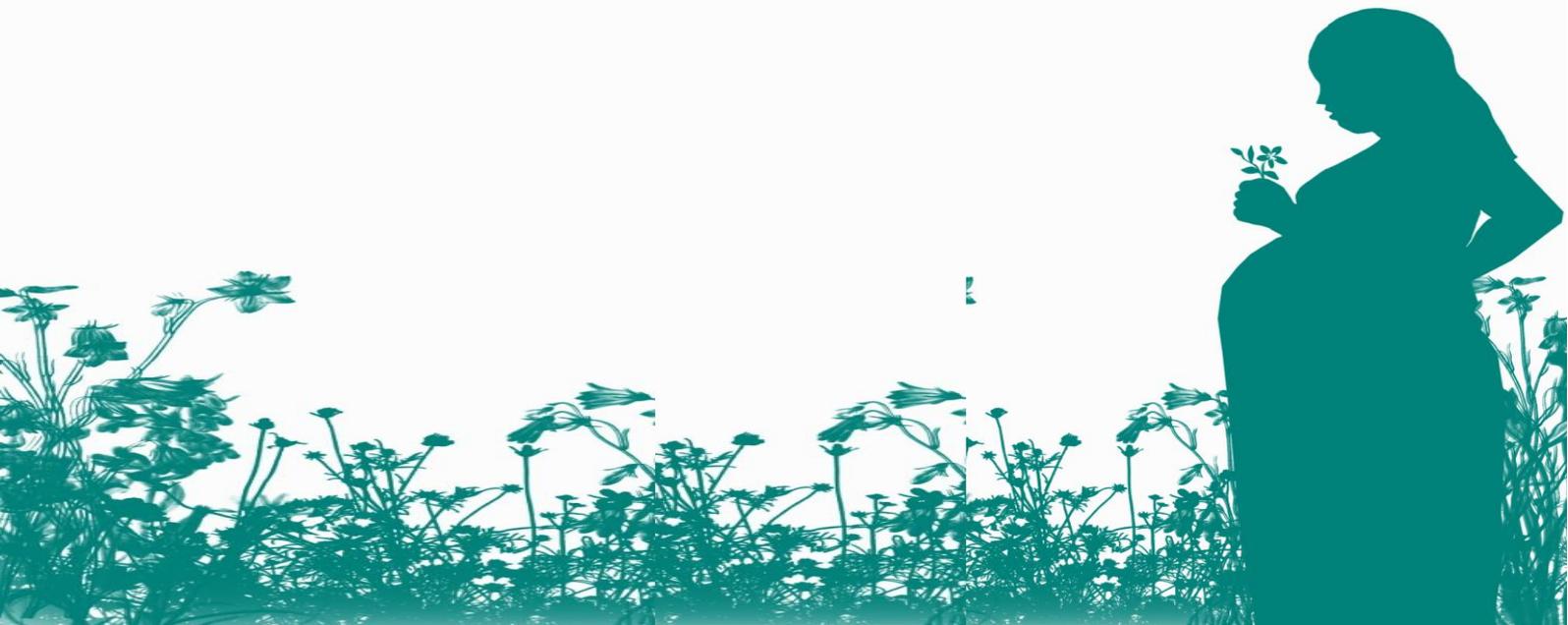




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Antenatal Screening **Wales**

Antenatal Screening Wales Annual Report

2019-2022

Version 1.0

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This document is also available in Welsh.



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Key messages for the public

Visit your midwife early to help you make the best choices for your pregnancy.

- Antenatal screening gives you important information about the health of you and your baby.
- Make an appointment with a midwife as soon as you find out you are pregnant.
- You will be given [information](#) to help you make a choice about taking part in antenatal screening.
- The midwife will talk to you about the different tests you can have and answer your questions as part of your routine antenatal care.
- Antenatal screening tests are not 100% accurate and some conditions may be missed.
- You may be offered further tests or treatment after your antenatal screening.

To find out more:

Visit: phw.nhs.wales/antenatal-screening

Executive summary

This report outlines the work undertaken by Antenatal Screening Wales (ASW) from 1 April 2019 to 31 March 2022. This summary report highlights the achievements of the team and provides an opportunity for us to reflect on what has been achieved working closely with colleagues across Wales and illustrates the wide variety of work carried out for the eight antenatal screening programmes.

Antenatal Screening Wales was formed following an ask by Welsh Government to establish policies, standards and a performance management framework for antenatal screening delivered by maternity services in Wales. Health boards are responsible for delivering screening in line with the policies, standards and protocols as part of routine antenatal care.

The report covers the Covid-19 pandemic period, during which it was accepted to continue with antenatal screening because of the time sensitive nature of the tests offered. For antenatal services, there was a comprehensive response from all agencies across local, regional, and national health and care systems to ensure that all services were able to continue to be delivered. The ASW team adapted to an urgent need to assist Public Health Wales in its emergency response while continuing to work with health boards to ensure antenatal screening services could be delivered safely and effectively.

ASW are extremely thankful for the way in which health board staff responded throughout the pandemic to ensure services continued. Despite the many challenges faced by health boards within Wales they were able to continue to provide antenatal screening.

All health boards in Wales have adopted ASW policies, standards and protocols for antenatal screening. This enables women in Wales access to services that are working to best practice and ensures an equitable antenatal screening service. Following the review of the [Policy, Standards and Protocols](#), the updated version was published on the 5 August 2019.

We developed a number of e-learning resources to support health professionals who deliver the antenatal screening programme within Wales. The resources developed included –

- First trimester screening resource for sonographers
- 18⁺⁰ to 20⁺⁶ week fetal anomaly ultrasound scan
- Antenatal Screening Wales fetal cardiac e-learning module.

We extended the offer of non-invasive prenatal testing (NIPT) to twin pregnancies with a higher chance screening result for Down's syndrome or Edwards'/Patau's syndrome and established an Evaluation Board to monitor the evaluative roll out of NIPT.

ASW implemented pathway changes for the management of isolated echogenic bowel identified at the fetal anomaly scan. This change highlighted all high-risk pregnancies were offered timely referred directly to fetal medicine for counselling, necessary support and to consider their options.



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We worked with health boards to implement 'Digital First' for the provision of antenatal and newborn screening public information, with formal transition across Wales planned for September 2022.

Working across organisational boundaries and with the dedication and support of stakeholders, service providers including every health board in Wales, ASW have continued to ensure consistency and stability of the antenatal screening programme in a climate of uncertainty and often in a challenging environment with many competing priorities.

Introduction

The health board maternity services in Wales offer antenatal screening tests to pregnant women as part of their antenatal care. Antenatal screening tests are offered for different reasons, and this makes antenatal screening a complex programme with several different purposes and unique ethical considerations and implications. Supporting individuals to make personal informed decisions about their antenatal screening choices is important during pregnancy.

The agreed purpose of the antenatal screening programme in Wales is:

- to detect defined conditions, present in either the mother or baby that are likely to have an effect on the health of either, and for which an effective intervention or treatment is available.

Antenatal Screening Wales (ASW) is funded by Welsh Government to support improvements in the standard of antenatal screening offered to women. The model of screening provision in Wales is unique to the UK. ASW is responsible for developing and supporting health boards in delivering all aspects of the antenatal screening programme, through a managed clinical network structure. This includes

- Planning,
- Policy development,
- Governance structures,
- Frameworks for Quality Assurance,
- Education.

ASW has established policies, standards and a performance management framework for antenatal screening delivered by maternity services in Wales.

