NSC UK National Screening Committee

Screening in the UK: making effective recommendations

1 April 2017 to 31 March 2018

Public Health England hosts the
UK National Screening Committee
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My role as Independent Chair of the UK National Screening Committee (UK NSC) continues to be stimulating, challenging and thoroughly enjoyable thanks to the enthusiasm and good humour of my colleagues on the committee.

As ever, evidence remains at the heart of everything we do and this review describes how it has been employed between 1 April 2017 and 31 March 2018.

We held a further stakeholder holder event in December 2017 where we focused on evaluation, quality, ethics, informed choice and inequalities. The event was well attended and generated lively discussion. We also held a second successful annual call for topics, and a further call will start in September 2018. We hope that stakeholders will take the opportunity to submit topics for consideration and we look forward to a further round of interesting proposals.

In order to assist the UK NSC with ethical considerations we have set up an ethics task group which met in September 2017 and again in March 2018. These meetings were ably led by Professor Roger Brownsword and provided an excellent framework for in-depth consideration of the important ongoing ethical issues related to screening.

The work of the Adult Reference Group (ARG) and the Fetal Maternal and Child Health (FMCH) Group continues apace, but I am sorry to have to announce that Dr Hilary Angwin has stepped down as Chair of FMCH having been appointed as National Lead for the Screening Quality Assurance Service. Hilary has done a wonderful job leading the group and will be greatly missed but we are glad not to have lost her from the screening community. We are now in the process of seeking a new chair. Dr Ros Given-Wilson has risen to the challenge of the ARG with great vigour and the group has greatly enhanced the main committee's ability to deal with the challenges posed by adult screening.

We are also very pleased to welcome two new members to the Committee: Dr Anne-Marie Slowther, Reader in Ethics at the University of Warwick, and Ms Claire Bailey, Lead Clinical Nurse Specialist in Breast Screening in South West London. We are delighted to have their expertise on the committee and I very much look forward to working with them.

As you will see from this review, we have had some very interesting issues during the past year. Going forward, the challenges of existing programmes and potential future programmes will keep us all very busy.

Professor Bob Steele
Chair, UK National Screening Committee

Personal informed choice is one of the core principles of screening in the UK.

We want the people we invite for screening to consider their invitation carefully before deciding to take part. They need to make an informed decision, and that decision will be personal to them.

During the year, the UK National Screening Committee (UK NSC) consulted on guidance covering the development, production and review of information to support all screening programmes in the UK.

The aim is to ensure all 4 nations in the UK share the same rigorous and transparent approach to developing and maintaining high quality information for the public and professionals.

Central to this guidance is making sure people have the information they need to weigh up their options and make fully informed decisions. That information needs to be understandable and meaningful.

In particular, we are going to use the term personal informed choice rather than just informed choice. This emphasises the fact that screening decisions need to be right for each individual, fitting in with their values and circumstances.

It is very important that we have the right people on the UK NSC to consider the many different challenges and questions facing us.

We are constantly monitoring the membership of the committee to make sure we get this right and have expert cover for all the main issues we deal with.

Ethical considerations are even more important for screening than other areas of healthcare because we send invitations to apparently healthy people who have not sought medical attention for a symptom or health problem. During the year, we therefore trained the committee members, appointed more ethics representatives to the UK NSC and set up an ethics tasks group. We also now have more user representation on the committee and it is very important that we continue to listen to the perspective of the users of screening.

