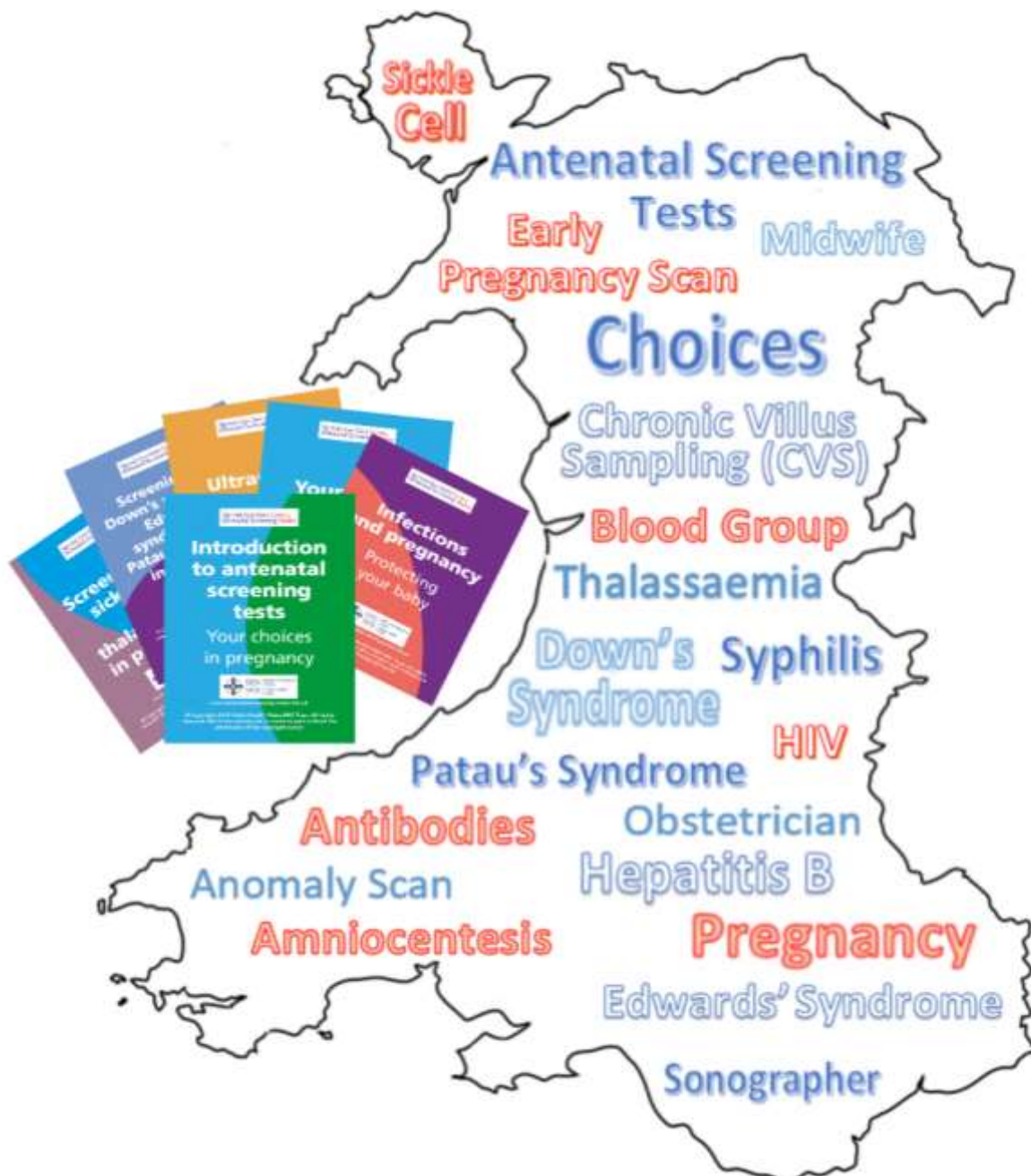




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Public Health
Wales

Antenatal Screening Wales Annual Report 2018-2019



Sgrinio Cyn Geni Cymru
Antenatal Screening Wales

About us

Public Health Wales exists to protect and improve health and wellbeing and reduce health inequalities for people in Wales.

We are part of the NHS and report to the Minister for Health and Social Services in the Welsh Government.

Our vision is for a healthier, happier and fairer Wales. We work locally, nationally and, with partners, across communities in the following areas:

Health protection – providing information and advice and taking action to protect people from communicable disease and environmental hazards

Primary, community and integrated care – strengthening its public health impact through policy, commissioning, planning and service delivery

Microbiology – providing a network of microbiology services which support the diagnosis and management of infectious diseases

Safeguarding - providing expertise and strategic advice to help safeguard children and vulnerable adults

Screening – providing screening programmes which assist the early detection, prevention and treatment of disease

Health intelligence – providing public health data analysis, evidence finding and knowledge management

NHS quality improvement and patient safety – providing the NHS with information, advice and support to improve patient outcomes

Policy, research and international development – influencing policy, supporting research and contributing to international health development

Health improvement – working across agencies and providing population services to improve health and reduce health inequalities

Further information

Web: www.publichealthwales.org
Email: general.enquiries@wales.nhs.uk
Twitter: @PublicHealthW
Facebook: www.facebook.com/PublicHealthWales

Rydym yn croesawu gohebiaeth a galwadau ffôn yn Gymraeg. Byddwn yn ateb gohebiaeth yn Gymraeg heb oedi / We welcome correspondence and phone calls in Welsh. We will respond to correspondence in Welsh without delay.

This document is also available in Welsh.

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Executive Summary

The following report outlines the work undertaken by Antenatal Screening Wales (ASW) from 1 April 2018 to 31 March 2019. This summary report highlights the achievements of the team 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 asked 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 and standards as part of routine antenatal care.

A full review of ASW Policy, Standards and Protocols has been undertaken and is planned for publication in August 2019. All health boards in Wales have adopted the ASW policies, standards and protocols for antenatal screening. This ensures women have equitable access to best practice services across Wales.

Performance management

ASW continues to work in partnership with a wide group of stakeholders throughout Wales and the UK to monitor the standards and protocols for antenatal screening. Monitoring of standards occurs via performance indicator reporting or regular audit. Results from these are fed back to the health boards and action plans devised where performance is not reaching the standard. ASW meet with key health professionals at each health board to discuss the performance indicator report on a regular basis. Health board colleagues develop action plans for areas identified that require improvement. Development and on-going training to manage the programmes within the health board are supported by ASW. A review of written information for women is undertaken on an annual basis and where evidence has changed, amendments are made.

Key achievements for the following programmes are highlighted:

Sickle cell and thalassaemia

A snapshot audit to monitor completeness of request cards was carried out within the health board laboratories during July 2018. ASW produced a teaching aid for antenatal screening coordinators to enable them to feed back to health professionals the importance of correct request card completion.

