



UK National
Screening Committee



SCREENING IN THE UK: MAKING EFFECTIVE RECOMMENDATIONS

2014 to 2015

Public Health England hosts the
UK National Screening Committee
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2014 to 2015 was a particularly interesting year for the UK National Screening Committee (UK NSC). We made recommendations on 16 topics, and the House of Commons Science and Technology Committee Inquiry into Health Screening published its recommendations. In addition, our regular triennial review began and was expanded to ensure best practice is applied to all aspects of UK NSC business and that we continue to operate to the most robust evidence base and criteria internationally. That adds up to a great deal of thought and reflection about the role, remit and responsibilities of the UK NSC and I am immensely grateful to everyone who contributed to these endeavours.

It is sometimes said we should relax the criteria for assessing or accepting new screening programmes and accept lower quality or less persuasive research when making our



recommendations. The Science and Technology Committee considered this issue when conducting its inquiry into health screening. After receiving verbal evidence from 19 witnesses and written evidence from 50 organisations, its report (published on 29 October 2014) concluded: "We agree that all screening programmes should be grounded in robust evidence and, given the difficulty of withdrawing a programme, support the idea that the evidential barrier to entry should remain high." The UK NSC will continue to require high quality evidence of the benefits of screening before recommending the introduction of a new programme. In the UK we are known for the rigour with which we assess topics against our appraisal criteria. This was recognised in the University of Warwick report, *International comparisons of screening policy making: a systematic review*, which praised the UK for implementing 'the most integrated and evidence-based screening programmes in the world'. That is why screening helps so many people each year, while minimising any harms.

In line with the Science and Technology Committee's recommendations, the UK NSC has been added to the list of Department of Health Scientific Advisory Bodies. It has also formally adopted the principles of scientific advice to Government and those elements of the Code of Practice for Scientific Advisory Committees (CoPSAC) relevant to the functions of the UK NSC. It also updated its evidence review and consultation process and made clearer what distinguishes a systematic population screening programme from other large scale health programmes.

A major success of the year was the expansion of the NHS Newborn Blood Spot Screening Programme following the UK NSC's recommendation to introduce screening for four additional rare but serious conditions. I am delighted the committee has played a role in identifying around 30 extra babies per year whose lives will be saved or made immeasurably better due to screening and that the programme implemented screening for these conditions so quickly and effectively.

www.gov.uk/government/publications/national-health-screening-government-response

Professor David Walker

Medical Director of University Hospitals of Morecambe Bay NHS Foundation Trust
Chair of the UK National Screening Committee

We have been working hard over the last year to strengthen our evidence process and continue to improve the quality of reviews, for example by bringing greater consistency to how they are written, and increasing the number of reviews we carry out each year. I hope this will help our stakeholders understand how we work and how to feed into our reviews.

Some conditions are much more in the public eye than others and last year we reviewed some with particularly high profiles. About 3.9 million people in the UK have diabetes and this figure is continuing to rise, so it is a huge public health issue. While diabetes seems to be a good candidate for a screening programme, our review showed that screening would not provide benefits over the existing ways that people with diabetes are identified and treated.

Dementia is another example. About 800,000 people in the UK have the condition and it is thought that about 1 in 3 people over 65 will develop dementia. One of Public Health England's priorities is to prevent dementia and reduce its prevalence among older people. So a screening programme would appear to be an obvious thing to take forward. But the UK NSC review showed that the current tests for dementia are not good enough and there would be a huge problem with false positive and false negative results.



In both these cases, we understand that our recommendations can seem counter-intuitive but the reviews have withstood public scrutiny and ensured that precious NHS money and staff can be used in better ways to help people with these conditions.

In this regard, I am pleased that the Science and Technology Committee review reaffirmed the need for the UK NSC to require the highest quality evidence of population benefits before a new screening programme can be recommended. It also confirmed that the UK NSC is the competent body to do this work.