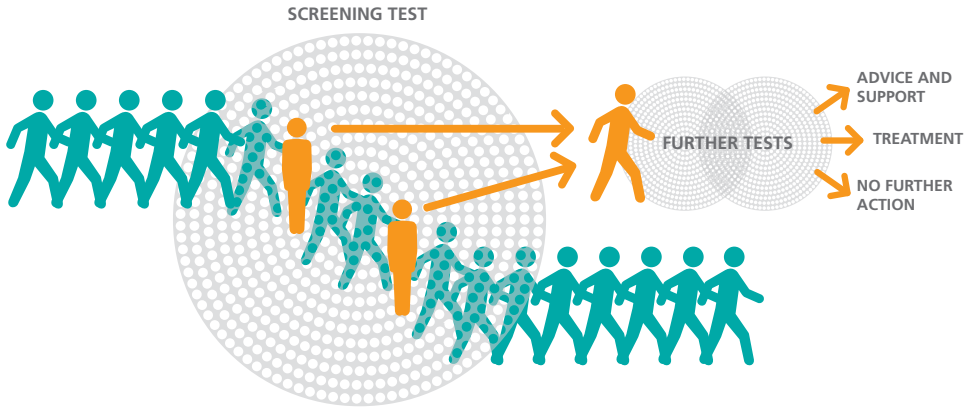
In addition, an Adult Reference Group (ARG) was created. This runs alongside our Fetal Maternal and Child Health (FMCH) Group in order to provide expert advice on screening evidence relating to conditions that affect adults, such as lung cancer and heart disease.

The committee has a wealth of knowledge and experience to call upon to consider some very difficult topics and make some tough choices. We will continue to look for ways to improve the way we work and we will always be guided by the evidence.

I would like to thank the committee members for their support for the work of screening and for their expert advice throughout the year.

Professor 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.

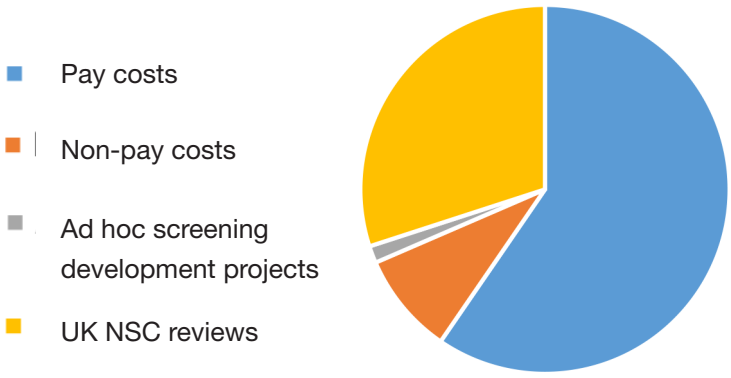


It can be helpful to think of screening like a sieve. In the diagram above a large group of people is invited for the test. The screening test is represented by the sieve. Most people pass through the sieve. This indicates they do not have the condition for which the test is looking.

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 2017 to 2018



	Expenditure (£)
Director's office	
Pay costs	1,191,000
Non-pay costs	216,000
Ad hoc screening development projects	38,000
Evidence review team	
Pay costs	322,000
Non-pay costs	11,000
UK NSC reviews	762,000
Total expenditure	2,540,000

Terms of reference

The UK NSC is an independent committee that:

- advises ministers and the NHS in the 4 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 4 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 4 chief medical officers (CMOs), who agree work plans for the UK NSC on an annual basis

The UK NSC's list of recommendations sets out more than 100 conditions, including recommendations to screen for more than 30. The committee meets 3 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 the UK NSC.

Membership

Chair

- Professor Robert (Bob) Steele, Professor of Surgery and Head of Division of Surgery and Oncology, University of Dundee

Vice-chair

- Dr Graham Shortland, Medical Director and Consultant Paediatrician, Cardiff and Vale University Health Board