Down's syndrome, Edwards' syndrome and Patau's syndrome

ASW have successfully led on the health board implementation of a new screening pathway for Down's syndrome, Edwards' syndrome and Patau's syndrome in singleton and twin pregnancies in Wales. The offer of Non-Invasive Pre-natal Testing (NIPT) as a contingency test for higher chance singleton pregnancies was also introduced and these changes were implemented on 30th April 2018.

An ongoing three year evaluation of the Programme has subsequently commenced. Wales is the first UK country to implement the UK NSC recommendations. The pre-test information for women has been reviewed following focus group work with women to ensure information enables women to make a personal informed choice and they are supported in their decision.

Ultrasound

Biannual monitoring of the ultrasound measurements for each Down's syndrome, Edwards' syndrome and Patau's syndrome screening test via the Down's Syndrome Quality Assurance Support Service (DQASS) is analysed and reported back to the individual sonographers via ASW. The programme continues to work alongside NHS Wales Informatics Service (NWIS) in development of the Radiology Information System (RadIS) which is a reporting module for radiology examinations including obstetric ultrasound scans to ensure that reporting is consistent throughout Wales thus allowing ease of data collection and analysis for audit purposes.

Blood group and antibody screening

ASW has commenced discussions with Welsh Blood Service (WBS) on a project to scope and develop an improved pathway on cell-free fetal DNA testing for all pregnant women in Wales who are RhD negative and not already sensitised to D antigen.

1. Introduction

Health board maternity services in Wales provide antenatal screening tests to pregnant women as part of their routine antenatal care. Antenatal screening tests are provided for different reasons, and this makes antenatal screening a complex programme with a number of different purposes and unique ethical considerations and implications.

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

to detect defined serious 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 is available. For some conditions, preventive treatment is available during the antenatal period or after delivery to improve the baby's health. For others, the condition can be identified during the antenatal period but no preventive treatment is available. With high quality counselling women can make a personalised choice about whether they wish to continue the pregnancy. Appropriate support should be offered to women whichever choice they make.

ASW has delivered the all-Wales Managed Clinical Network for antenatal screening since 2003. ASW was asked by Welsh Government to establish 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, and has sat within Maternal and Child Screening (MAC) since 2014 (see appendix 1). The Quality and Clinical Governance Group and the programme specific sub groups provide governance for the work. ASW does not provide, or directly manage, any antenatal screening services.



2. The team

During 2018-2019, the composition of the all-Wales team changed. The team consists of:

- Head of Programme (1.0wte) for the 3 MAC programmes
- 3 Regional Coordinators – 3 midwives (2.8wte)
- 1 Obstetric Ultrasound Screening Coordinator (0.4wte)
- Programme Support Manager (1.0wte) for the 3 MAC programmes
- Administrative Support (2.4wte) for ASW and Newborn Bloodspot Screening Wales (NBSW)



3. Operational plan

The team worked to an operational plan within 2018-2019 that covered the following areas:

Audit

Sickle cell and thalassemia request card completion
Down's syndrome, Edwards' syndrome and Patau's syndrome request card completion
Specific measurements and views on the anomaly scan
Biannual service user experience
Hepatitis B positive/reactive results in pregnancy

Development

Revision of the student midwife education packages for principles of screening and antenatal screening
The MAC governance lead role
The fetal cardiac lead role
Focus groups for revision of pretest leaflet, 'Screening for Down's syndrome, Edwards' syndrome & Patau's syndrome in pregnancy'

Changes to the Down's syndrome screening programme and pathway

Review

Pre- and post-test information for women leaflets
ASW 2015 Policy, Standards and Protocols
Biannual analysis of DQASS report
Antenatal Screening Wales base menu for anomaly scan reporting
Screening Handbook for Midwives
Obstetric Ultrasound Handbook for Sonographers

Performance Management

Biannual performance indicators report
Health board visits post-Performance indicator reports
Ultrasound scan image review
Quality assurance for sonographers
Ongoing support for sonographers
Working with stakeholders

4. What the team has accomplished in 2018-2019

4.1.1 Review of 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.

Having previously been fully reviewed in 2015, a robust process of reviewing the ASW Policy, Standards and Protocols commenced in September 2018.

The stages of the review process included:

All proposed changes made following internal review by the ASW team were discussed and agreed with the relevant sub group members.

Following internal and stakeholder review the revised Antenatal Screening Wales Policy, Standards and Protocols 2019 were

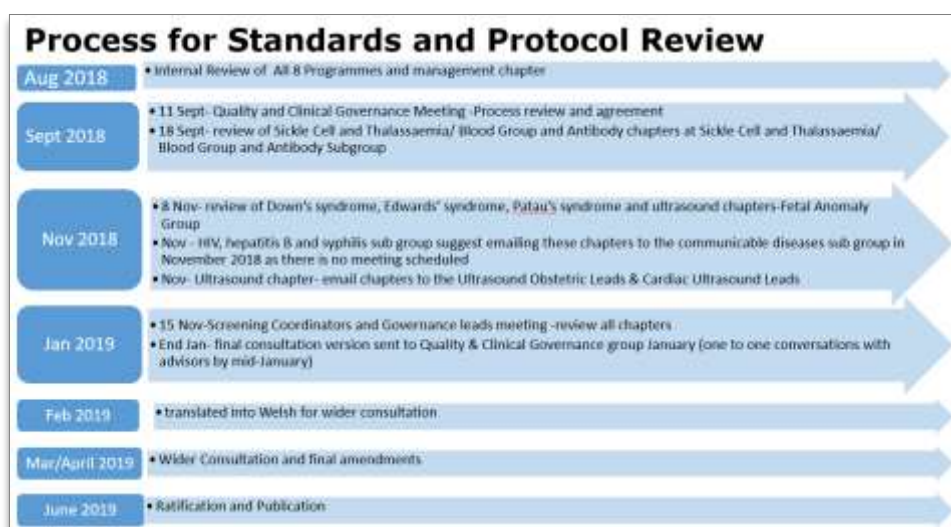
sent for a six week wider consultation and were made available for comment on the ASW website. The wider consultation group included Directors of Public Health, NHS health board leads, Royal Colleges and organisations from the third sector.

Each comment received was taken into consideration and formal responses sent following ratification and publication.