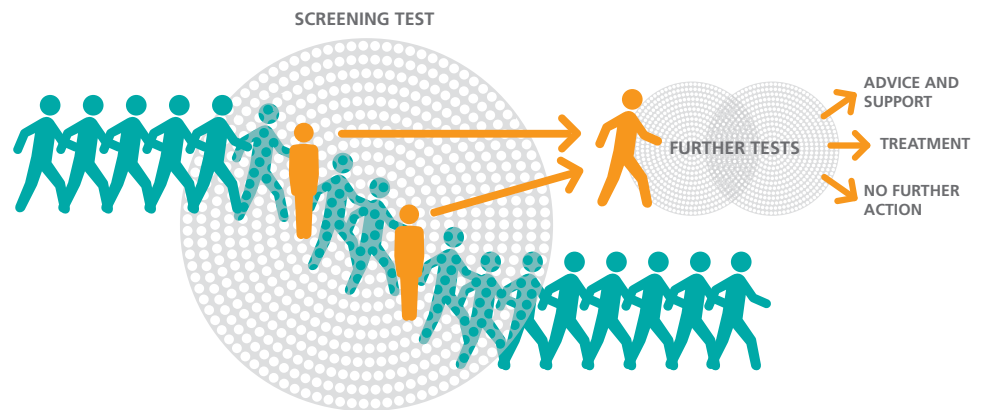
Finally, I would like to offer my huge thanks, as ever, to all the academics and clinicians involved in carrying out the world-class research on which the UK NSC relies to make its recommendations. I am also immensely grateful to the many thousands of dedicated professionals around the country who deliver screening to the public. Without you, the UK NSC recommendations would be meaningless as it is only by implementing and delivering high quality screening services that we put evidence into action and provide real public health benefits.

Dr Anne Mackie

Director of Programmes

UK National Screening Committee

Screening is a process of identifying apparently healthy people who may be at increased risk of a disease or condition. They can then be offered information, further tests and appropriate treatment to reduce their risk and/or any complications arising from the disease or condition.

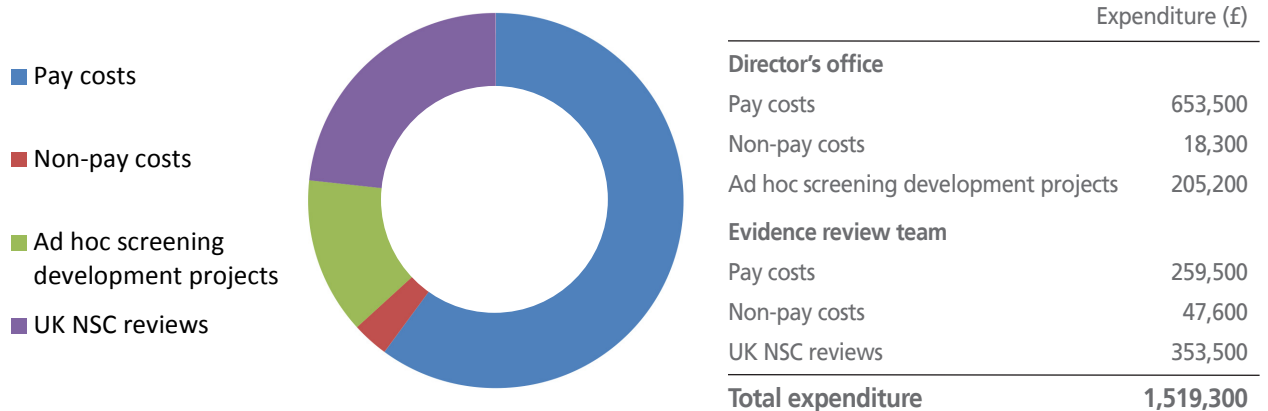


It can be helpful to think of screening like a sieve. In the diagram above a large group of people is invited for the test. The screening test is represented by the sieve. Most people pass through the sieve. This indicates they do not have the condition for which the test is looking.