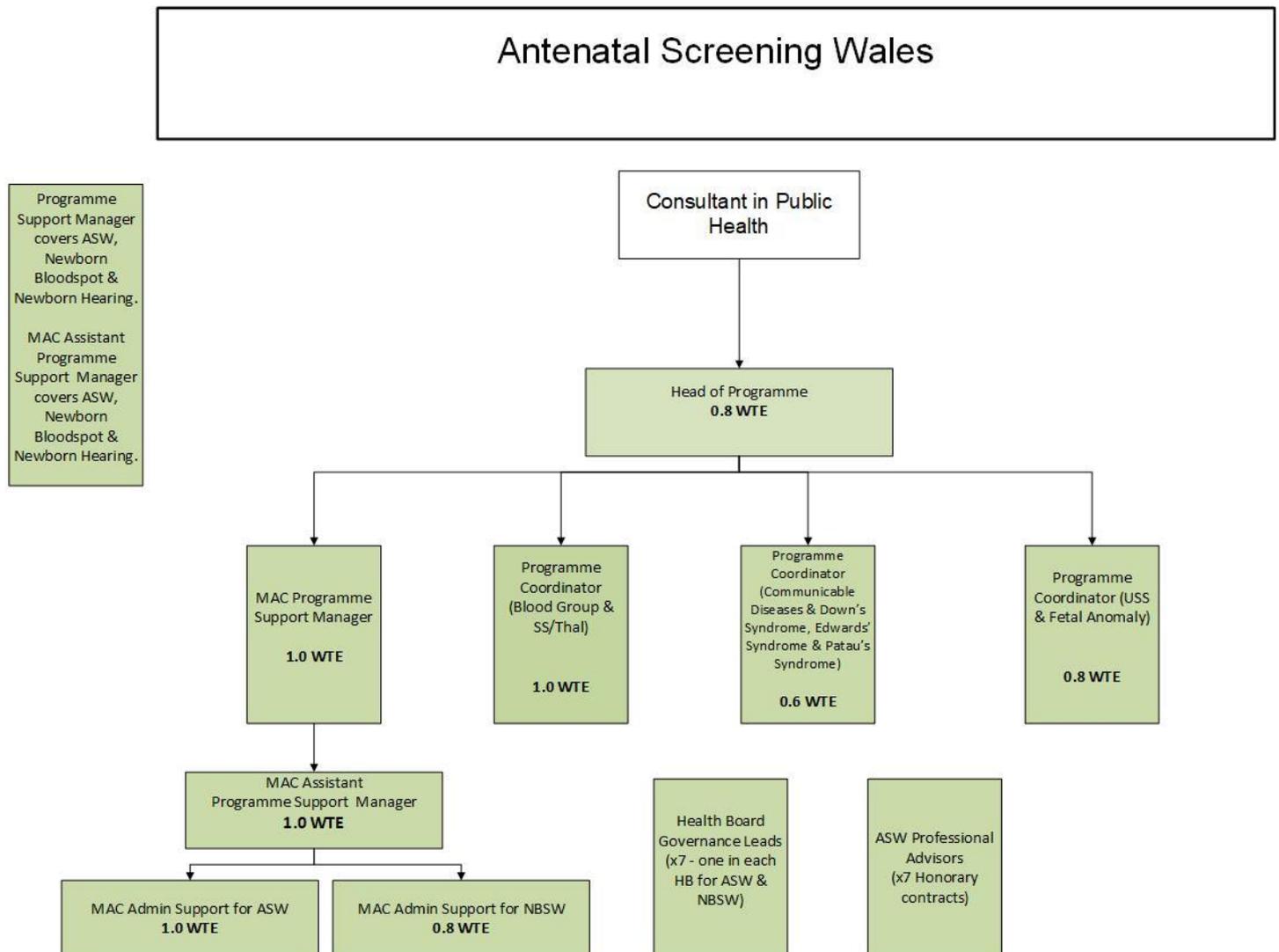
ASW is part of Public Health Wales, Screening Division, who have extensive expertise in the management and provision of population-based screening programmes. ASW has delivered the All-Wales Managed Clinical Network for antenatal screening since 2003. The Quality and Clinical Governance Group and the programme specific advisory groups provide governance for the network. Antenatal screening provision is undertaken by the health board providing care. ASW does not provide or directly manage any antenatal screening services.

The team

During 2019-2022, the composition of the Antenatal Screening Wales team changed in response to workforce developments and service review changes. The ASW team consists of:

- Head of Programme (0.8wte)
- 3 Programme Coordinators – 2 midwives (1.6wte) and 1 Radiographer/Sonographer (0.8wte)
- Programme Support Manager (1.0wte) for the 3 MAC programmes
- Assistant Programme Support Manager (1.0wte) for the 3 MAC programmes
- Administrative Support (1.0wte) for ASW

During the period covered by this report the four members of the established antenatal screening team retired from posts. These included the Head of Programme, two Programme Coordinators (one returning to work) and the Obstetric Ultrasound Screening Coordinator.



Professional advisors

The ASW team and Quality and Clinical Governance Group (Q&CG) are supported by Professional Advisors who are employed through honorary contracts. The honorary contracts are for a 3 year period. As the antenatal screening programmes have become established, the professional advice, quality assurance advice, support and governance requirements need to be reviewed to ensure that the professional advisor structure and make up is what best suits the requirements of ASW and the antenatal screening programmes. A review of the provision of professional advice for the antenatal screening team was commenced in May 2021.

The review process consisted of internal team meetings to discuss the requirements and service needs of ASW and the antenatal screening programmes. There was a series of meetings and a questionnaire for the existing professional advisors to explore their experiences, views and ideas. Discussions were held within the ASW team and included the previous Head of Programme and the Consultant in Public Health. Meetings were held with the current Professional advisors to discuss their roles, responsibilities and obtain their views, thoughts and ideas on the future requirements and service needs of ASW and the ASW programmes.

The review established that there was a requirement to increase the number of Obstetric Professional Advisors to support ASW and antenatal screening programmes.

Following the review, the current Professional Advisors for ASW are –

- Consultant obstetrician x2
- Consultant haematologist
- Consultant geneticist
- Consultant virologist
- Biochemist (special interest in Down's syndrome, Edwards' syndrome and Patau's syndrome screening)
- Consultant Sonographer (special interest in antenatal ultrasound/screening).

Health board maternal and child screening governance lead

Each health board has a named governance lead for Maternal and Child Screening who manage the strategic governance of the antenatal and newborn screening programmes. These positions are funded by PHW (0.2wte).

These roles manage the strategic governance for the MAC screening programmes within each health board. The governance leads meet quarterly with ASW to discuss programme performance governance matters and provide support to each other within this role. A health board governance lead represents the group in the ASW Quality and Clinical Governance Group, advisory groups and workstream meetings.

Antenatal Screening Wales advisory groups

Following new ways of working implemented during the Covid-19 pandemic, particularly the ability to collaboratively work virtually, ASW reconvened the advisory groups for the antenatal screening programmes. This provided a clear focus for each of the programmes, reduced the reliance on individual knowledge and skills and promoted a robust clinical governance framework to support the screening pathways. The advisory groups for the antenatal screening programmes are –

- Communicable Diseases Screening Advisory Group
- Sickle Cell & Thalassaemia/Blood Group & Antibodies screening Advisory Group
- Fetal anomaly/ Down's syndrome, Edwards' syndrome and Patau's syndrome Screening Advisory Group.

The groups' remit would be to provide professional advice and consultation to the ASW Quality & Clinical Governance Group. The groups would meet every 6 months initially. The use of virtual meetings and discussions would be used to promote engagement. The advisory groups would have clear terms of reference and a defined membership.

Working in partnership with health boards

ASW meet regularly, and work closely with health board governance leads, antenatal screening coordinators, ultrasound obstetric leads, ultrasound fetal cardiac leads and ultrasound nuchal translucency (NT) leads to provide professional advice to the All Wales Quality and Clinical Governance Group on all aspects of the antenatal screening programmes in Wales.

Head of Midwifery Advisory Group (HOMAG)

The Head of Programme and ASW Programme Coordinators attended the Head of Midwifery Advisory Group (HOMAG) meeting and provided a summary paper to inform on work streams and provide discussions on ASW and health boards partnership working. A representative from HOMAG is also a member of the ASW Quality and Clinical Governance Group.

What the team has accomplished – 2019 - 2022

Summary of key activity in the reported years.

The team worked to an operational plan that covered some of the areas below. The operational plan was updated in March 2020 to reflect the impact of the COVID response.