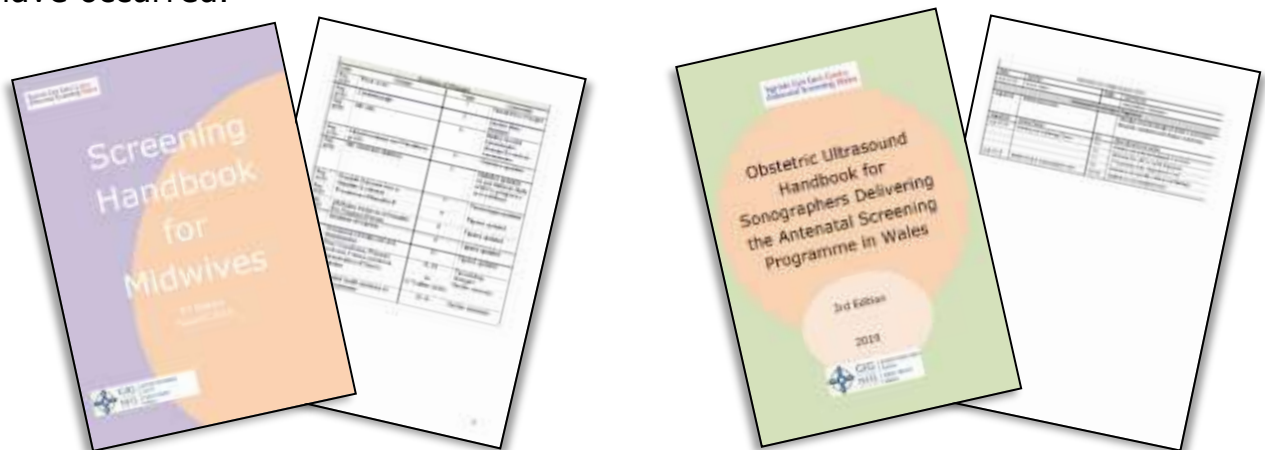
The Antenatal Screening Wales [Policy, Standards and Protocols 2019](#) are due to be published on 5 August 2019.

4.1.2 Review of midwives screening handbook and obstetric ultrasound handbook

The ASW Screening Handbook for Midwives and Ultrasound Handbook for Sonographers Delivering the Antenatal Screening Programme in Wales



have both been reviewed in line with the updated Antenatal Screening Wales Policy, Standards and Protocols 2019. A summary of change document has been added to both handbooks to highlight where changes have occurred.



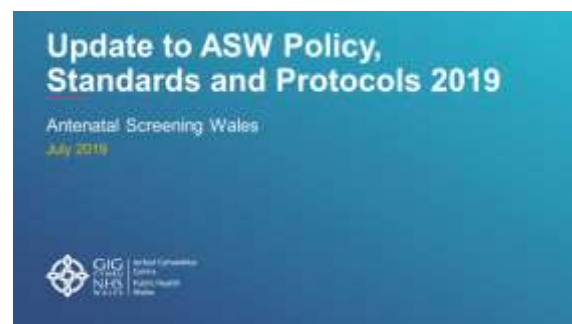
4.1.3 ASW Policy, Standards and Protocols 2019

Education update

Based on the review and changes to the ASW Policy, Standards and Protocols 2019, a power point presentation has been developed to assist health boards with the delivery of on-going local provision of in service education. This will be disseminated to health board antenatal screening coordinators and MAC governance leads.

The presentation shows evidence of any changes to ASW Policy, Standards and Protocols and also gives the opportunity for health board specific issues to be added for discussion. Its use will:

- ensure all health professionals involved in antenatal screening have current and up-to-date information of antenatal screening tests offered to women in their health boards
- ensure pre- and post-test discussion with women is consistent
- support clinical governance arrangements



4.2 Cross-programme work

4.2.1 Working with stakeholders

Head of Midwifery Advisory Group (HOMAG)

The Head of Programme and ASW Regional 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.

Laboratories

Within the timeframe of April 2018-March 2019, ASW liaised closely with the laboratories below and engaged in work specifically related to the programmes:

- Haemoglobinopathy laboratories
- Down's Syndrome Screening Laboratory and DQASS (Down's Syndrome Quality Assurance Support Service)
- Virology/microbiology laboratories
- All Wales Medical Genetics
- Welsh Blood Service

UK national screening programmes

The Director of Screening and Public Health Consultant lead for the Antenatal Screening Programme chairs the Fetal and Maternal and Child Health meeting which is an advisory group for the UK National Screening Committee.

ASW Regional Coordinators attend Public Health England meetings of:

Infectious Diseases in
Pregnancy Screening
Programme (IDPS)

Sickle Cell and Thalassaemia
Screening Programme

Fetal Anomaly Screening
Programme (FASP) Advisory
Group

FASP Laboratory and
Ultrasound Subgroup

FASP Non Invasive Prenatal
Testing (NIPT) Project Board

FASP NIPT Patient Information
and Education Subgroup

FASP NIPT Data Group

Radiology service meetings

ASW attended and have engaged in work specifically related to ultrasonography:

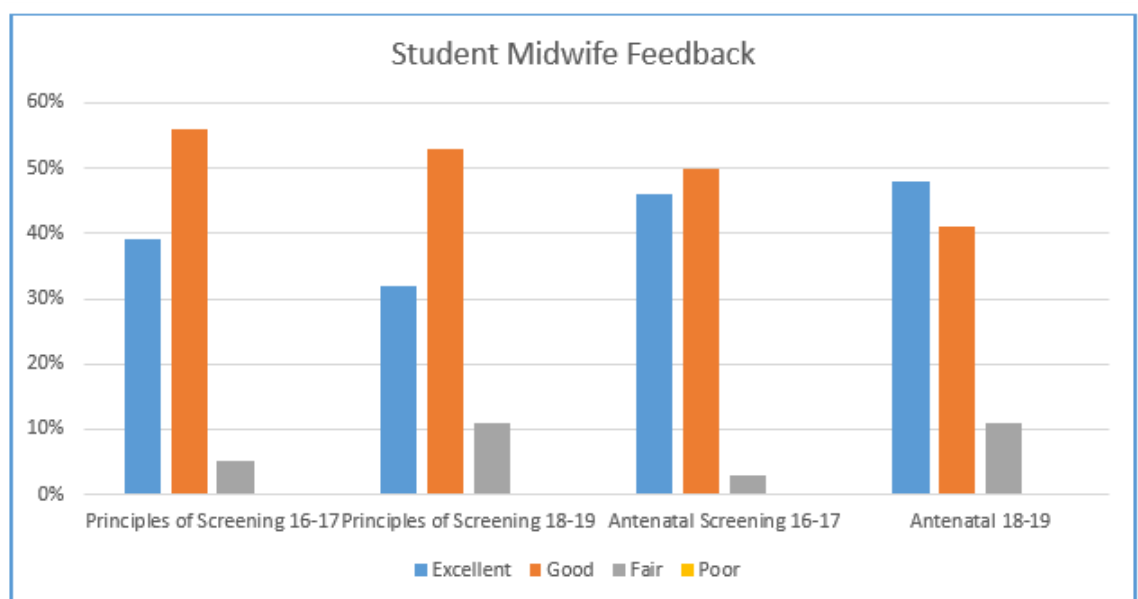
- Welsh Radiology Information System management meetings
- British Medical Ultrasound Society(BMUS)

HOMed and universities

ASW provides training on the antenatal screening programmes to student midwives in the four Welsh universities. Maternal and Child Screening (MAC) and Head of Midwifery educationalist group (HOMed) wanted to ensure that education for student midwives was offered in a consistent manner for all three MAC programmes. Two half days training are provided for four Welsh universities where each of the MAC programmes provide screening updates.