The people left in the sieve have been identified as needing further investigation. This may mean they have the condition being screened for. They will usually have a further test to clarify the risk.

Trained health professionals will explain the result and take people through the various choices. These may include further tests, treatment, advice and support. At each stage people are free to make their own choices.

UK NSC central expenditure 2014 to 2015



Remit

The UK NSC advises ministers and the NHS in the four UK countries about screening policy and supports the implementation of screening programmes. Conditions are reviewed against internationally recognised criteria according to the UK NSC's [evidence review process](#).

Terms of reference

The UK NSC is an independent committee that:

- advises ministers and the NHS in the four UK countries about all aspects of screening including the case for introducing new population screening programmes and for continuing, modifying or withdrawing existing population programmes based on a set of [internationally recognised criteria](#) and a rigorous evidence review process
- supports implementation of screening programmes in the four countries, including the development of high level standards, and maintains oversight of the evidence relating to the balance of good and harm as well as the overall cost effectiveness of existing programmes
- works with partners to ensure it keeps abreast of scientific developments in screening, including screening trials, screening policy in other countries and emerging technologies
- is accountable to the four chief medical officers (CMOs), who agree work plans for the UK NSC on an annual basis

The UK NSC's [database of recommendations](#) sets out more than 100 conditions, including recommendations to screen for more than 30. The committee meets three times a year to make new recommendations or update existing ones based on reviews of the best quality evidence available at the time. The evidence review process includes details of how to propose a new topic for consideration, request an early update of a topic where there is new evidence, or suggest a change to an existing screening programme.

Screening in the UK

Each UK health department is responsible for setting its screening policy with the agreement of their respective ministers, taking into account advice from UK NSC.

There are currently 11 managed NHS population screening programmes in England.

Antenatal and newborn:

- sickle cell and thalassaemia
- fetal anomaly
- infectious diseases in pregnancy
- newborn and infant physical examination
- newborn blood spot
- newborn hearing

Young person and adult:

- diabetic eye
- abdominal aortic aneurysm
- breast
- cervical
- bowel cancer

Membership

Chair

Professor David Walker, Medical Director of University Hospitals of Morecambe Bay NHS Foundation Trust

Members

Dr Eric Bajjal, Joint Director of Public Health, NHS Borders

Dr Sunil Bhanot, GP, Basingstoke

Ms Alison Brown, Consumer Representative

Professor Roger Brownsword, School of Law, King's College London

Professor Martin Buxton, Emeritus Professor of Health Economics, Brunel University

Professor Alan Cameron, Obstetrician at The Queen Mother's Hospital, Glasgow

Professor D Gareth R Evans, Consultant in Genetics Medicine, St Mary's Hospital, Manchester

Ms Jane Fisher, Patient and Public Voice (PPV)

Dr Surendra Kumar, GP, Widnes

Moira Morris, Patient and Public Voice (PPV)

Observers:

Dr Hilary Angwin, Chair of Fetal Maternal and Child Health Sub group and Screening and Immunisation lead

Dr Margaret Boyle, Senior Medical Officer, Department of Health, Social Services and Public Safety Northern Ireland

Ms Majella Byrne, Acting Director, National Cancer Screening Service, the Republic of Ireland

Dr David Elliman, Consultant in Community Child Health, Great Ormond Street Hospital

Dr Rosemary Fox, Director of Screening Division, Public Health Wales

Dr Nick Hicks, National Co-ordinating Centre for HTA

Dr Dorian Kennedy, Sexual health and Screening, Department of Health

Dr Janet Little, Public Health Consultant, Public Health Agency Northern Ireland

Dr Heather Payne, Consultant Paediatrician, Senior Medical Officer for Maternal and Child Health, Welsh Government

Dr Terry O'Kelly, Senior Medical Officer, Scottish Government

Mr Scott Sutherland, Scottish Government

Ms Jo Taylor, Sexual health and Screening, Department of Health

Secretariat:

Dr Anne Mackie, UK NSC Director of Programmes
Professor Julietta Patnick, NHS Cancer Screening Programme Director

Mr John Marshall, Evidence Manager

Mr Nick Johnstone-Waddell, Public and professional information lead, PHE screening


Ms Zeenat Mauthoor, Secretariat Expert Committee & DH Policy Liaison Manager, Public Health England

The UK NSC uses the best available evidence worldwide to assess whether a screening programme should be set up for a new condition. Evidence is used both to recommend the introduction of a new screening programme and to monitor the effectiveness of existing programmes. This evidence usually needs to have been published in peer-reviewed journals, which means it has been subject to critical analysis by other experts.


Evidence is also important for explaining why screening is not recommended for some conditions which people might instinctively feel it should be. In addition, some conditions are tested for as part of the routine care a person may receive. In these cases, testing is the responsibility of the National Institute for Health and Care Excellence (NICE) rather than the UK NSC.

The UK NSC updated the following recommendations during 2014 to 2015:


Atrial fibrillation screening in adults

The condition	Atrial fibrillation causes a fast and erratic heartbeat. It is a complication of various diseases. Medication can slow the heart rate back to normal and ease symptoms. In some cases, treatment can restore the heart back to a normal rhythm.
UK NSC recommendation	A systematic population screening programme is not recommended. 
Reasons	<p>It is not clear that those identified as at risk through screening would benefit from early diagnosis.</p> <p>There are concerns over the available test and the quality of current treatment pathways for atrial fibrillation.</p> <p>The UK NSC identified a need to improve clinical management and standardise the treatment services currently available to those diagnosed with atrial fibrillation.</p>
Next review due	2017/18
More information	legacy.screening.nhs.uk/atrialfibrillation


Bacterial vaginosis screening in pregnancy

The condition	Bacterial vaginosis is the most common cause of abnormal vaginal discharge in women of childbearing age. The condition occurs when there is a change in the natural bacterial balance in the vagina. Although the condition is generally not serious, it has been suggested that it can lead to complications during pregnancy, such as premature birth..
UK NSC recommendation	A systematic population screening programme is not recommended. 
Reasons	The available evidence is limited and could not demonstrate that the presence or absence of bacterial vaginosis could accurately identify which women would suffer complications, specifically preterm labour, and which would not. There is conflicting research on whether the recognised treatment – antibiotics – is effective at reducing the risk of premature birth. Some studies show antibiotics have no effect, while others show a positive or even a negative effect on the rate of preterm labour or the health of the baby.
Next review due	2017/18
More information	legacy.screening.nhs.uk/bacterialvaginosis


Coeliac disease screening in adults

The condition	Coeliac disease is a common bowel condition occurring when the immune system is overly sensitive to a protein called gluten, causing damage to the small intestine. Gluten is found in wheat, rye and barley, which are often used to make foods such as bread, pasta and biscuits.
UK NSC recommendation	A systematic population screening programme is not recommended. 
Reasons	There is no evidence that the early detection and treatment of the condition, before a person experiences symptoms, would lead to any benefit to their overall health outcome.
Next review due	2017/18
More information	legacy.screening.nhs.uk/coeliacdisease


Pulse oximetry testing as part of congenital heart disease screening in newborns

The condition	Congenital heart defects (CHDs) affect about 8 in 1,000 newborn babies (approximately 1%). CHDs cover a wide range of problems of the heart. Some defects resolve by themselves while more severe defects require urgent treatment. In the vast majority of cases, the cause of the problem is not known. In families where there is an affected child there is usually only a slight increase in risk of around 3% for future pregnancies. In some families with a recognised genetic cause, the risk of recurrent heart problems in future pregnancy is much higher.
UK NSC recommendation	A systematic population screening programme is not recommended. 
Reasons	The UK NSC recommends piloting the use of the pulse oximetry test to evaluate the potential benefits of its use as a new screening test for congenital heart disease.
Next review due	Upon completion of the pilot
More information	legacy.screening.nhs.uk/congenitalheartdisease

