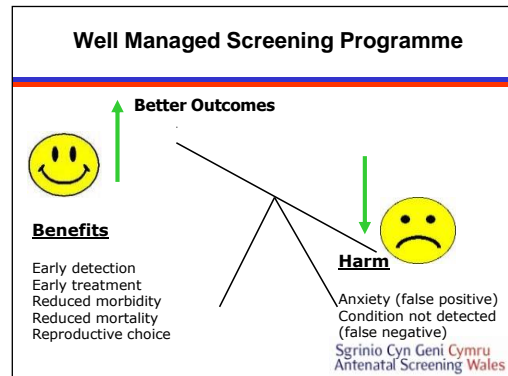


## Information for Professionals

### 2009 Training Needs Analysis Results

Screening programmes can cause harm as well as benefit. As all programmes have the possibility of providing benefit as well as harm, the recommendations of the UK National Screening Committee should be followed on the screening tests that should be offered. This information is available on <http://www.screening.nhs.uk>

Screening programmes have the potential to save lives or improve quality of life through early diagnosis of serious conditions, or offer women reproductive choice. There are always risks involved in providing a screening programme. It is important that the public and health professionals have realistic expectations of what a screening programme can achieve.



### What is a TNA?

A Training Needs Analysis or TNA is a process to find out what training is required and allows prioritisation of education resources. Health Boards are responsible for the provision of in-service education on antenatal screening but Antenatal Screening Wales (ASW) provides training materials for the antenatal screening coordinators to support them in their role.

Undertaking a multi-professional TNA on antenatal screening is a requirement of the Welsh Risk Pool (Standard 15: Maternity, assessment 4.1). ASW has led this exercise

since 2007 and has provided Trusts with individual reports as well as collating an all Wales report.

### TNA Response Rates 2009

Different health professional groups were provided with specific TNAs:

- Midwives and sonographer's were given a quiz and a self reported knowledge rating scale
- Doctors were given a self reported knowledge rating scale.

There was a return rate of 51% from midwives, 42% from doctors and a 61% return rate from sonographers.

### Self Assessed Knowledge

The majority of staff assessed their own knowledge as basic or good knowledge. Some health professionals identified their knowledge as minimal or less and this training need has been reported back to the Health Boards. Particular learning needs were identified as being about;

#### Genetics and inheritance

Information on genetics and inheritance is available at the following web pages:

- ASW: [www.antenatalscreening.org](http://www.antenatalscreening.org)
- National Genetics Education and Development Centre: [www.geneticseducation.nhs.uk](http://www.geneticseducation.nhs.uk)

### Invasive procedures (amniocentesis/ CVS), risks and benefits and cytogenetic results

Amniocentesis is the most common invasive prenatal diagnostic procedure undertaken in the UK. The potential for maternal anxiety and difficulties in informed decision making in relation to accepting or declining an amniocentesis or chorionic villus sampling (CVS) procedure were the principal reasons for the development of the Policy, Standards and Protocols for amniocentesis and CVS document (available at: [www.antenatalscreening.org](http://www.antenatalscreening.org)).

A Health Professional Fact Sheet on amniocentesis and CVS has been produced by ASW (available at: [www.antenatalscreening.org](http://www.antenatalscreening.org)).

## Information for Professionals

### 2009 TNA Multiple Choice Quiz results

Over 90% of answers were correct for most of the questions.

Some of the responses to some of the multiple choice questions have given cause for concern, as the answers indicate that there may be some very basic knowledge gaps for some health professionals providing antenatal screening advice. The results of the questions that caused most concern were the screening test for open spina bifida, information giving and informed consent, reasons for offering screening for hepatitis B and syphilis and the inheritance of sickle cell and thalassaemia disorders. The results and correct answers are discussed in more detail below.

### Neural tube defect screening

#### 1. Question: What test is offered to women in Wales to screen for spina bifida?

**Correct answer: 18-20 weeks scan**

Options	Midwives		Sonographers	
	No.	%	No.	%
<b>18-20 weeks scan</b>	<b>301/377</b>	<b>80</b>	<b>69/90</b>	<b>77</b>
AFP/HCG	35/377	9	5/90	6
AFP	35/377	9	16/90	18
Serum folic acid	2/377	0.5	0	0

The screening test for open spina bifida is the fetal anomaly scan performed between 18+0 and 20+6 weeks gestation. Using raised AFP levels as a screening test for open spina bifida is no longer recommended by the UK National Screening Committee (UKNSC) and has been discontinued in Wales for a number of years.

The 18 to 20 week scan is a better test for neural tube defects than AFP levels, as AFP has higher false positive rates. The fetal anomaly scan performed between 18+0 and 20+6 weeks gestation has a 90% detection rate for open spina bifida. In a small number of cases the presentation of open spina bifida is unusual and may not be detected on the scan.

Perhaps confusingly, AFP remains an incidental finding of the Triple test (used as part of Down's syndrome screening). Health Boards have developed local guidelines for handling raised AFP levels when identified on the Down's syndrome screening test. This is very different to 'screening' for open spina bifida. If the first trimester combined test is implemented for Down's syndrome screening then handling raised AFP results will no longer be an issue.

### Information giving and informed consent

#### The complexities of information giving...


Giving information about antenatal screening tests and screening test results can be complex. A substantial number of midwives and doctors are involved in counselling women or providing some aspect of antenatal screening. Studies have highlighted a lack of professional knowledge that hinders the provision of information to women about antenatal screening. It is therefore essential that health professionals are aware of the aim of screening programmes.

Obtaining informed consent is a legal and ethical principle within screening programmes. Consent must be given

voluntarily following appropriate information by people who have the mental capacity to make that decision. Within a very regularised maternity care framework, great care needs to be taken that 'routine tests' are offered in such a way that the woman has a true opportunity for informed consent.