4.2.2 Student midwife education sessions

In preparation for the 2018-2019 student midwife education sessions, students were invited to complete the ASW e-learning package on Down's syndrome, Edwards' syndrome and Patau's syndrome prior to attending a face-to face presentation. This enabled interactive training sessions, which had been suggested in student feedback. This allowed time to focus on questions arising from the Down's syndrome, Edwards' syndrome and Patau's syndrome screening e-learning package and focussed group work on communication and informed consent.



4.2.3 Student midwives conference

ASW were invited to attend the All Wales Student Midwife Conference in May 2018. The event was hosted by the University of South Wales midwifery society and was well attended by midwifery students from across the UK.



MAC/ASW were available to highlight information resources and address screening queries during the conference and were subsequently invited to attend the 2019 conference.



4.2.4 Principles of screening education update

A revision of the MAC generic Principles of Screening presentation was carried out in collaboration with the other MAC screening programmes to heighten student midwives awareness of informed consent.



4.2.5 Maternal and Child (MAC) governance leads

The health boards in Wales have an identified named governance lead for Maternal and Child Screening. These roles manage the strategic governance for the MAC screening programmes within each health board and are funded by MAC for one day per week. 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, sub group and workstream meetings.



4.3 Working in partnership with health boards

Antenatal screening coordinators



ASW meet regularly, and work closely with health board 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. This includes performance management and high level programme risk issues, in conjunction with the MAC governance leads.



Ultrasound obstetric leads and NT leads

Radiology service managers

ASW work with health board radiology service managers (RSM) on quality matters pertinent to antenatal screening ultrasound issues. These include exploration of data retrieval in a more robust and streamline manner and liaising directly with ultrasound obstetric leads where there are issues with the all Wales sonographer performance monitored via DQASS.

4.4 Engaging with the public and professionals

You said, we did information leaflet for fathers

You said

Antenatal screening coordinators said it would be beneficial to have a leaflet for fathers when they are offered screening for sickle cell and thalassaemia

We did

We asked permission from PHE and amended the leaflet to use in Wales



You said

You preferred us to talk about "your baby" rather than "the baby"

We did

We changed the wording in our information for women leaflets

Service user experience

To monitor service improvements new mothers were invited to complete a biannual service user survey. The survey consists of core questions about each of the MAC screening programmes. Approximately 300 surveys were distributed in two week periods during September 2018 and April 2019 with a return rate of 96% and 99% respectively. The survey results are analysed by ASW and fed back to health board MAC governance leads.

"Staff were always good at explaining the procedures and happy to help if we wanted further information"

"20 week scan, would have liked more information on what we could see"

The survey also gives the opportunity for qualitative feedback in the form of free text comments which relate largely to the health boards providing the screening.

Pre-test information for women leaflets

An annual review of literature for women was undertaken. Amendments were made where current guidance had changed. ASW worked with stakeholders to ensure that leaflets were amended in line with up to date research and evidence.



Ensuring websites are current

ASW website review

Reviews of the ASW professional and public pages of the website have been incorporated into the operational plan, and are regularly reviewed to enable easier navigation and ensure information is accurate. During this timeframe, the ASW Policy, Standards and Protocols consultation document has been made available on the website for a period of public consultation prior to publication.



On both public and professional sections of the website, a link to a feedback form has been provided. The opportunity to seek further feedback from service users has also been utilised by asking service users

to complete an on line survey regarding some new information for women which has been included on the website.

NHS Direct Wales website review

ASW continues to work closely with NHS Direct Wales to ensure antenatal screening information published on their website reflects the antenatal screening programmes in Wales.



4.5 Performance management and governance within the health boards

ASW monitor the performance of specific standards and feedback this performance to the health boards. Health board leads for the specific specialties are responsible for producing and managing action plans where performance is below standard with the aim of improving the standards in their health board. ASW meet regularly with the health board antenatal screening coordinators, MAC governance leads, and ultrasound obstetric leads to discuss performance and provide support.

Biannual performance indicators report

Unlike the other population-based screening programmes in Wales, antenatal screening is not funded, or directly managed, by Public Health Wales, but is delivered by and funded within health boards. 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 Regional Coordinators meet biannually with the lead professionals within each health board to discuss and provide support in relation to the performance indicator report. However, due to data collection issues the

All Wales - Six Monthly Report Summary						
April 2019						
<p>Service Description</p> <p>Antenatal screening is undertaken to detect defined serious conditions present in either the mother or baby that may have an adverse effect on the health of either, and for which an effective intervention is available and warranted. For some conditions, preventative treatment is available during the antenatal period or after delivery to improve the baby's health. For others, the condition can be identified during the antenatal period but no preventative treatment is available. With high quality counselling, women can make an informed choice about whether they wish to continue the pregnancy and appropriate support, depending on their ultimate choice, can be arranged.</p>						
Indicator	Name	Anticipated Standard	Oct-17	Apr-18	Oct-18	Apr-19
ASW-1	Communicable disease screening: Results provided to women	≥100% by 15 working days				
ASW-11a	Completion of Down's syndrome screening request cards - Combined	≥100% complete				
ASW-11b	Completion of Down's syndrome screening request cards - Quad	≥98% complete				
ASW-15	Maternal hepatitis B vaccination (first dose only)	100%				
ASW-16	Maternal Anti D given	100%				
ASW-23	Dating of early pregnancy scan	≥100%				
ASW-24	Severely preterm counselling	≥95%				
ASW-25	Re-use of HIV screening	100%				
ASW-26	Hardness of testing of biological father of the baby for sickle cell and thalassaemia	90% (Applicable from October 2018)				
ASW-27	Hardness of neonatal tests for sickle cell and thalassaemia	100% (Applicable from October 2018)				
ASW-28	Record Keeping: Antenatal Blood Group & Antibodies Screening History Taken Recorded in the Local Midwifery Record	100%				
ASW-29a	Record Keeping: Antenatal Blood Group & Antibodies Screening Results Recorded in the Local Midwifery Record	100%				
ASW-29b	Not met achievement of early pregnancy dating scan for combined screening	≤7%				

October 2018 Performance Indicators were not reported whilst work to investigate data collection problems was undertaken.

Performance indicator workshop

During the 2017-18 performance indicator reporting rounds it became evident that there were discrepancies with data received from health boards, which was reflected throughout Wales.

In September 2018 ASW facilitated a multi-disciplinary workshop to explore health board data collection issues and possible solutions.

Some of the multifactorial issues identified included:

- Inconsistent use of ultrasound codes and phrases
- Screening blood tests and ultrasound scans being performed at different times
- Variation in health board methods of recording and storing data
- Differences in local processes of data collection

Following the All Wales meeting, ASW formulated an options appraisal for further discussion with health boards and Welsh Government. ASW are continuing to work collaboratively with health boards to ensure data provided is as robust as possible.