Dementia screening in adults

The condition	Dementia is a common condition that usually affects people over the age of 65. It is a syndrome associated with an ongoing decline of the brain and its abilities, such as memory loss, thinking speed and judgement. Most types of dementia cannot be cured, but with early detection it can be slowed down to maintain mental function.
UK NSC recommendation	A systematic population screening programme is not recommended. 
Reasons	<p>About 7 out of every 100 people over the age of 65 have dementia. If this age group was screened using current tests, about 18 out of every 100 people would receive a positive test result, but:</p> <ul style="list-style-type: none"> • only 6 of these people would actually have dementia • 12 people would receive a positive result but would not have dementia • 1 person who does have dementia would be missed and be falsely reassured <p>Between 7 and 17 out of every 100 people over the age of 65 demonstrate a mild cognitive impairment using current tests. This does not always mean the person has or will develop dementia. Only about 5-10% of these people will develop dementia each year. Because of this, many people would receive positive test results when they would not actually develop dementia.</p>
Next review due	2017/18
More information	legacy.screening.nhs.uk/dementia


Dental disease screening in children

The condition	Tooth decay (also known as dental decay and dental caries) results from a bacterial infection of the teeth.
UK NSC recommendation	The UK NSC confirmed the decision that there is no evidence to support population screening for dental disease among children aged six to nine years. 
Reasons	Nationally, resources would be more effective focusing on prevention of dental disease, especially in relation to tackling health inequalities which form a key part of primary dental care services.
Next review due	2017/18
More information	legacy.screening.nhs.uk/dental


Diabetes screening in adults

The condition	<p>Type 1 diabetes occurs when the body produces no insulin. It is often referred to as insulin-dependent diabetes. It is also sometimes known as juvenile diabetes, or early-onset diabetes, because it usually develops before the age of 40, often in the teenage years.</p> <p>Type 2 diabetes occurs when not enough insulin is produced by the body for it to function properly, or when the body's cells do not react to insulin. This is called insulin resistance. Type 2 diabetes is far more common than type 1 diabetes.</p>
UK NSC recommendation	<p>A systematic population screening programme is not recommended. X</p>
Reasons	<p>It is not clear that early detection through screening would provide any benefit to the overall health of individuals compared to current diagnostic methods.</p> <p>Concerns over the available screening tests include:</p> <ul style="list-style-type: none"> • some people who do not have diabetes may be identified as having other conditions such as high blood pressure, or be at risk of developing diseases such as heart attacks and strokes, and it is not clear what would happen to these individuals • the preferred method of testing could miss up to 20% of people who do in fact have diabetes <p>There have been improvements in the care and treatment for those with diabetes and current opportunistic testing methods have been effective.</p>
Next review due	2017/18
More information	legacy.screening.nhs.uk/diabetes


Gaucher disease screening in newborns

The condition	<p>Gaucher disease is the most common of a group of conditions called lysosomal storage diseases. It is a rare inherited condition caused by a faulty or missing enzyme (a chemical found naturally in the body) used to break down fatty substances from cells. The part of certain cells affected is called the lysosome and the condition leads to the build-up of a fatty substance in cells and organs that become swollen.</p> <p>The severity of symptoms for people with Gaucher disease varies significantly but typical symptoms include bruising, fatigue, low levels of substances needed in the blood (iron and platelets) and enlarged organs such as the liver, spleen, bone and lungs.</p> <p>Left untreated, the condition can cause multiple problems. In rare, more severe cases, it can be fatal for newborn babies and infants. There is no cure but the most common treatment is enzyme replacement therapy and this can often limit the effects of Gaucher disease.</p>
UK NSC recommendation	A systematic population screening programme is not recommended. 
Reasons	<p>There are a number of uncertainties with Gaucher disease, including:</p> <ul style="list-style-type: none"> • predicting how severely an individual, detected through screening, might be affected by the condition – it is not currently possible to identify who will be severely affected by the condition and who will never experience any problems • it is unclear whether earlier treatment following a screening test would be more beneficial than current medical practice of identification and treatment when symptoms develop
Next review due	2017/18
More information	legacy.screening.nhs.uk/gauchers