**Are women confused by your explanation?**

- Keep it simple
- Use non professional language
- Try words not numbers
- Seek feedback
- Use visual aids and supporting literature



Sgrinio Cyn Geni Cymru  
Antenatal Screening Wales

## Information for Professionals

### Communicable Disease Screening

#### 2. Question: Antenatal communicable disease screening is compulsory in the UK?

Correct answer: **false**

Answers	Midwives	
	No.	%
True	55/377	15
<b>False</b>	<b>319/377</b>	<b>85</b>

We are very concerned that some professionals might think pregnant women must have antenatal screening rather than be offered antenatal screening. Some midwives were also unclear as the main reasons for offering antenatal screening for hepatitis B and syphilis.

**The current antenatal screening policy in Wales is that...**all women resident in Wales should be offered antenatal screening in every pregnancy for HIV, hepatitis B, syphilis and rubella susceptibility.

Although all pregnant women should be offered communicable disease screening, the woman can choose whether to accept or decline the tests. Any screening or treatment without consent would have medico-legal consequences.

#### 3. Question: Why should antenatal screening for hepatitis B be offered in pregnancy?

Correct answer: **to enable the baby to be vaccinated**

Options	Midwives	
	No.	%
To protect the public	1/377	0.3
To alert staff to the danger of infection	8/377	2
To enable screening of the family	31/377	9
<b>To enable the baby to be vaccinated</b>	<b>331/377</b>	<b>88</b>

Hepatitis B screening is to enable the identification of maternal hepatitis B carriers, whose infants will be at significant risk of contracting hepatitis B at or around the time of delivery and enable the offer of post exposure prophylaxis to the neonate. The

anticipated outcome is that mother to baby transmission of hepatitis B will be significantly reduced by the provision of an appropriate vaccination programme.

There are about 50 women a year in Wales who are hepatitis B positive and whose babies require vaccination. Without immunisation, 90% of neonates infected by hepatitis B can become chronic hepatitis B carriers. The importance of completing the immunisation course should be emphasised to the mother. The hepatitis B vaccine should be given soon after birth, at one month, two months and twelve months. About 95% of perinatal transmission can be prevented by hepatitis B immunisation.

#### 4. Question: Why should antenatal screening for syphilis be offered in pregnancy?

Correct answer: **to prevent congenital syphilis**

Options	Midwives	
	No.	%
To protect NHS staff	3/377	1
<b>To prevent congenital syphilis</b>	<b>335/377</b>	<b>89</b>
For partner screening	15/377	4
For national statistics	0/377	0.0

**The ASW standards state that syphilis screening is...**to identify women who have syphilis in early pregnancy and offer appropriate treatment to substantially reduce the risks of the fetus contracting congenital syphilis. The identification and treatment of this communicable disease also has potential health benefits for the mother. The anticipated outcome is that with early diagnosis and treatment of the mother if required, the risk of a fetus contracting congenital syphilis is reduced.

Women diagnosed with syphilis infection should be referred to a specialist GUM physician and if treatment required, this should be started promptly. Most cases of congenital syphilis can be prevented if maternal treatment occurs before the 19<sup>th</sup> week of pregnancy. Any organ damage already caused by the disease cannot be reversed.

## Information for Professionals

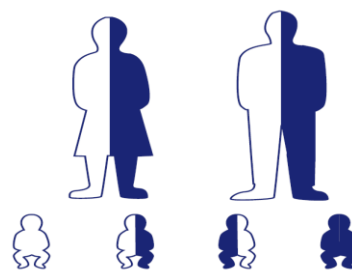
### Sickle cell and Thalassaemia screening

**5. Question: A baby can be affected by a sickle cell disorder or thalassaemia major if..?**

**Correct answers: Both parents are carriers or have a sickle cell disorder or thalassaemia major...**

Answers	Midwives	
	No.	%
Only one parent is a carrier or has a sickle cell disorder or thalassaemia	79/377	21
Neither parent is a carrier or has a sickle cell disorder or thalassaemia major	2/377	0.5
<b>Both parents are carriers or have a sickle cell disorder or thalassaemia major</b>	<b>287/377</b>	<b>76</b>
None of these	5/377	1

- 50% chance of inheriting the sickle cell or thalassaemia gene from one parent and a normal haemoglobin gene from the other, resulting in a carrier state
- 25% chance of the baby inheriting the sickle cell or thalassaemia gene from both parents, resulting in a clinically significant genetic disorder, for example, sickle cell disorder or beta thalassaemia major.



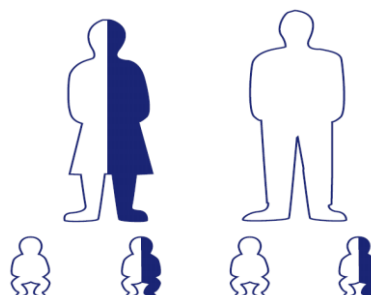
If one parent is a carrier and one is not, there is a 50% or 1 in 2 chance of the baby inheriting the haemoglobin gene variant from one parent and a normal gene from the other, i.e the child would be a carrier.

### What is the inheritance pattern of sickle cell or thalassaemia disorders?

The vast majority of sickle cell and thalassaemia disorders are inherited in an autosomal recessive manner, which means an individual needs to inherit the gene variant **from both parents** in order to have the clinical features of the condition.

If both parents carry the gene there is a

- 25% chance of the baby inheriting a normal haemoglobin gene from both parents



### 2010 TNA

The 2010 TNA will mainly focus on communication skills. Questionnaires will be distributed in January 2010 and the results should be available to help coordinators plan their education sessions by April 2010.