5. Programme specific

5.1.1 Down's syndrome, Edwards' syndrome and Patau's syndrome screening

On 30 April 2018 all health boards in Wales implemented the offer of screening for Down's syndrome, Edwards' syndrome and Patau's syndrome to women who are between 11-14 weeks of pregnancy using the combined test for singleton and twin pregnancies. For women whose early pregnancy scan is later than 14 weeks, or if the nuchal translucency measurement is not obtained, the quadruple screening test is offered at 15 to 18 weeks of pregnancy. Health boards commenced the offer of NIPT (non-invasive prenatal testing) as a contingency test for women with a singleton pregnancy who have a higher chance result from either the combined or quadruple test, or an invasive test. The project was led by ASW and the NIPT Project Board consisted of representation from Welsh Government, stakeholders and third sector organisations.



Prior to implementation of the screening offer in health boards, work was undertaken by members of the NIPT Project Board on a number of workstreams:

Updating

ASW Policy,
Standards and
Protocols

Screening
information
leaflets for women

Supporting

The All Wales Down's Syndrome Screening
Laboratory and All Wales Medical Genetic
Laboratory to ensure successful
implementation

Health board implementation teams pre and
post introduction of the offer of the screening

Developing

An education
strategy and
resources for
professionals

Producing

An information sheet for professionals discussing screening for Down's syndrome, Edwards' syndrome and Patau's syndrome in a twin pregnancy

An information booklet for women who are at a higher chance of having a baby with a chromosomal abnormality

5.1.2 Interview and focus group work

In 2019 prior to republishing the pre-test 'Screening for Down's syndrome, Edwards' syndrome and Patau's syndrome in pregnancy' leaflet ASW sought to gather the views of women about the pre-test information given prior to being offered a screening test for Down's syndrome, Edwards' syndrome and Patau's syndrome, and, more specifically, the medical conditions associated with Down's syndrome.

This was undertaken by working collaboratively with Public Health Wales Screening Engagement Team (SET). The SET team work across all national screening programmes in Wales and with a variety of partners in relation to screening.

Women were recruited into focus groups via health board and third sector partners. Each of the focus groups were asked to consider three slightly different versions of the pre-test information leaflet.



Focus group findings and actions

Findings	Actions
There was a consensus that statistical detail included about dementia was not necessary to include in the leaflet.	Medical information regarding dementia has been removed from the newly printed versions of the leaflet.
With complex information, such as in the current leaflet, it was suggested that tiered information with less detail at the start of the screening pathway and signposting to more detailed information for those who require it may be a preferred option.	ASW will be undertaking further user engagement with pregnant women throughout Wales regarding the pre-test information leaflet, Screening for Down's syndrome, Edwards' syndrome and Patau's syndrome during 2019-2020 to discuss this further.
There was no clear consensus with regards to the medical information	Each of the participants in the focus group meetings has been informed of the outcome actions. There is further engagement work planned for 2019-20 to clarify further

5.1.3 Evaluation of the NIPT project

The UKNSC recommended screening using the NIPT test as an evaluative roll out and addressing specific questions during evaluation of the project.

The Project Evaluation Board agreed an evaluation format to address the questions raised by the UKNSC.

The Evaluation Board has recommended which data needs to be collected from the laboratories and other parts of the service to answer the evaluation questions. Also a review of the resources for women has been undertaken, to include the Down's syndrome, Edwards' syndrome and Patau's syndrome film clip and the Information for women offered further tests for suspected chromosomal conditions booklet.

5.1.4 Information for women review

Down's syndrome, Edwards' syndrome and Patau's syndrome film clip review.



A [film clip](#) was produced by ASW to give women more information for Down's syndrome, Edwards' syndrome and Patau's syndrome screening and as an aid in their decision making on whether to have the screening test or not. A survey asking women's

views on the film clip was carried out in all antenatal clinics in Wales over a one week period during June 2018.



of women who answered the questionnaire found the film clip easy to understand



of women reported that the film clip contained information to help them decide whether they wanted to have the screening test.



of respondents replied that the questions at the end of the film clip were useful in their decision-making



of women said they would recommend this film clip to a friend or family member who was pregnant.

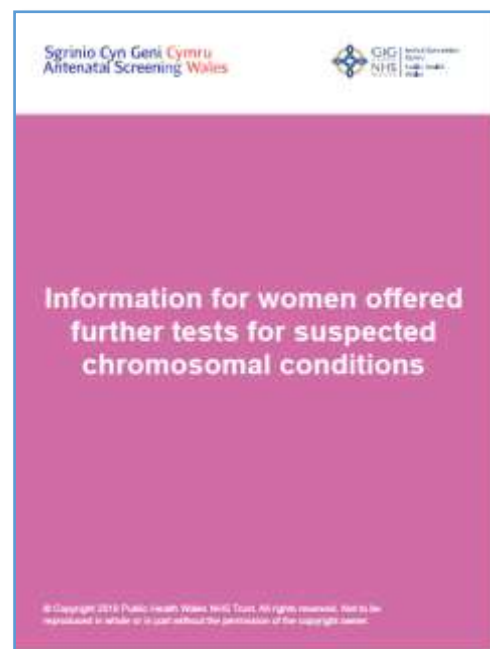
Information for women offered further tests for suspected chromosomal conditions' review

This ASW booklet was written for health professionals to provide to women after the verbal discussion where the woman has a higher chance of having a baby affected by a chromosomal condition. ASW asked health professionals who were using the 'tests for suspected chromosomal conditions' to review the usability of the booklet with women each time they used the booklet over a three month period (July-September 2018).

It was written as a generic booklet and has chapters pertinent to certain conditions and testing. The booklet contained new information on NIPT and a revision of the information for invasive testing.



of health professionals found the booklet easy to navigate



ASW asked the health professionals to provide any feedback on the booklet they had received from women.

Some of the comments received were,

Really easy to identify relevant sections

A lot of information, a bit put off by the size of the booklet

Useful to read at home following discussions

Further evaluation of the booklet will be carried out at the end of 2019.

5.2. Sickle cell and thalassaemia

Audit of antenatal sickle cell and thalassaemia request card

ASW carried out an annual audit of request card completion, following identification of a trend in errors being made in antenatal screening sickle cell and thalassaemia request card completion.

The snapshot audit was carried out within the health board laboratories during June 2018 and information analysed by ASW. A teaching aid has been produced for antenatal screening coordinators, for use within the health board, to help with correct request card completion

Completion of Antenatal Sickle Cell and Thalassaemia Screening Request Card

Lead professional/hospital
Clear details of where to send the report are required. Please state if Royal Glamorgan or Royal Gwent. RGH is not sufficient as a location.