Members

- Claire Bailey (appointed January 2018), Lead Clinical Nurse Specialist, Breast Screening, SW London Breast Screening Service
- Professor Roger Brownsword, Professor in Law at King's College London and Bournemouth University
- Professor Alan Cameron, Consultant Obstetrician, Queen Elizabeth University Hospital, Glasgow
- Eleanor Cozens, International Development Consultant, Independent
- Dr Paul Cross, Consultant Cellular Pathologist, Queen Elizabeth Hospital Gateshead Health NHS Foundation Trust
- Dr Hilary Dobson, Deputy Director of the Innovative Healthcare Delivery Programme, University of Edinburgh
- Professor Stephen Duffy, Director of the Policy Research Unit in Cancer Awareness, Screening and Early Diagnosis and Professor of Cancer Screening, Centre for Cancer Prevention, Wolfson Institute of Preventive Medicine
- Professor Gareth R Evans, Consultant in Genetics Medicine, St Mary's Hospital, Manchester
- Jane Fisher, Patient and Public Voice
- Hilary Goodman, Midwife, Hampshire Hospitals NHS Foundation
- Professor Alastair Gray, Director, Health Economics Research Centre, Nuffield Department of Population Health University of Oxford
- Dr John Holden, Joint Head of Medical Division, Medical and Dental Defence Union of Scotland
- Professor Chris Hyde, Professor of Public Health and Clinical Epidemiology, University of Exeter Medical School
- Dr Greg Irving, Clinical Lecturer in General Practice, University of Cambridge
- Mrs Margaret Ann Powell, Patient and Public Voice
- Dr Anne-Marie Slowther (appointed January 2018), Reader in Clinical Ethics, Warwick Medical School, University of Warwick

Four country representatives

- Dr Carol Beattie (appointed July 2017), Senior Medical Officer, Department of Health, Social Services and Public Safety Northern Ireland
- Dr Ailsa Wight, Deputy Director Health Protection, Department of Health
- Sarah Manson, National Screening Programmes, Scottish Government
- Dr Heather Payne, Consultant Paediatrician, Senior Medical Officer for Maternal and Child Health, Welsh Government

Observers

- Natasha Alleyne, Screening Team, Emergency Preparedness and Health Protection Policy, Global and Public Health Group, Department of Health
- Dr Hilary Angwin (stepped down February 2018), Chair of Fetal Maternal and Child Health Group (FMCH)
- Sam Cramond, NHS representative
- Dr David Elliman, Clinical Lead for NHS Newborn Infant Physical Examination Programme and NHS Newborn Blood Spot Screening Programme
- Tim Elliott, Senior Cancer Policy, Department of Health
- Dr Ros Given-Wilson, Chair of Adult Reference Group (ARG)
- Dr Nick Hicks, National Co-ordinating Centre for HTA
- Dr Sharon Hillier, Director of Screening Division, Public Health Wales
- Charles O'Hanlon, Assistant National Director, Head of Screening, National Screening Service, Ireland
- Jean Nicol, Screening Team, Emergency Preparedness and Health Protection Policy, Global and Public Health Group, Department of Health
- Dr Sue Payne, Public Health, Scottish Government

Secretariat

- Professor Anne Mackie, Director, PHE Screening
- John Marshall, Evidence Lead, UK NSC
- Jo Harcombe, National Lead for Stakeholder Information and Professional Education and Training, PHE Screening
- Nick Johnstone-Waddell, Public and Professional Information Lead, PHE Screening
- Zeenat Mauthoor, Secretariat Expert Committee and DH Policy Liaison Manager, 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 cancer
- cervical cancer
- bowel cancer

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 between 1 April 2017 and 31 March 2018:

Biliary atresia

The condition	Biliary atresia is a rare condition that causes the bile ducts to become blocked or inflamed. Bile is a digestive fluid necessary to digest fatty acids and vitamins. If it cannot drain away from the liver, bile can build up and cause serious liver damage in the early years. An operation to allow drainage of the bile ducts can prevent or delay the need for liver transplant which would otherwise be needed. This is called the Kasai procedure. It is important that this is performed before the liver becomes badly damaged. The aim of a screening programme for biliary atresia would be to allow for earlier detection of biliary atresia and reduce the age at which the Kasai procedure is performed.
UK NSC recommendation	Following a review of the evidence against strict criteria, the UK NSC does not currently recommend introducing newborn screening for biliary atresia. ✗
Reasons	A national screening programme is not recommended in the UK because: • there is no reliable test which could be used to find babies with biliary atresia in the first week of life • a small number of countries have introduced screening using stool colour cards, but the age at which babies with biliary atresia have the Kasai procedure is similar in those countries to what it is in the UK
Next review due	2020 to 2021
More information	legacyscreening.phe.org.uk/biliaryatresia