Development

- Evaluation of NIPT
- Development of a questionnaire for services users' for revision of pretest leaflet, 'Screening for Down's syndrome, Edwards' syndrome & Patau's syndrome in pregnancy'
- Evaluation of 'Information for women offered further tests for suspected chromosomal conditions'
- Development of Education/e-learning for health professionals
 - First Trimester Screening Resource for Sonographers
 - Antenatal Screening Wales Fetal Cardiac e-learning module
 - 18+0 to 20+6 Fetal Anomaly Ultrasound Scan
 - Update to Down's syndrome, Edwards' syndrome and Patau's syndrome to include the additional contingent offer of NIPT in a twin pregnancy

Performance Management

- Biannual performance indicators report
- Health board visits post-Performance indicator reports
- Quality assurance for sonographers

Audit

- Audit of Fetal Anomaly Images
- Antenatal Diagnosis and Management of Syphilis
- Hepatitis B positive/reactive results in pregnancy
- Sickle cell & thalassaemia request card audit

Review

- Pre and post-test information for women leaflets
- ASW 2019 Policy, Standards and Protocols
- Biannual analysis of DQASS report

Antenatal Screening during the COVID- 19 pandemic

In March 2020, Wales along with the other home nations, Wales entered into lockdown due to the COVID-19 pandemic. The Welsh Government suspended non-urgent health appointments and procedures in order to redirect staff and resources to support the response to COVID-19. All non-essential social contact and travel ceased. Within ASW, programme specific work streams were suspended and ASW and Maternal and Child Screening (MAC) staff formed part of the Public Health Wales (PHW) COVID response team.

During this time, it was accepted to continue with the Antenatal Screening, Newborn Bloodspot Screening and Newborn Hearing Screening programmes. This was because these screening programmes all have short windows of intervention, can prevent impactful complications for pregnant women and newborns and are part of routine evidence based antenatal and post-natal care.

The COVID-19 pandemic response has been the biggest public health challenge that has faced the NHS. For antenatal services, there was a comprehensive response from all agencies across local, regional, and national health and care systems in order to ensure that all services were able to continue to be delivered.

ASW Wales are extremely thankful for the way in which health board staff responded throughout the pandemic to ensure services continued. Despite the many challenges faced by health boards within Wales they were able to continue to provide antenatal screening.

Across the ASW programmes, performance monitoring and service development activities were suspended or changed to relieve the pressure within health boards and on operational delivery of the programmes.

Despite the many challenges faced by health boards within Wales they were able to continue to provide antenatal screening.

With increased restrictions in place and the suspension of face-to-face visits, health boards adjusted their antenatal care pathways. ASW, along with the other MAC programmes, recognised that timing of screening would be dependent on staffing levels and the availability of women to attend screening if they had to self-isolate, if they were symptomatic or household members were symptomatic. ASW considered the pathways for antenatal screening and identified where there could be flexibility in the unprecedented times to reduce the impact to women and babies and the service.

In collaboration with stakeholders we developed COVID specific public information to ensure women were kept informed and up to date with ever changing circumstances. The information was circulate to health boards and hosted on the ASW website.

Sgrinio Cyn Geni Cymru
Antenatal Screening Wales
<http://www.antenatalscreening.wales.nhs.uk>



Frequently Asked Questions about Your Pregnancy Scans During the COVID-19 Pandemic

During the COVID-19 pandemic, the health service are doing everything possible to keep you and health board staff safe. We understand that some of this may be difficult for you. However, staff will be there to care for you and be able to answer any questions that you have. The Welsh Government has developed guidance, which sets out the baseline for visiting in Wales during the pandemic and acknowledges that health providers may have to depart from the guidance when required. The guidance is available at [Hospital visiting during the coronavirus outbreak, guidance](#). Please see below some questions and answers, which may be helpful to you at this time.

Should I attend my routine antenatal ultrasound scan appointments?

Yes, it is important that you attend your routine antenatal ultrasound appointments unless you are self-isolating. Guidance on why you need to self-isolate, how to self-isolate and how to look after yourself at home is available at [Staying safe and social distancing](#). Antenatal care is important in keeping women and babies safe in pregnancy.

- If [you](#) or [someone in your household](#) have symptoms of a new continuous cough,
- high temperature,
- or a loss of, or change in your normal sense of taste or smell,

Please do not attend and follow self-isolation guidance. Contact your midwife on the telephone numbers you were given early in pregnancy. If you have symptoms, you should arrange to [have a test to see if you have COVID-19](#).

Your midwife will advise you about arranging your ultrasound scan after your isolation period is over.

When can your partner/ nominated adult, accompany you to your antenatal appointment?

Information for Women

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If you are attending the hospital for the following specified scans then your partner or nominated adult (preferably from the same household) may accompany you:

- early pregnancy assessment unit scan (EPAU)
- early pregnancy dating scan (11² to 14¹ weeks)
- fetal anomaly scan (18⁰ to 20⁶ weeks)
- attendance at Fetal Medicine Department.

In addition to this, consideration will be given to the needs of women who require additional support to access maternity services and for whom reasonable adjustments may be required. This may be in the following situations, which are by no means exhaustive:

- Women with a mental health issue, a learning disability or autism, where not being accompanied would cause them to be distressed.
- Women with cognitive impairment who may be unable to recall health advice provided. Where the treatment/procedure is likely to cause the woman distress and the partner/nominated other can provide support.
- Where a woman has specific communication needs and may require support to understand information.

Women with support needs such as those listed above may also require an essential support assistant to accompany them to appointments when in a hospital setting.

There may be some differences in how things are organised in different parts of Wales. In periods of local/ national lockdowns or falling levels of transmission in their local area, health boards should revise guidance according to need, working with Maternity Service Liaison Committees, local staff representatives (including health and safety representatives), other professional groups (e.g. sonographers) as well as appropriate infection control and public health experts.

Check with your midwife if you are unsure about the arrangements in the unit that you are attending.

Information for Women

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2

Figure 1: Antenatal Public Information – Frequently Ask Questions.

ASW Policy, Standards and Protocols

All health boards in Wales have adopted ASW policies, standards and protocols for antenatal screening. This enables women in Wales access to services that are working to best practice and ensures an equitable antenatal screening service.

Following the review of the [Policy, Standards and Protocols](#), the updated version was published on the 5 August 2019.

The stages of the review process included:



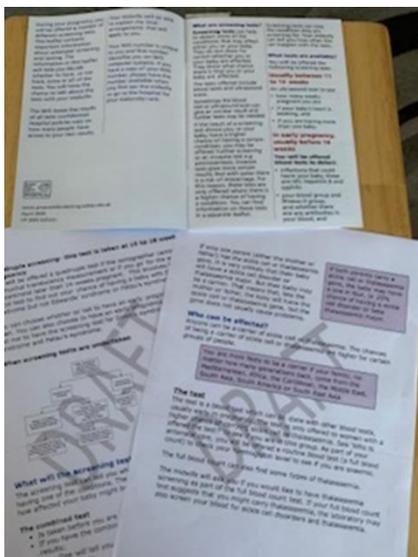


Process for Standards and Protocol Review

August 2018	<ul style="list-style-type: none"> Internal review of all 8 programmes and management chapter
September 2018	<ul style="list-style-type: none"> 11 Sept – Quality and Clinical Governance meeting – process review and agreement 18 Sept – Review of Sickie Cell and Thalassaemia/Blood Group and Antibody chapters at Sickie Cell and Thalassaemia and Blood Group and Antibody subgroup
November 2018	<ul style="list-style-type: none"> 8 Nov - Review of Down’s syndrome, Edwards’ syndrome, Patau’s syndrome and ultrasound chapters at Fetal Anomaly Group HIV, hepatitis b and syphilis sub group suggest emailing these chapters to the communicable diseases sub group in November 2018 as there is no meeting scheduled Ultrasound chapter – email chapters to the Ultrasound Obstetric Leads and Cardiac Ultrasound Leads
January 2019	<ul style="list-style-type: none"> 15 Nov – Screening Coordinators and Governance Leads meeting – review all chapters End of Jan – Final consultation version sent to Quality and Clinical Governance Group (one to one conversations with advisors by mid January)
February 2019	<ul style="list-style-type: none"> Translated in to Welsh for wider consultation
March/April 2019	<ul style="list-style-type: none"> Wider consultation and final amendments
June 2019	<ul style="list-style-type: none"> Ratification
August 2019	<ul style="list-style-type: none"> Publication

Service user experience

In 2020 ASW worked with women to find the best way to present our written information about the antenatal screening tests available on the NHS in Wales. A new A4 Antenatal Screening test leaflet was created to reflect the views of the women who participated in a pre test questionnaire for Down’s syndrome, Edwards’ syndrome and Patau’s syndrome screening leaflet. The new format incorporates all 6 of the current information leaflets, with a colour scheme to identify each programme and allows for the inclusion of flow charts and important information to be highlighted in pathway boxes. An online survey was undertaken in July 2020 and found that women preferred the new A4 booklet rather than 6 separate leaflets.