Patient ID
Clear identification of the patient is required to ensure results are attributed to the correct individual

Sample type
Blood ☐ FBC ☐ FBC and iron studies ☐ FBC and iron studies and thalassaemia screen ☐ Urine ☐ CSF ☐ Other: _____

Fasting status
FASTING ☐ NON-FASTING ☐

Ethnic origins
Tick one request box only:
☐ Both mother and father of the baby ethnic origins must be documented by country to assess the possible significance of the findings. Do not use the term "Caucasian". If the ethnic origins are unknown please document "unknown".
☐ Tick this box if: the woman declines sickle cell and thalassaemia screening. A FBC only will be performed.
☐ Tick this box if: the woman and father of the baby are from UK or Ireland and the woman has consented to further testing if MCH<27
☐ Tick this box if: family origin of mother or father of the baby non-UK or Ireland, or adopted, or unknown-egg donor or sperm donor or family history of sickle cell or thalassaemia

Date of collection
It is essential to date the sample for the laboratory to test in a timely manner.

Both boxes:
* requested by and *signature are required to be completed.

Both mother and father of the baby ethnic origins must be documented by country to assess the possible significance of the findings. Do not use the term "Caucasian". If the ethnic origins are unknown please document "unknown".

Tick this box if:
the woman declines sickle cell and thalassaemia screening. A FBC only will be performed.

Tick this box if:
the woman and father of the baby are from UK or Ireland and the woman has consented to further testing if MCH<27

Tick this box if:
family origin of mother or father of the baby non-UK or Ireland, or adopted, or unknown-egg donor or sperm donor or family history of sickle cell or thalassaemia

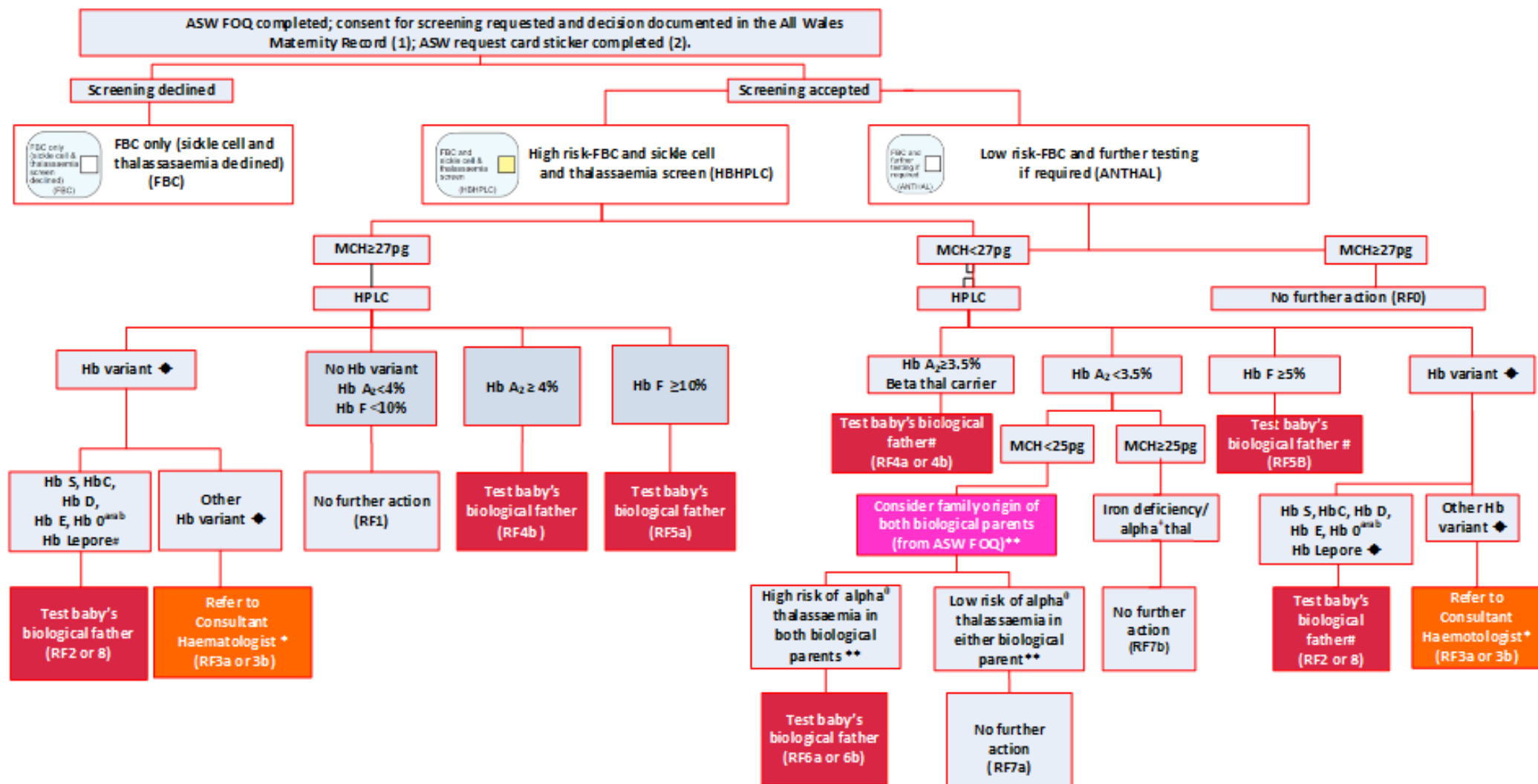
Both mother and father of the baby ethnic origins must be documented by country to assess the possible significance of the findings. Do not use the term "Caucasian". If the ethnic origins are unknown please document "unknown".

Visits to haemoglobinopathy laboratories in Wales

ASW visited every health board haemoglobinopathy laboratory in Wales during this timeframe. Discussions concentrated upon

- Sickle cell and thalassaemia audit for the health board
- Generic emailing of results and errors to the health board
- Changes to ASW standards and protocols
- Neonatal testing of high risk babies
- Low prevalence algorithm used in Wales

Low prevalence algorithm for use in Wales



* Refer analytical results to consultant for an opinion on the need for a clinical referral.

** Consider high risk if any family origins in China (including Hong Kong), Taiwan, Thailand, Cambodia, Laos, Vietnam, Burma (Myanmar), Malaysia, Singapore, Indonesia, Philippines, Cyprus, Greece, Sardinia, Turkey, or if ethnic/family origin uncertain/unknown. Reconsider low risk couples if fetal anaemia/hydrops seen on ultrasound scanning or if there is a family history of hydrops fetals.