Glutaric aciduria type 1 (GA1) screening in newborns

The condition	<p>A baby with Glutaric Aciduria Type 1 (GA1) has problems breaking down the amino acids lysine and tryptophan. A minor illness, such as a chest infection or stomach upset, can lead to serious problems and the need for immediate hospital treatment. Early signs can include vomiting, excessive sleepiness and breathing difficulties. Without treatment the child can go into a coma and many patients die in early adulthood. If they recover from the coma there is a high likelihood of brain damage that can affect their ability to control muscles and movements. This means they may be unable to sit, walk, talk or swallow.</p>
UK NSC recommendation	A systematic population screening programme is recommended. 
Reasons	A one year evaluation in the UK found that screening for this rare inherited organic acid disorder will identify babies early and lead to treatment to help prevent serious problems developing.
Next review due	2017/18
More information	legacy.screening.nhs.uk/ga1


Homocystinuria (HCU) screening in newborns

The condition	Homocystinuria (HCU) is a rare disorder that prevents the breakdown of the amino acid homocysteine. Without treatment, most children with HCU have learning difficulties and problems with their eyes. They may also develop bone abnormalities (osteoporosis), blood clots or strokes.
UK NSC recommendation	A systematic population screening programme is recommended. 
Reasons	A one year evaluation in the UK found that screening for this rare inherited organic acid disorder will identify babies early and lead to treatment to help prevent serious problems developing.
Next review due	2017/18
More information	legacy.screening.nhs.uk/hcu


Isovaleric acidaemia (IVA) screening in newborns

The condition	Babies with IVA have problems breaking down the amino acid leucine. Eating too much protein can cause harmful substances to build up in the blood. They can become severely unwell. Early signs can include vomiting, excessive sleepiness, floppiness and rapid breathing. Without treatment, IVA can lead to a coma and permanent brain damage. Some babies with IVA have problems within a few days of birth. Other children become unwell at a few months or years of age, maybe during a minor illness, such as a chest infection or stomach upset. IVA can vary in severity – it is only severe cases that screening aims to identify.
UK NSC recommendation	A systematic population screening programme is recommended. 
Reasons	A one year evaluation in the UK found that screening for this rare inherited organic acid disorder will identify babies early and lead to treatment to help prevent serious problems developing.
Next review due	2017/18
More information	legacy.screening.nhs.uk/iva


Long Chain Hydroxyacyl CoA Dehydrogenase Deficiency (LCHADD) screening in newborns

The condition	LCHADD is a rare condition where babies have problems breaking down certain types of fat to produce energy. Babies with LCHADD are missing an enzyme that helps them break down certain fats. Babies with LCHADD become ill when their body cannot produce enough energy and develop symptoms including poor feeding, irritability, sleepiness, vomiting, breathing difficulties, floppiness and low blood sugar (hypoglycaemia). Without treatment they can develop heart problems, fall into a coma and die. Treatment involves changing the diet so it is low in particular types of fat.
UK NSC recommendation	A systematic population screening programme is not recommended. 
Reasons	A one-year evaluation found no evidence that the test was effective at diagnosing the condition in babies who had no previous symptoms.
Next review due	2017/18
More information	legacy.screening.nhs.uk/lchadd