The new A4 booklet was distributed to health boards in December 2020.

Digital first for the provision of antenatal and newborn screening pre-test information

In September 2021 the Maternal and Child Screening Programmes within Public Health Wales (PHW) made a decision to provide antenatal and newborn screening information to pregnant women/parents of newborn babies primarily in a digital format. A limited number of hard copy print versions would still be produced and provided to those users who were unable or unwilling to access the digital information. PHW supported this change because:

- Two recent Welsh government publications had outlined how the use of technology and greater access to information help improve the health and wellbeing of the people of Wales.
- The information accessed can be more individualised
- The methods of presentation can be more engaging
- The resources are more accessible as they can be adapted to meet different communication needs
- Digital resources are easier to update
- A digital first approach results in reduced printing costs
- Digital resources support a reduced environmental impact
- There is a recognised public expectation for information in digital format.

There had been a drive to improve the digital access to this information which was accelerated by the Covid pandemic. The web analytics to the ASW public information showed site traffic had increased significantly at the start of the pandemic in response to the changes in care. However, the antenatal and newborn information screening information contained in the pages was primarily used to support the provision of the hard copy information and consequently the resources were not accessibly friendly and anecdotal evidence from health professional had indicated that navigation of the public platforms was troublesome.

Figure 2: Antenatal Screening Wales web analytics (October 2020 onwards there was a change of server)



The screening programmes needed to ensure that programme digital platforms were user friendly, easy to navigate and the information could be accessed in a variety of ways (written, video, BSL and audio), allowing women to access screening information in a format of their choice. To do this the Maternal and Child Digital Working Group developed new resources and improved existing resources to ensure they were accessible to all. The resources included the development of [pre-test animations](#) detailing the key messages of the screening information and a digital version of all the antenatal and newborn screening pre-test information in a mobile friendly HTML format that women could be given a link to and save the link to their home screen.



Home > Services and Teams > Screening > Antenatal Screening Wales > Information Resources > Leaflets > Antenatal Screening Tests

Listen

Antenatal Screening Tests

Information about the screening tests you will be offered during your pregnancy.

Published January 2022, IFWa 3rd edition

Section 1 - Introduction to antenatal screening tests Information about the screening tests you will be offered during your pregnancy.	Section 2 - Your blood group and pregnancy This section explains the tests that can be done during pregnancy to find out your blood group.	Section 3 - Infections in pregnancy This section explains about some of the infections that can cause problems for you or your baby, but which can be treated.	Section 4 – Screening for sickle cell and thalassaemia in pregnancy This section explains the tests you can have during pregnancy to find out if you are a carrier of sickle cell or thalassaemia.
Section 5 - Ultrasound scans in pregnancy This section explains the two ultrasound screening tests you will be offered during pregnancy.	Section 6 - Screening for Down's syndrome, Edwards' syndrome and Patau's syndrome This section explains the tests that can be done during pregnancy to find out if your baby has Down's syndrome, Edwards' syndrome or Patau's syndrome.	Section 7 - Invasive tests This section explains chorionic villus sampling (CVS) amniocentesis.	Section 8 - More information You can also get information about screening tests from your midwife or your hospital doctor (your obstetrician) and from the Antenatal Screening Wales website.

The Antenatal and Newborn programmes worked with health boards to implement 'Digital First' for the provision of antenatal and newborn screening public information, with formal transition across Wales planned for September 2022.

From the beginning, the approach to the project was to ensure:

- the changes do not affect people's satisfaction with the antenatal and newborn screening programmes
- there was no disadvantage from the change for those without internet access or those who have specific information needs
- there was clear communication regarding the changes to screening providers, stakeholders, and patient groups
- the opportunities of digital methods to expand and improve content, such as using interactive and multimedia content, would be maximised.

An evaluation of the change was produced and reported in December 2023.

Development of education for health professionals

During 2020 and 2021 ASW developed a number of e-learning resources to support health professionals who deliver the antenatal screening programme within Wales. The resources developed included –

- First trimester screening resource for sonographers
- 18+0 to 20+6 week fetal anomaly ultrasound scan
- Antenatal Screening Wales fetal cardiac e-learning module
- Update to Down's syndrome, Edwards' syndrome and Patau's syndrome to include the additional contingent offer of NIPT in a twin pregnancy with a higher chance combined screening test

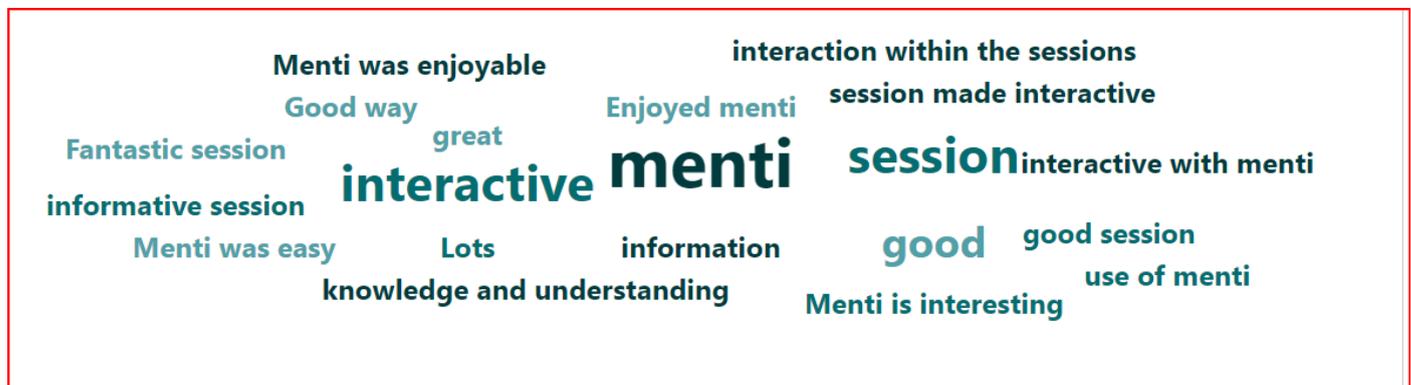
A requirement guide was published which outlined the suggested recommended frequency each resource should be completed and by which staff group. The resources can be accessed via [ESR](#) or students or those without an ESR login they can also be accessed via [Learning@Wales](#).



During the same period, e-learning resources for Communicable disease screening and Sickle Cell and Thalassaemia screening were commenced with planned implementation for 2022/23.

Student midwife education

Antenatal Screening Wales have been providing education sessions for midwifery students in each of the Welsh universities, who provide midwifery training, since 2016. The teaching sessions cover the principles of screening and the screening pathways related to each of the antenatal screening programmes. During the Covid-19 pandemic the ASW team continued to provide the education sessions for the university students but adapted the teaching material and format delivery, using software such as mentimeter, to be more amenable and interactive during the virtual delivery of the sessions.



Biannual performance indicators report

Performance indicators are reported by the health boards to ASW every 6 months, in April and October. They monitor health board performance against ASW standards. Performance indicators are reported to the health board's Director of Public Health, head of midwifery, MAC governance leads, antenatal screening coordinators and ultrasound obstetric leads for escalation within individual health boards. ASW Programme Coordinators meet biannually with the lead professionals within each health board to discuss and provide support in relation to the performance indicator report.

Performance indicators are usually carried out in April and October as a way of auditing standards and protocols in health boards. After consulting with health boards, it was agreed to suspend the April and October 2020 rounds to alleviate some pressures from the health boards during the Covid-19 pandemic. A reduced round was completed for August, looking at data from January – June 2020.

The All Wales reduced report included the following indicators:

ASW11a & 11b Completion of Down's syndrome, Edwards' syndrome and Patau's syndrome request cards.

ASW 15 Neonatal hepatitis B vaccination

ASW 23 Timing of early pregnancy scans

ASW 24 Sonographer competence

ASW 25 Timeliness of testing of biological father of the baby for sickle cell and thalassaemia

ASW 29 NT not achieved at early pregnancy dating scan for combined screening.

From April 2022, the full performance indicators were re-instated.