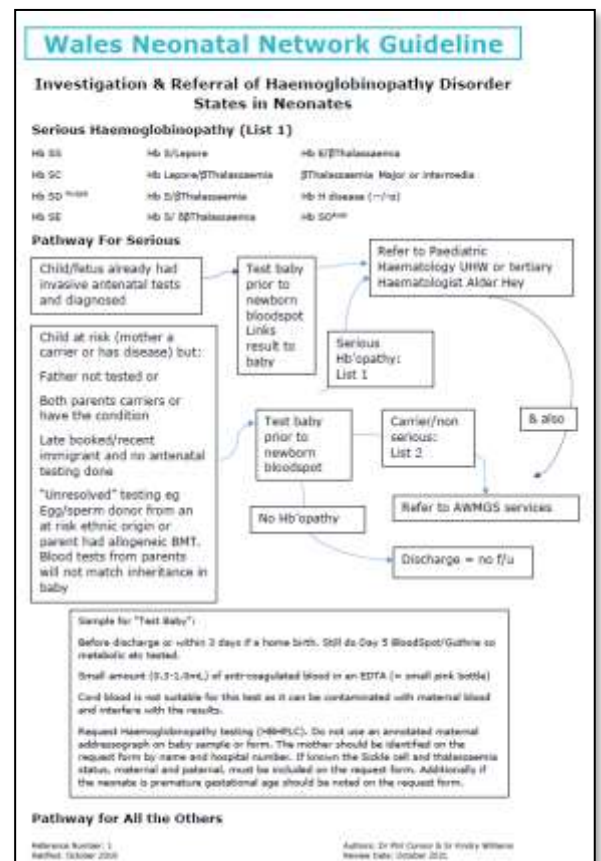
*** Low risk or high risk as determined by the ASW family origin question. Note if a baby's biological father is in a high risk family origin group, test the mother's sample regardless of her family origins.

In all cases consider co-existing α^0 thalassaemia if both parents are from a high risk area (***) and MCH < 25 pg.

\blacklozenge Consider co-existing beta thalassaemia.

Review of antenatal and neonatal pathway for babies identified as at risk for haemoglobinopathies

ASW has been working in partnership with the health board antenatal screening co-ordinators, All Wales Medical Genetics and the Neonatal Network and have produced an All Wales pathway to identify, refer and test babies identified as being at risk of a serious haemoglobinopathy. This pathway is now available on the Wales Neonatal Network website.



5.3 Blood group and antibody screening

Cell-free DNA testing in non-sensitised RhD negative women in pregnancy

ASW is collaborating with Welsh Blood Service (WBS) on a project to scope and develop an improved pathway for cell-free fetal DNA testing for all pregnant women in Wales who are RhD negative and not already sensitised to D antigen.

ASW have commenced initial discussions with WBS regarding this project and will continue to collaborate with WBS and health boards in Wales to scope the feasibility of introducing an improved pathway.

5.4 Communicable Diseases

Audit of hepatitis B positive/reactive results in pregnancy

In 2017 ASW implemented a protocol to recommend hepatitis B DNA (viral load) testing at the time of the confirmatory sample to all pregnant women who were diagnosed with hepatitis B. This was to identify the 'at risk' babies so that treatment could be offered to a mother with a high viral load in the third trimester, thus reducing the risk of transmission to her baby. Following implementation, an audit of hepatitis B positive, antenatal samples received in the Cardiff PHW virology laboratory has been undertaken. The audit was of samples received in the laboratory between October 2017-November 2018.

- ASW developed audit questions for all antenatal samples received which had hepatitis B positive results or hepatitis B reactive results.
- Audit and analysis of the sample requests were performed by PHW virology laboratory University Hospital of Wales
- Audit results will be shared with:
 - health boards, head of midwifery, antenatal screening coordinators and MAC governance leads
 - Virology/microbiology laboratories in Wales
 - health boards Gastroenterology/hepatology teams

5.5 Ultrasound

Vanished twin literature review and recommendations

This guidance was updated in 2018 to reflect the changes to the Down's syndrome screening programme.

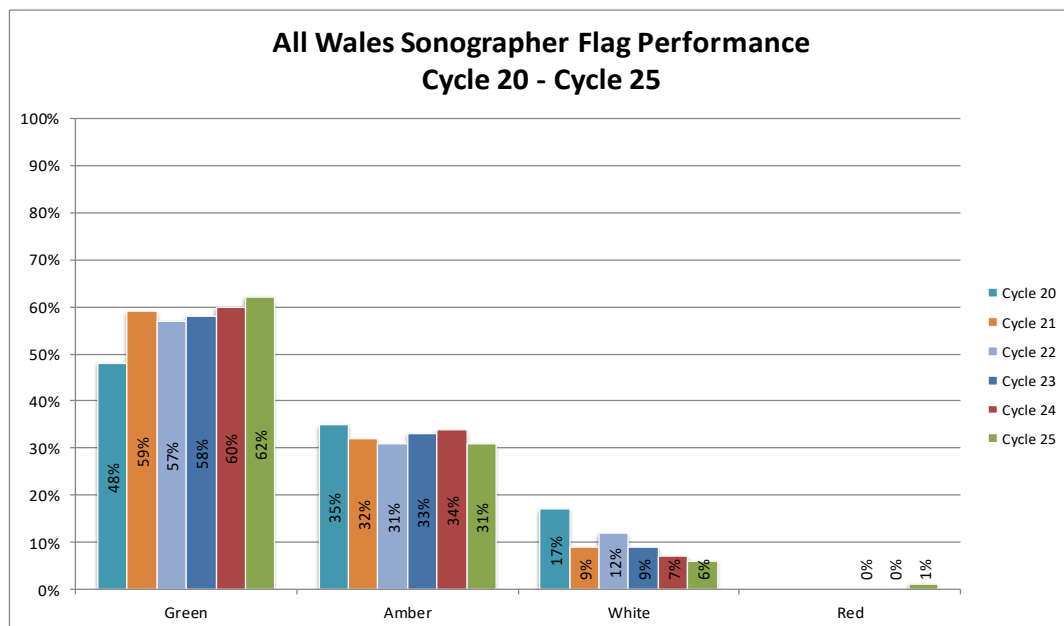
The guidance now includes information on screening for Edwards' syndrome and Patau's syndrome and screening for the three conditions in a twin pregnancy.

Biannual DQASS report

Every Down's syndrome, Edwards' syndrome and Patau's syndrome combined screening test must have an accompanying request card including the fetus' CRL (crown rump measurement) and NT (nuchal translucency) measurement recorded. These measurements are obtained by ultrasound by a sonographer on the day that the maternal blood sample is collected. Each sonographer has a unique identification code which is submitted along with the measurements on the same request card to the All Wales Down's



Screening Laboratory. The All Wales Down's Screening Laboratory sends all the data, including the sonographer codes, to DQASS every 6 months. DQASS produce a plot for each individual sonographer who participates in the NT Programme from this information. Cycles 24 and 25 of this DQASS report were reported to the health boards in 2018-2019.



The changed flagged status in cycle 25 emphasised the requirement for sonographers to maintain their own diagnostic plots and for health board monitoring of ultrasound images and NT diagnostic plots. Learning around the changed flag status also indicated that some ultrasound machine settings may require further adjustment. ASW have invited ultrasound machine applications specialists to the 2019 ASW joint NT lead and obstetric lead sonographers meeting to present "How to obtain the best images from your machines".