Newborn screening for biotinidase deficiency

The condition	Biotinidase is an enzyme that the body needs to recycle a vitamin called biotin. Biotinidase deficiency is a rare genetic condition where people do not make enough of this enzyme. Babies can inherit the condition from their parents if both parents carry a mutation in the biotinidase gene. There are 2 forms of the condition: a severe or 'profound' deficiency and a milder 'partial' deficiency. Without treatment, people with severe deficiency may develop problems with their nervous system, coordination problems and seizures. People with the milder deficiency may only develop symptoms if they have other illnesses, like an infection. Biotin supplements are the highly effective, lifelong treatment, with no known side effects. Screening may help to identify individuals earlier before symptoms develop.
UK NSC recommendation	Following a review of the evidence against strict criteria, the UK NSC does not currently recommend newborn screening for biotinidase deficiency. ✗
Reasons	A national screening programme for biotinidase deficiency is not recommended in the UK because: • it is not known how many children in the UK are affected • it is still not clear if all screen-detected children need treatment • the optimal screening test threshold and the timing of the test have not been clarified • most children are treated at diagnosis so evidence is not available to inform which screen-detected children would develop symptoms and need biotin treatment, or the optimal dose to give • it is not known whether screening improves outcomes
Next review due	2021 to 2022
More information	legacyscreening.phe.org.uk/biotinidasedeficiency

Chlamydia in pregnancy

The condition	Chlamydia is the most common sexually transmitted infection in the UK. Most people who have chlamydia do not have any obvious signs or symptoms, or the infection may be mild and go undetected. There are some reports that the untreated infection may cause problems during pregnancy, but the evidence on this is not clear. The newborn baby can also be infected; the most common problems for the baby are conjunctivitis and respiratory infections. Usually these are not too serious and can be treated effectively with antibiotics. It has been suggested that offering screening to identify mothers with chlamydia may: • prevent problems during pregnancy • prevent mothers from passing the infection on to their babies
UK NSC recommendation	Following a review of the evidence against strict criteria, the UK NSC does not currently recommend screening for chlamydia in pregnancy. ✗
Reasons	A national screening programme for chlamydia in pregnancy is not recommended in the UK because there is: • currently not enough consistent evidence that having chlamydia in pregnancy will cause any adverse outcomes to the pregnancy • no evidence that screening during pregnancy had benefits for the pregnancy or the outcomes for babies • no evidence of the effects of chlamydia treatment (antibiotics) during pregnancy
Next review due	2021 to 2022
More information	legacyscreening.phe.org.uk/chlamydia-pregnancy

Newborn screening for cytomegalovirus

The condition	Cytomegalovirus (CMV) is a common viral infection found in children and adults. It does not always have symptoms. It does not always need to be treated. It is called congenital CMV infection if it is passed from mother to baby during pregnancy. In most cases the virus does not cause harm to the baby. However, for some it can interfere with the baby's development and cause problems later on, such as hearing loss. Most babies identified as having CMV infection will show symptoms in the first 2 weeks and will be treated using an antiviral drug. The aim of screening would be to identify which babies have the infection and to treat them before they become affected.
UK NSC recommendation	Following a review of the evidence against strict criteria, the UK NSC does not currently recommend introducing newborn screening for cytomegalovirus. ✗
Reasons	An option for newborn screening would be to test a saliva sample, but research is needed to understand if this test is suitable for screening. It is not currently possible to know which babies are going to develop long-term health problems. More research is needed to distinguish between babies who will suffer from the infection and babies who will not. Screening is likely to identify a greater number of babies with the infection who have no symptoms and will not have problems from it. Currently, it is not clear what is the best approach for managing these children and it is unknown whether screening improves their outcomes.
Next review due	2020 to 2021
More information	legacyscreening.phe.org.uk/cytomegalovirus