Maple Syrup Urine Disease (MSUD) screening in newborns

The condition	MSUD is a rare amino acid disorder in which a baby or child has a problem breaking down the amino acids leucine, isoleucine and valine. Most babies with MSUD start to become unwell within a few days of being born. They have problems such as poor feeding, vomiting and excessive sleepiness. Without treatment, this can lead to a coma and permanent brain damage. In older children, a minor illness such as a chest infection or stomach upset can lead to serious problems.
UK NSC recommendation	A systematic population screening programme is recommended. 
Reasons	A one year evaluation in the UK found that screening for this rare inherited organic acid disorder will identify babies early and lead to treatment to help prevent serious problems developing.
Next review due	2017/18
More information	legacy.screening.nhs.uk/msud


Parvovirus B19 infection screening in pregnancy

The condition	Parvovirus B19 is a common infection, usually presenting as erythema infectiosum (rash) in school age children. Parvovirus is an airborne virus usually transmitted through respiratory droplets. The infection usually manifests as a flu-like illness and is often characterised by a rash on the cheeks which can spread. The infection usually lasts a few weeks. However, in both adults and children, about 20-30% of cases do not present any symptoms.
UK NSC recommendation	A systematic population screening programme is not recommended. 
Reasons	The review identified the need for further research into the prevalence and testing methods for the condition. Although screening would identify a large number of susceptible women, there are currently no agreed treatment or prevention methods to protect babies from being infected.
Next review due	2017/18
More information	legacy.screening.nhs.uk/parvovirus

Preterm labour screening in pregnancy

The condition	Preterm babies are born before the 37th week of pregnancy. In the UK, over 7% of babies are born prematurely (preterm labour) each year. Preterm babies are at risk of short and long-term health issues, the severity of which are often linked to how early the baby is born.
UK NSC recommendation	A systematic population screening programme is not recommended. 
Reasons	<p>The measurement of cervical length in asymptomatic women is not reliable enough for use as a screening tool. There are unanswered questions over the timing of the test and there is no standardised 'normal' measurement of cervical length in order to establish what an 'abnormal' measurement is.</p> <p>It is not known when the test should be offered or whether it is reliable in identifying which pregnancies are at risk and which are not. Screening would identify many women as being at risk when they are not, leading to unnecessary preventative treatment. There is not enough evidence that vaginal progesterone (a hormone treatment) is effective at preventing preterm labour or reducing the most severe outcomes (death or disability) for the baby.</p>
Next review due	2017/18
More information	legacy.screening.nhs.uk/pretermlabour

Trisomy 18 (T18) and trisomy 13 (T13) syndromes screening in pregnancy

The condition	<p>Trisomy 18 (Edwards' syndrome) and Trisomy 13 (Patau's syndrome) are rare but very serious conditions which affect a small number of babies every year. As with Down's syndrome, babies with T18 or T13 have an incorrect number of chromosomes in every cell. Chromosomes are structures that carry important information that determine how we develop.</p> <p>Most babies with T18 or T13 die before they are born, are stillborn or die shortly after birth. Some babies may survive to adulthood but this is rare. All babies born with Edwards' or Patau's syndrome have a wide range of problems, which are usually extremely serious. These may include major brain abnormalities, heart problems, unusual head and facial features, growth problems, inability to stand, walk, or talk and problems with their kidneys.</p> <p>Women of any age can have a baby with Edwards' or Patau's syndrome but the risk increases as women age. Edwards' syndrome affects about 3 of every 10,000 births and Patau's about 2 of every 10,000 births. When a woman is tested for Down's syndrome in early pregnancy the ultrasound scan may also suggest that her baby has Edwards' or Patau's syndrome.</p>
UK NSC recommendation	A systematic population screening programme is recommended. 
Reasons	Although Edwards' and Patau's syndromes may be identified through the current 18 – 20 week scan, the UK NSC reviewed the evidence and recommended screening for these conditions earlier in pregnancy. First trimester screening helps provide an earlier diagnosis, allowing women to make decisions about their pregnancy at an earlier stage.
Next review due	N/A
More information	legacy.screening.nhs.uk/t18andt13



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