Image review in line with DQASS report

An ultrasound image review is carried out on a biannual basis. The ASW ultrasound coordinator reviews and assesses three paired images of crown rump length (CRL) and nuchal translucency (NT) for each of the Health Boards NT lead sonographers. In turn, the NT lead, on receipt of the biannual DQASS report, will assess the individual sonographer's plot and review it with the sonographer making comparisons with the previous cycle. The review follows strict criteria which assess the quality of the scans being performed for the screening programme.

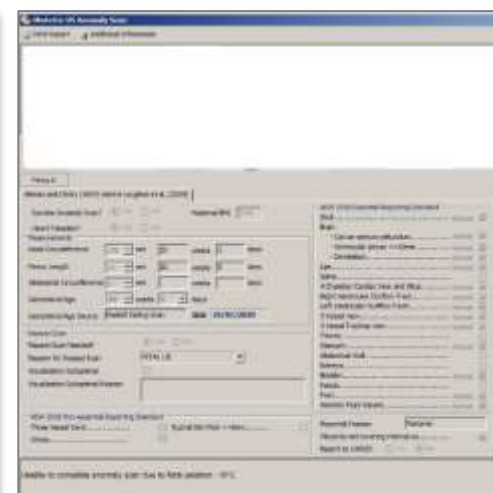
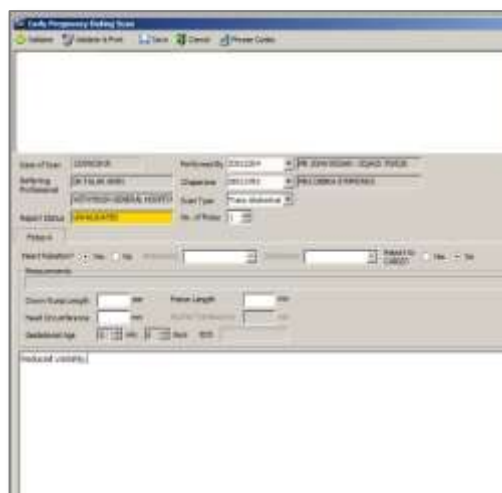


Ongoing training and audit of cardiac leads and obstetric leads role

Each health board in Wales has an obstetric ultrasound lead, nuchal translucency lead and a fetal cardiac ultrasound lead. They monitor and audit their respective aspects of the antenatal ultrasound screening programme. ASW support these roles. During this report timeframe, ASW has provided patient based clinical hands-on training from Fetal Cardiology Consultants in Wales on cardiac views and fetal arrhythmias. They have also received training on facilitating anomaly audits.

RadIS reporting module

The RadIS obstetric reporting module is an electronic information system for radiological data reporting which in the ASW programme is used for two obstetric ultrasound screening tests: the early pregnancy dating scan and the fetal anomaly scan. ASW work with NHS Wales Informatics



Service (NWIS) to continuously develop the reporting module to ensure that there is consistency in reporting throughout Wales and ease of data collection and analysis for audit purposes. However, there are slight

differences in templates used in some of the health boards in Wales. A newer version of RadIS is currently being rolled-out throughout Wales. ASW are supporting the roll-out and ensuring that the sonographers are using the CARIS reporting tool within the screen which enables ultrasound anomalies detected on the early pregnancy dating scan and anomaly scan to be directly sent to the Congenital Anomaly Register and Information Service (CARIS) for early and more accurate reporting.

Audit of fetal anomaly images

A second audit of ultrasound images focussed on the anomaly scan was carried out in March 2018. Images audited were of:

- Head circumference (HC),
- Femur length (FL) and
- transverse section of the abdomen at the level of the kidneys on the anomaly scan.



Every sonographer undertaking anomaly scans was asked to participate in this audit. The images were assessed by the ultrasound obstetric lead on each site against the proforma provided by ASW and the results were returned to ASW. The ASW obstetric ultrasound coordinator assessed the ultrasound obstetric leads using the same criteria.

There were improvements in achieving adequate measurements in each category audited. Recommendations from the audit are:

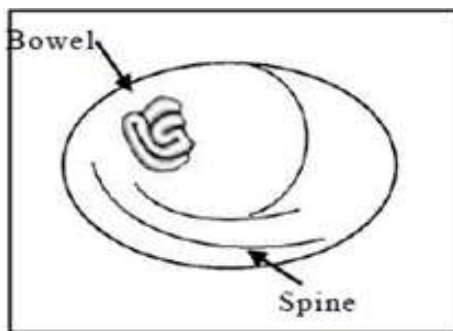
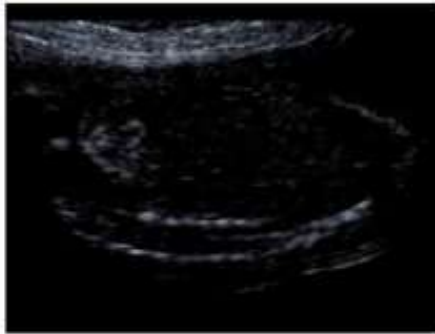
- That every sonographer undertaking anomaly scans in Wales should participate in regular audits of these views and measurements
- Health Board ultrasound obstetric leads action the results of their own audit

Ultrasound Observations Pathways: isolated echogenic bowel, isolated renal pelvis dilatation and isolated ventriculomegaly

Following consultation, all Wales pathways were developed for the reporting of isolated ultrasound observations. Review of the data, from the Welsh Study of Mothers and Babies follow-up study and CARIS, identified best practice for relevant ultrasound observations. Information for women leaflets, pathways and audit protocols have been produced for use within the health boards. Implementation of the new pathways commenced on 1 August 2018.

ASW will audit images from all cases of echogenic bowel recorded for a 12-month period. The aim is to quality assure the accuracy of the echogenic bowel image that is identified on the anomaly scan.

Example of echogenic bowel



Example of incorrect image



The gain is too high in this image and needs to be reduced to show echogenic bowel.

6. Conclusion

This year has been very busy with ASW focussed on the review of the ASW Policy, Standards and Protocols and subsequent development of an education package to inform of the evidence around the changes.

There has been implementation of the offer of screening for Down's syndrome, Edwards' syndrome and Patau's syndrome to include twin pregnancies and the offer of NIPT as a contingency test to women with a singleton pregnancy identified with a higher chance result. The evaluative process of the roll out of the offer of NIPT has commenced and is ongoing. ASW have engaged service users in the review of pre-test information and will be developing this further.

ASW have also commenced discussions to scope and develop a pathway on cell-free fetal DNA testing for all pregnant women in Wales who are RhD negative and not already sensitised to D antigen.

The regular work of ASW has continued including monitoring of screening, supporting health board antenatal screening coordinators, MAC governance leads and lead sonographers. Regular audits, production and roll out of education materials, including some hands on ultrasound training, has also taken place.

Appendix 1

Organisational Structure 2018-2019 ASW within Maternal and Child Screening (MAC)