Programme specific

Extending the offer of non-invasive prenatal testing (NIPT) to twin pregnancies with a higher chance screening result for Down's syndrome or Edwards'/Patau's syndrome

In April 2018 all health boards across Wales implemented the changes requested by the Welsh Government (WG) as part of the non-invasive prenatal testing (NIPT) project. The addition of NIPT as part of this change was a recommendation from the UK National Screening Committee (UKNSC) as an evaluative roll out for singleton pregnancies. Extending the offer of NIPT to twin pregnancies with a higher chance screening result for Down's syndrome or Edwards'/Patau's syndrome was successfully implemented (following a recommendation from the UKNSC) in all health boards Wales on the 7th June 2021 after having been paused due to the COVID pandemic.

The change required the co-ordination of several different programme elements, in particular project management, involving health boards in the implementation, education for health professionals and written information for women.

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Screening for Down's syndrome, Edwards' syndrome and Patau's syndrome in twin pregnancies

1. Introduction to twins and screening

Twin pregnancies account for 1.6% of all pregnancies in the UK. In order for women to be able to make a fully informed decision about entering the screening pathway they need to understand the stages in the pathway prior to deciding whether to have screening or further tests. Decision making for women around the offer of screening for these conditions in a twin pregnancy is more complicated than in singleton pregnancies. Invasive testing in a twin pregnancy carries a higher risk of miscarriage than a singleton pregnancy and there are risks associated with selective termination if that is the decision taken if one fetus has one of the conditions screened for.

N.B Screening for Down's syndrome, Edwards' syndrome and Patau's syndrome is not offered in triplets or higher multiple pregnancies.

The accuracy of the combined test and the risks associated with invasive testing will be different for:

- dizygotic twins (70% of all twin pregnancies) - arise from two separate eggs that are fertilised by separate sperm and are non-identical
- monozygotic twins (30% of all twin pregnancies) - occur when a single fertilised egg later divides into two embryos. These twins usually share the same genetic material (are identical).

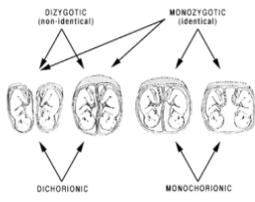
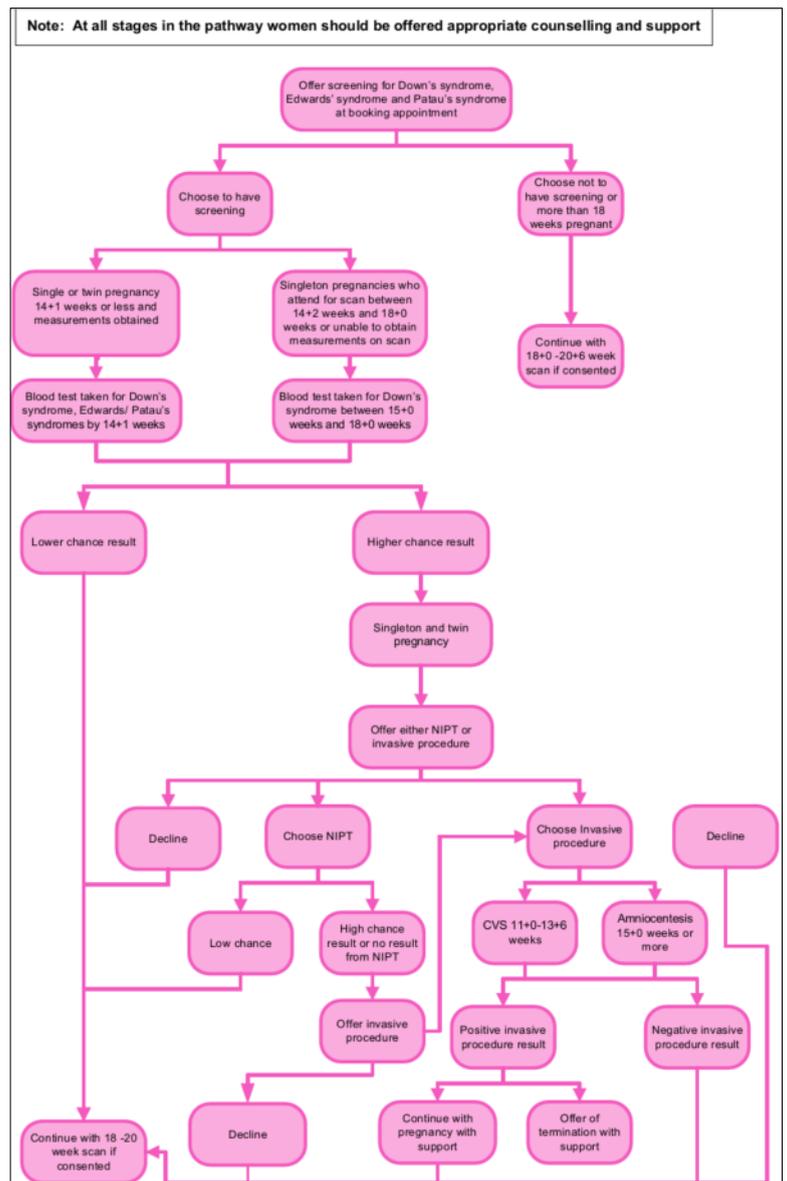


Diagram 1
Lambda λ sign =dichorionic T sign = monozygotic

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Further clinical validation was performed before NIPT for twin pregnancies could be implemented in Wales as a screening test for Down's, syndrome Edwards' syndrome and Patau's syndrome. The clinical validation determined whether the performance of the test, in terms of accuracy, met the diagnostic standards.

NIPT evaluation

The UKNSC recommended that the addition of the offer of non-invasive prenatal testing be implemented as an evaluative roll out. The evaluation of NIPT aimed to answer the following four questions:

1. What impact does NIPT have on the decisions women and their partners make?
2. What is the performance of the test for Edwards' syndrome and Patau's syndrome?
3. How often is there a "no result" from NIPT?
4. What is the time taken for women to receive NIPT results?

Following the successful implementation, ASW established an Evaluation Board to monitor the evaluative roll out of NIPT. This evaluative period included 3 years of the offer of NIPT. This would include all pregnancy outcomes for women who opted for Down's syndrome, Edwards' syndrome and Patau's syndrome screening between April 2018 and November 2021.

Audit for the reasons women undergo quadruple screening

Since the implementation of the combined test (11+2-14+1) to the antenatal screening pathway for the offer of Down's syndrome, Edwards' syndrome and Patau's syndrome, the number of quadruple screening tests for Down's syndrome only (15+0-18+0) expectedly decreased. It was noted on Performance Indicator reporting that there was a variation in ratio of combined to quad screening noted within the health boards and within individual sites within the health boards. The variation also changed within each health board on a monthly basis. An all Wales snapshot audit was performed to explore the reasons why women undergo quadruple screening.

Findings on why women underwent a quadruple test:

- 60% due to the inability of the sonographer to accurately measure nuchal translucency (NT) ((due to fetal lie, large BMI))
- 17% of women booked to late to undergo combined screening
- 5% of women unsure of their pregnancy dates and therefore ultrasound was booked to late to undergo combined screening
- 9% due to women cancelling or non-attendance of their screening appointment, and rescheduled
- 8% where the calculated gestation from last monthly period (LMP) was incorrect-hence scheduled appointment was too late to undergo combined screening
- 1% of women declined screening and subsequently changed their minds and then too late to undergo combined screening

Recommendations from the audit

- To review the health board process for correct completion of the screening request card (ultrasound-as limited obstetric history, LMP on some requests)
- To review the admin process of receipt of request and timely appointing of appointment in a timely manner
- Recommend to arrange the ultrasound scan and screening appointment for ideally 12+ weeks gestation-to allow LMP to be inaccurate by 2 weeks
- Health board nuchal translucency leads to monitor where NT was unachievable to identify trends in health board sites and individual sonographer.
- Continue to offer quadruple screening for women who consent to screening where a combined screening test has not been possible

To re-audit whether recommendations have had impact.

Management of isolated echogenic bowel identified on at the fetal anomaly scan

Following recommendations from a Task & Finish Group, established to review suggestions from the All-Wales Medical Genomics department to amend the pathway for isolated echogenic bowel identified on at the fetal anomaly scan, the pathway was updated and implemented by all health boards in Wales on the 14th June 2021. The pathway changes ensured referral of all high-risk pregnancies (ie both maternal and paternal found to be carriers of cystic fibrosis gene mutations) directly to fetal medicine for counselling on the option of invasive testing for cystic fibrosis. This change would ensure that women receive the offer, necessary support and counselling and consider their options in a timely manner.

