standards

Following consultation, the standards development group reconvened to review the comments received and agree any required changes. More information can be found in the consultation feedback report, which is available on request from the standards and indicators team.

Quality assurance

All development group members were responsible for advising on the professional aspects of the standards. Clinical members of the development group advised on clinical aspects of the work. The chair had lead responsibility for formal clinical assurance and sign off on the technical and professional validity and acceptability of any reports or recommendations from the group.

All development group members made a declaration of interest at the beginning of the project. They also reviewed and agreed to the development group's terms of reference. More details are available on request from his.screeningstandards@nhs.scot.

An editorial panel met in November 2024 to review and agree the pregnancy screening standards as a final quality assurance check. Membership of the editorial panel is outlined in Appendix 3.

The editorial panel ensured that:

- the standards are developed according to agreed Healthcare Improvement Scotland methodologies
- the standards document addresses the areas to be covered within the agreed scope
- any risk of bias in the standards development process will be minimised.

The standards were developed within the Operating Framework for Healthcare Improvement Scotland and the Scottish Government, which highlights the principles of independence, openness, transparency and accountability. For more information about the direction and priorities of Healthcare Improvement Scotland, please visit: https://www.healthcareimprovementscotland.scot.

Appendix 2: Membership of the standards development group

Name	Position	Organisation
Lorna Rashid (Chair)	Consultant Clinical Scientist and Director of Scottish Antenatal Screening Laboratory	NHS Lothian
Julie Anderson	Portfolio Manager – Screening Services	NHS National Services Scotland
Nicola Andrew	Deputy Head	East of Scotland Regional Genetic Service
David Baty	Consultant Clinical Scientist & Head of Laboratory	NHS Tayside
Catherine Calderwood	Programme Board Chair for Pregnancy and Newborn Screening	NHS Lothian
Sarah Campbell	Senior Midwifery Manager	NHS Grampian
Michelle Clarke	Lead Midwife, Fetal Medicine	NHS Lanarkshire
Katie Dee	Public Health Consultant/Screening Coordinator	NHS Lothian
Jacqueline Dunlop	Principal Genetic Counsellor	NHS Tayside
Elaine Gardiner	Programme Lead MSc Medical Ultrasound / Diagnostic Imaging Lecturer	Glasgow Caledonian University
Jo Hughes	Head of Service Development	Down's Syndrome Scotland
Lyn Hutchison	Senior Programme Manager	NHS National Services Scotland

Name	Position	Organisation
Marieanne Ledingham	Consultant Obstetrician	NHS Greater Glasgow & Clyde
Karen McIntosh	Scottish Co-ordinator	Antenatal Results and Choices (ARC)
Antony Nicholl	Consultant Obstetrician	NHS Tayside
Jocelyn Reid	Lead Midwife Sonographer	NHS Highland
Tasmin Sommerfield	Scottish Clinical Advisor (Screening)	NHS National Services Scotland
Varshali Swadi	Professional Engagement and Development Lead	Down's Syndrome Scotland
Judith Tait	Principal Information Analyst	Public Health Scotland

The standards development group were supported by the Healthcare Improvement Scotland's standards and indicators team:

- Stephanie Kennedy – Administrative Officer
- Carolyn Roper – Project Officer
- Jen Layden – Programme Manager
- Fiona Wardell – Team Lead

Appendix 3: Membership of the editorial panel

Editorial panel members for meetings held on 27 June and 28 November 2024.

Name	Position	Organisation
Jo Hughes	Head of Service Development	Down's Syndrome Scotland
Lyn Hutchison	Senior Programme Manager	National Specialist and Screening Services Directorate (NSD)
Jen Layden	Programme Manager	Healthcare Improvement Scotland
Safia Qureshi	Director of Evidence and Digital	Healthcare Improvement Scotland
Lorna Rashid	Standards Development Group Chair Principal Clinical Scientist	NHS Lothian
Fiona Wardell	Team Lead, Standards and Indictors	Healthcare Improvement Scotland

Glossary

Term	Definition
Accessible and timely	ensuring people can access care when and where they need it.
Care partner	refers to an individual who shares the pregnancy with the person or is associated with the person as part of a couple. They may also be a family member, friend or representative.
Chromosomal condition	chromosomes carry genes that determine how we develop. People usually have 46 chromosomes, 23 from the biological mother and 23 from the biological father. If babies have an extra full or partial chromosome in their cells, they will have a chromosomal condition. If this is only in some of their cells, it may be called mosaicism. Down's syndrome, Edwards' syndrome and Patau's syndrome are chromosomal conditions.
Effective	providing care based on evidence and which produces a clear benefit.
Equitable	providing care that delivers equity of outcomes for everyone, which recognises the different needs of protected characteristics.
Failsafe	refers to processes designed to ensure that all aspects of the screening process are safe and effective, and that there are appropriate mechanisms where an issue or adverse event occurs.
High/higher chance result	indicates that the baby is more likely to have a health condition or have Down's syndrome, Edwards' syndrome or Patau's syndrome.

Term	Definition
Person-centred and personalised	providing care that responds to individual needs and preferences, and ensures individuals are partners in its planning and delivery.
Safe	ensures people using health and care services feel safe and the care they receive does not harm them.
Specialist support organisations	refers third sector organisations providing support and advice on chromosomal and health conditions covered in the standards. Further information can be found in the introduction.
Staff	includes midwives, obstetricians, sonographers or any other professional involved in pregnancy screening.
Ultrasound scan	refers to an examination that uses high-frequency sound waves to create an image of the unborn baby. Ultrasound scans are undertaken at relevant stages as part of pregnancy screening.
Women/pregnant person	anyone who is pregnant including transgender and non-binary people, who access services or receive care and support across the pregnancy screening pathway. This includes people with a Community Health Index (CHI) number as well as those not registered with a GP.

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