In line with this pathway modification, professional and [public information](#) was updated.

Sgrinio Cyn Geni Cymru Antenatal Screening Wales



This information is for you if your fetal anomaly scan has shown that your baby has echogenic bowel

The information applies if echogenic bowel is the only unexpected finding on the scan (known as isolated echogenic bowel).

Every pregnant woman in Wales is offered a fetal anomaly scan when they are between 18 and 20 weeks pregnant. The scan is a way of checking that your baby appears to be developing as expected. This means it may show up unexpected findings that would then need to be checked by other tests.

Echogenic bowel

Echogenic bowel is found in approximately 4 in 1000 (0.4%) fetal anomaly scans performed in Wales.

What is echogenic bowel?

Echogenic bowel (sometimes known as echogenic gut) is where a part of the baby's bowel looks brighter (whiter) than the baby's bones on an ultrasound scan.

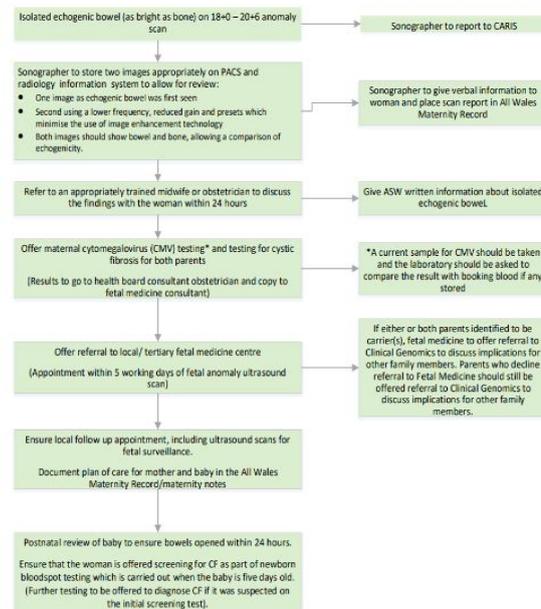
It is thought that echogenic bowel is most commonly caused by the baby having some bloodstained fluid in its bowel, probably because the baby has swallowed it. The baby normally swallows amniotic fluid and if there is blood in the amniotic fluid, this will appear brighter than clear amniotic fluid on the scan.

In Wales, when echogenic bowel has been seen as the only finding on the 18 to 20 week scan, about 7 in 10 (70%) babies are born with no other conditions associated with echogenic bowel.

The following are some of the conditions that have been found in babies with echogenic bowel.

- Babies born smaller than would be expected (about 9 in 100 babies (9%))
- Babies born too early (about 12 in 100 babies (12%))
- A higher than expected incidence of stillbirth (about 3 in 100 babies (3%))
- Babies born with cystic fibrosis (2 in 100 (2%))
- Babies born with cytomegalovirus infection (2 in 100 (2%))

Pathway for Isolated Echogenic Bowel



Audit of fetal anomaly images

A re-audit of fetal anomaly images was undertaken in 2019. This was a re-audit of an original audit in 2018. ASW has an agreed list of essential images to be recorded and saved at the fetal anomaly scan. The list is published in the ultrasound handbook.

Images to be stored at the fetal anomaly scan

The Obstetric Lead sonographers agreed the following set of images as a minimum requirement for storage, and to provide a quality assessment of the examination.

- ❖ Head Circumference
- ❖ Nose/Lips and Chin
- ❖ Femur Length
- ❖ Four Chamber Heart View
- ❖ Transverse Section of Kidneys in the Abdomen
- ❖ Three Vessel Trachea View with colour
- ❖ Midline Longitudinal Section to include the Internal OS
- ❖ Sagittal Spine

Any abnormality or other measurement included in the report should have an image to support the finding.

Following the initial audit in 2018 and education/recommendations to improve practice, the obstetric leads from each site in each health board were asked to assess the images of their sonographers to ensure the scans are being carried out to an acceptable standard.

The re-audit found that the standard has improved from the previous audit and recommended that–

- Health board audits need to be carried out regularly by the ultrasound obstetric leads
- Sonographers should be encouraged to self-audit which was one of the findings of this audit. Sonographers benefited more by their self-audit and recognised their own weaknesses.
- There is no requirement for ASW to undertake the audits within the health boards, but as a learning tool, and as a quality assurance measure, health board audit results could be fed back to ASW and presented at the annual ASW meeting by the Obstetric Leads.

Biannual DQASS report

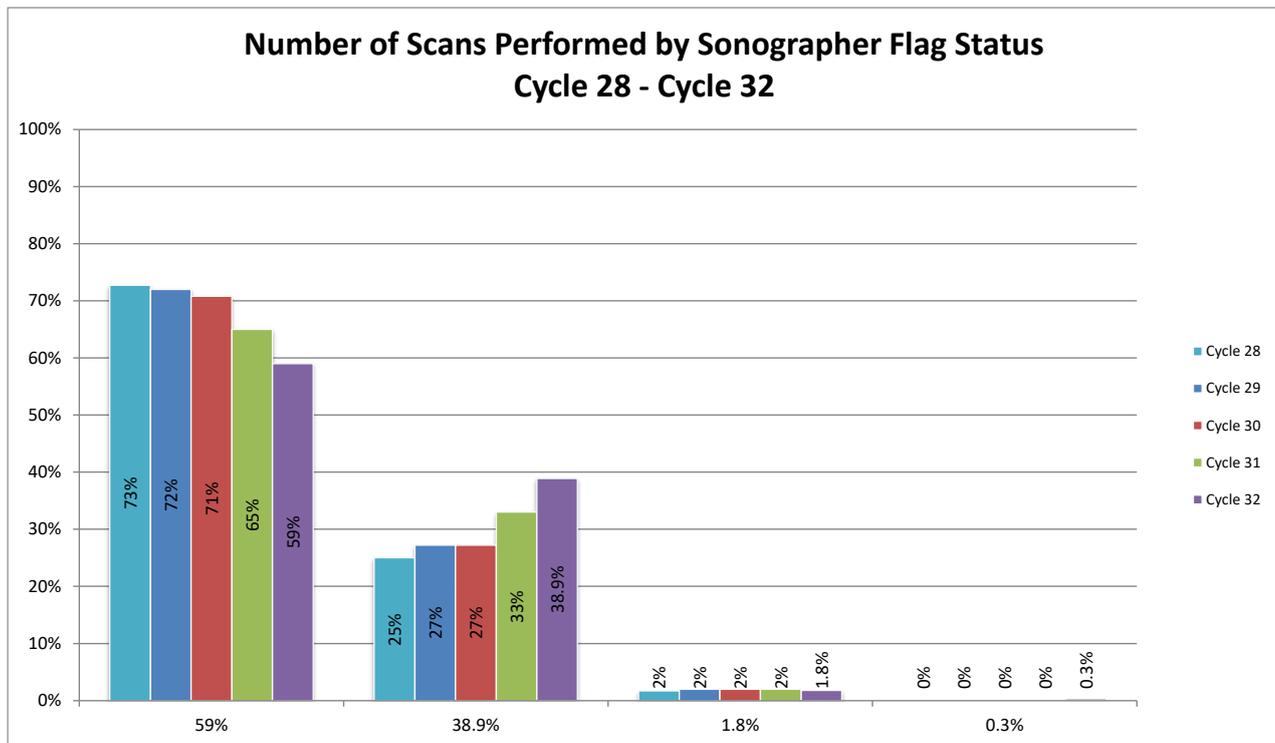
The All Wales performance of sonographers providing screening is reported by the Down's syndrome Screening Quality Assurance Support Service (DQASS). Every crown rump length (CRL) and nuchal translucency (NT) measurement that is obtained by a sonographer is documented on the Down's syndrome, Edwards' syndrome and Patau's syndrome screening request card. Each sonographer has a unique identification code (DQASS code) which is submitted along with the measurements on the same form.

The All Wales Biochemistry (UHW) laboratory sends all their data including the sonographer codes to DQASS every 6 months. DQASS produce a plot/graph for each individual sonographer from this information. The data within each plot/graph is assessed in three areas (bias, spread and trend) to indicate performance against the Fetal Medicine Foundation (FMF) reference curve.

Sonographers are awarded a flag to record their performance.

- Green flag is where the bias for the plot is less than 0.1 and there is no evidence of substantive difference in spread or trend from the FMF reference curve
- Amber flag is where the bias is between 0.1 and 0.3 or there is a substantive difference in spread or trend from the FMF reference curve
- Red flag is where the bias is greater than 0.3. No red flags are given for spread or trend differences.
- White flag is where there are less than 25 measurements on the plot.

DQASS provide the information to ASW who then provide a report for each site in the health boards. This report looks at the performance across Wales.



The DQASS information allows a look back at the past six months performance in order to maintain the quality of the programme in Wales and ultimately provide an accurate chance result to women. Any issues highlighted by the DQASS reporting are fed back by ASW to the health boards for actioning. The NT Leads are required to form action plans and discuss issues with their ultrasound obstetric leads, radiology service managers and MAC governance leads if required.

Laboratory audit of results for the management of chronic hepatitis B in pregnancy

In 2017, ASW reviewed the protocols for hepatitis B screening in pregnancy. An additional protocol to recommend hepatitis B DNA (viral load) testing at the time of the confirmatory sample, was offered to all pregnant women who were diagnosed with hepatitis B. This was so that treatment could be offered to a mother with a high viral load in the third trimester, thus reducing the risk of vertical transmission and to identify the at-risk babies and to further decrease vertical transmission.

This amendment was implemented in September 2017. In 2019 a retrospective audit to check compliance with ASW standards and protocols was undertaken. Data was collected from all health boards in Wales in collaboration with Public Health Wales, ASW, and the health board clinical teams. Audit and analysis of the data collected was performed by PHW Virology Laboratory University Hospital of Wales.



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The compliance to the ASW standards for confirmatory serology samples and HBV DNA viral-load testing following a reactive or positive HBsAg result respectively was high. Barriers to following the appropriate clinical pathway included non-attendance of the patient, late booking of the pregnancy, and patients moving outside of the health board.

A high percentage of patients had a review with Gastroenterology/ Hepatology, although a sub-optimal proportion of these reviews were within 6 weeks of a positive antenatal screening result.

Compliance to the ASW standards for reactive hepatitis B results was high. All samples that had a reactive result during the audit period were confirmed as negative when the samples were repeated, thus providing reassurance of the ASW protocol for management of reactive results in pregnancy.



An Audit of Clinical Practice Against the Antenatal Screening Wales Guidelines for the Diagnosis and Management of Hepatitis B in Pregnant Women in Wales

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INTRODUCTION

Hepatitis B is an infection of the liver caused by the hepatitis B virus (HBV). HBV is spread by direct contact with body fluids. Most adults develop acute hepatitis and will clear the virus, recovering fully from the infection. However, some will go on to develop chronic hepatitis, which carries the risk of cirrhosis and hepatocellular carcinoma if left untreated. Neonates that acquire HBV by vertical transmission at birth have a 90% chance of developing chronic hepatitis.

All pregnant women in Wales are offered antenatal screening for hepatitis B surface antigen (HBsAg) with the aim of reducing the risk of mother-to-baby HBV transmission. In line with Department of Health 2011 guidelines, Antenatal Screening Wales (ASW) have recently recommended that all pregnant women with a HBV infection have a HBV DNA viral-load measured during the course of their pregnancy. In addition, a pathway was introduced for the management of 'reactive' results to reduce anxiety generated as a result of 'non-specific' reactivity that can occur with screening samples¹.

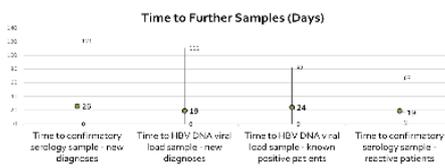
METHODS

A retrospective audit of clinical practice against the standards outlined for the diagnosis and management of hepatitis B in the ASW guidelines was conducted, to determine how successfully these new developments have been implemented.

The audit was performed on all pregnant women with positive or reactive HBsAg antenatal screening result between October 2017 and November 2018, inclusive. Data was collected from Welsh Health Boards in a collaboration between PHW Microbiology, ASW, and the clinical teams.

RESULTS

Fifty-nine women with positive HBsAg antenatal screening results were identified, 26 (44%) of which were new diagnoses and 33 (56%) were from known Hepatitis B positive patients. Thirty-eight women with 'reactive' HBsAg screening results were identified.



RESULTS (continued)

• HBsAg Positive Samples (n=59)

The appropriate follow-up samples were taken for 53 (90%) patients.

Standard	Result
Was all the required demographic/clinical information completed on the request card?	Yes - 69%
Is there evidence that the antenatal clinic is contacted with the positive hepatitis B result in women newly diagnosed with hepatitis B?	Yes - 98%
Is there evidence that a referral was made to the Gastroenterology/Hepatology team in women newly diagnosed with hepatitis B?	Yes - 98%

Of the 33 patients with previously known Hepatitis B, 31 (94%) had a HBV DNA viral load sample taken.

Fifty-one (86%) patients had reviews with the Gastroenterology/Hepatology team, 24 (41%) were within 6 weeks of the antenatal screening sample result.

Reasons Why Patients Did Not Have A Gastroenterology/Hepatology Review



• HBsAg Reactive Samples (n=38)

The appropriate follow-up samples were received for 35 (92%) out of 38 patients.

Standard	Result
Was all the required demographic/clinical information completed on the request card?	Yes - 97%
Is there evidence that the antenatal clinic was contacted with the reactive result?	Yes - 97%

Evidence of reactive HBsAg results being communicated with the midwives is likely an underestimate as this information is not routinely recorded. All results are reported electronically.

All 35 patients showed no indication of HBV infection on confirmatory testing.

DISCUSSION

The compliance to ASW standards for confirmatory serology samples and HBV DNA viral-load testing following a reactive or positive HBsAg result respectively was high.

Barriers to following the appropriate clinical pathway include non-attendance of the patient, late booking of the pregnancy, and patients moving outside of the Health Board.

A high percentage of patients had a review with Gastroenterology/Hepatology, although a sub-optimal proportion of these reviews were within 6 weeks of a positive antenatal screening result.

REFERENCES

1. Antenatal Screening Wales Policy, Standards and Protocols 2015. Version 8, 2018. Public Health Wales.

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Acknowledgements: Thankyou to the midwives and clinical teams that helped to collate the audit data, and to the Welsh microbiology laboratories that performed the laboratory testing.



The audit results were shared with health board heads of midwifery, antenatal screening coordinators, MAC governance leads, virology/microbiology laboratories in Wales and the all-Wales health board gastroenterology leads. Audit results were presented and discussed at the joint screening coordinator and governance leads meeting in October 2019. A poster presentation of the audit was accepted for inclusion at the Public Health Wales Research and Evaluation Conference. ASW, in conjunction with screening coordinators and MAC governance leads, decided to develop a template/checklist for Hepatitis B positive women for use by health boards.

A re-audit will be undertaken in 2023.

Antenatal diagnosis and management of syphilis (ADAMS) audit

This audit examined the management of women in Wales with positive and reactive syphilis test results, and the care and follow up of these women's babies, assessing against the ASW standards and protocols and The British Association for Sexual Health and HIV (BASHH) guidance on the management of syphilis. The intention of the audit was to develop an all-Wales pathway (including clear definition of terminology) for pregnant women with positive and reactive syphilis results, and to strengthen communication links between teams to allow delivery of integrated care.

The audit was led by a consultant virologist at the PHW virology laboratory in University Hospital of Wales, Cardiff with support from a consultant paediatrician, consultant obstetrician, consultant in integrated sexual health and a programme coordinator from Antenatal Screening Wales. Local leads were identified for syphilis management and data collection within antenatal, sexual health and paediatric teams for each health board.

Audit results were measured against the ASW Standards and protocols and BASHH guidance on the management of syphilis. Analysis was performed by the PHW virology laboratory University Hospital Wales.

Strengths identified by the audit included –

- there was good compliance to confirmatory testing for women with both positive and reactive results.
- the audit captured the importance of the antenatal screening programme in identifying women with previously unknown infection.

Areas for improvement highlighted by the audit include documentation and multi-disciplinary team working. Specific areas for improvement include the time and place women receive positive syphilis results, the referral of high-risk pregnancies to fetal medicine, obtaining paired maternal samples at birth and ensuring no babies are bled un-necessarily. There was a further recommendation to improve the surveillance within Wales of pregnant women with syphilis and babies born with congenital syphilis.

Audit results were presented and discussed at the joint screening coordinator and governance leads meeting in June 2022. The existing pathways and the outcome of this audit by presentation of cases was presented at local health board meetings. A poster presentation of the audit was accepted for inclusion at the Public Health Wales Research and Evaluation Conference. ASW, in conjunction with screening coordinators and MAC governance Leads, decided to develop a template/checklist for Syphilis positive women for use by health boards. CARIS have agreed with governance leads and screening coordinators to collect data for any positive cases of Syphilis in Pregnancy.

A re-audit will be planned following implementation of the recommendations.

Sickle cell and thalassaemia request card audit

A snapshot audit (one month period), on the completion of antenatal sickle cell and thalassaemia request cards, has been carried out annually since 2016. The haemoglobinopathy laboratory identified that a proportion of request cards entering the laboratory were not completed correctly. This consisted of request cards not having the family origins of both the woman and the baby's biological father going back at least 2 generations. Incorrect screening tests were being requested, leading to potentially high risk pregnancies not being diagnosed and sickle cell and thalassaemia tests being carried out unnecessarily.

An audit template was forwarded to the health board laboratories requesting that all antenatal request cards that enter the laboratory from 1st-30th June 2019 were included in the audit. Information from 1337 antenatal screening sickle cell and thalassaemia request cards were analysed from the health boards in Wales. It was pleasing to record that comparing the audit results with those of 2017 and 2018 that completion of "test requested" had improved. It is noted that there is an improving trend in the accuracy of documentation of family origins recorded on the request card with "unknown" being documented in preference to being left blank in instances where the family origins were not known.

There was a slight reduction in errors in request card completion, however errors identified in the 2019 audit are similar to previous audits. Within this audit one percent of the request cards (16/1337) received did not have family origins of mother or father of the baby written on the request card.

Following this audit, ASW produced a teaching aid for professionals to identify country of ethnic origin more accurately. This is included below.



Countries of the World

When requesting screening for Sickle Cell and Thalassaemia you **must** document the **country** of family origin, not the continent

Countries of Europe:

Albania, Austria, Andorra, *Armenia, *Azerbaijan, Belarus, Belgium, *Cyprus, Czechia, Bosnia and Herzegovina, Bulgaria, Croatia, Denmark, Estonia, Finland, France, *Georgia, Germany, Greece, Hungary, Iceland, Italy, Kosovo, Latvia, Lichtenstein, Lithuania, Luxembourg, Malta, Moldova, Monaco, Montenegro, Netherlands, North Macedonia, Norway, Poland, Portugal, Romania, *Russia, San Marino, **Sardinia, Serbia, UK, Slovakia, Slovenia, Spain, Sweden, Switzerland, *Turkey, Ukraine, Vatican City

*These Countries span both Asia and Europe **Sardinia is not a country, but an autonomous region of the Republic of Italy however should be recorded seperately

Countries of North America and the Caribbean:

Antigua and Barbuda, Bahamas, Barbados, Belize, Canada, Costa Rica, Cuba, Dominica, Dominican Republic, El Salvador, Grenada, Guatemala, Haiti, Honduras, Jamaica, Mexico, Nicaragua, Panama, St Kitts and Nevis, St Lucia, USA, St Vincent and the Grenadines, Trinidad and Tobago.

Countries of South America:

Argentina, Bolivia, Brazil, Chile, Colombia, Ecuador, Guyana, Paraguay, Peru, Suriname, Uruguay, Venezuela



Countries of Asia:

Afghanistan, Bahrain, Brunei, Bangladesh, Bhutan, Cambodia, China, India, Indonesia, Iran, Iraq, Israel, Japan, Jordan, *Kazakhstan, Kuwait, Kyrgyzstan, Laos, Lebanon, Malaysia, Maldives, Mongolia, Myanmar, Nepal, North Korea, Oman, Pakistan, Philippines, Qatar, Saudi Arabia, Singapore, South Korea, Sri Lanka, Syria, Taiwan, Tajikistan, Thailand, Timor Leste, Turkmenistan, UAE, Uzbekistan, Vietnam, Yemen.

*These countries span both Europe and Asia

Countries of Africa:

Algeria, Angola, Benin, Botswana, Burundi, Burkina Faso, Chad, Cabo Verde, Cameroon, Central African Republic, Comoros, Ivory Coast, Democratic Republic of Congo, Djibouti, Egypt, Equatorial Guinea, Eritrea, Eswatini, Ethiopia, Gabon, Gambia, Ghana, Guinea, Guinea Bissau, Kenya, Lesotho, Liberia, Libya, Madagascar, Malawi, Mali, Mauritania, Mauritius, Morocco, Mozambique, Namibia, Niger, Nigeria, Republic of Congo, Rwanda, Sao Tome and Principe, Senegal, Seychelles, Sierra Leone, Somalia, South Africa, South Sudan, Sudan, Tanzania, Togo, Tunisia, Uganda, Zambia, Zimbabwe

Countries of Oceania:

Australia, Fiji, Kiribati, Marshall Islands, Tonga, Micronesia, Nauru, Samoa, New Zealand, Palau, Tuvalu, Papua New Guinea, Solomon Islands, Vanuatu.

Cell-free fetal DNA (cffDNA) Screening.

ASW was asked by Welsh Government (WG) to meet with Welsh Blood Service (WBS) and scope the feasibility of introducing the offer of cell-free DNA testing for fetal RHD genotype to pregnant women who are D negative and not sensitised to D antigen.

Following discussions between ASW and WBS a briefing paper with high-level intent was presented to Wales Screening Committee (WSC) to gain agreement to take this work stream forward. This project was approved by WSC in 2018. The project in Wales is called Cell-free fetal DNA (cffDNA) Screening.

With the start of the Covid-19 global pandemic the project was suspended with discussions recommencing in January 2022 and the first project board meeting planned for June 2022.

Summary

This has been a busy period for Antenatal Screening Wales. The Team has worked hard to ensure that the screening programmes are delivered and managed in a coordinated way within the health boards. ASW has continued to work in partnership with colleagues throughout Wales to improve the screening pathways, provide informative material for women and their families and educational material for health professionals to ensure women who choose to have antenatal screening have made a personal informed choice.

The regular work of ASW has continued including monitoring of screening, supporting health board antenatal screening coordinators, MAC governance leads and lead sonographers.

The Covid-19 pandemic presented many challenges to the NHS in Wales, despite this, health boards within Wales were able to continue to provide high quality antenatal screening.

Looking Ahead

ASW looks to 2022/23 to build on the strong relationships and dedicated commitment from each of the health boards to continue to ensure the successful delivery of the antenatal screening programmes.

Key developments will include –

- Implementation and evaluation of moving towards digital first for the provision of antenatal and newborn screening pre-test information.
- Evaluation report for the Implementation of non-invasive prenatal test (NIPT) as a contingent test following a higher chance screening test for Down's syndrome, Edwards' syndrome and Patau's syndrome (July 2022)
- Implementation of the offer cell free fetal DNA testing for fetal RhD genotype (cffDNA). By offering cell free fetal DNA testing to pregnant women who are RhD negative, it is possible to identify the RhD status of a fetus and would therefore remove the need for RhD negative women carrying a RhD negative fetus to have anti-D injections as part of Routine antenatal anti-D prophylaxis (RAADP) or after potentially sensitising events.
- Review of the ASW, Policy, Standards and Protocols due to commence May 2022.
- Review the Infections and Rashes in Pregnancy: A Guide for Health Professionals. This resource is to provide guidance to Health Professionals on the management of rashes in pregnancy and when serological tests should and should not be offered in pregnancy and which tests may be relevant following specific ultrasound findings.
- Scope the ability within Wales to strengthen the surveillance of syphilis in pregnancy. Collecting and reporting on screening outcome data for syphilis in pregnancy will support Antenatal Screening Wales and health boards to assess the impact, monitor performance, review all positive cases and to identify new areas for further audit and research. This will lead to recommendations being made locally and nationally, strengthening policy and practice, and improving care for mothers and their children within Wales.



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