HTLV (human t-cell lymphotropic virus) in pregnancy

The condition	Human T-cell lymphotropic virus (HTLV) can be passed from person to person through blood transfusion or unprotected sexual contact. HTLV infection can also be passed from mother to child. This is usually through breastfeeding for longer than 6 months. HTLV is common in some parts of the world but not in Western countries such as the UK. Only a small number of people with HTLV develop serious illness. These illnesses can include leukaemia (a form of cancer) or myelopathy (a nervous system condition). There is no cure for HTLV. In areas where HTLV infection is common, the focus is on preventing it being passed from mother to child. This is done by avoiding breastfeeding or limiting the length of time that an infected mother breastfeeds her child.
UK NSC recommendation	Following a review of the evidence against strict criteria, the UK NSC does not currently recommend introducing screening for HTLV infection in pregnancy. 
Reasons	A national screening programme for HTLV is not recommended in the UK because: • the balance of benefit and harm from screening has not been studied • the number of people infected with HTLV in the UK is not known • the risk of a mother passing HTLV to her child through breastfeeding is low unless breastfeeding is continued beyond 6 months • most infants infected with HTLV do not develop symptoms and the risk of developing a serious illness appears to be low • there is no treatment for HTLV found in screened women or babies who acquire the infection despite avoidance of breastfeeding • anxiety, depression and stigma have been reported in women who have been screened and their families
Next review due	2020 to 2021
More information	legacyscreening.phe.org.uk/htlv

Iron deficiency anaemia in children under 5 years of age

The condition	Iron deficiency anaemia (IDA) is the most common form of anaemia and occurs when iron levels are too low to support the production of red blood cells, usually because of a lack of iron in the diet. Children aged under 5 years are especially at risk. It is possible that IDA may affect a child's development, but this is not known for certain. Screening could potentially lead to earlier diagnosis and treatment which may improve health outcomes for young children.
UK NSC recommendation	Following a review of the evidence against strict criteria, the UK NSC does not currently recommend introducing screening for IDA in children under 5 years. 
Reasons	A national screening programme for IDA is not recommended by the UK NSC because: • it is not known how many children in the UK are affected • it is uncertain whether IDA in children under the age of 5 causes adverse developmental outcomes and whether it gets better without treatment • a suitable test is not yet available • it is not clear whether treatment improves long-term developmental outcomes in children
Next review due	2020 to 2021
More information	legacyscreening.phe.org.uk/irondeficiency

Lead poisoning in children

The condition	Lead poisoning is a serious health hazard that can lead to severe health problems, especially in young children. Lead is naturally present in the environment in small amounts and in a number of other potential sources including industry, leaded petrol, older paint, water piping and hobbies that use lead. At high levels, lead poisoning in children can cause anaemia, damage to internal organs, seizures, coma and death. Low levels of lead within the environment may cause developmental and behavioural problems. Children are at higher risk of lead poisoning. The aim of screening would be to identify those children at risk before physical, developmental and behavioural problems occur.
UK NSC recommendation	Following a review of the evidence against strict criteria, the UK NSC does not currently recommend screening for elevated blood lead levels in children aged 1 to 5. 
Reasons	A national screening programme for elevated blood lead levels is not recommended in the UK because: • it is not known how many children in the UK are affected • an acceptable screening test is not available • it is not known how well treatment works in children identified through screening
Next review due	2021 to 2022
More information	legacyscreening.phe.org.uk/leadpoisoning

Severe combined immunodeficiency (SCID)

The condition	Severe combined immunodeficiency (SCID) refers to some rare inherited conditions which affect the development of a baby's white blood cells. These are an important part of the immune system. SCID makes it difficult for babies to fight infections. Around 15 to 25 babies are born with the condition every year in the UK. After about 3 months of age infections that are not serious in most babies can be life-threatening in those with SCID. The treatment is a bone marrow transplant, which can repair the damaged immune system. Newborn screening, as part of the newborn blood spot screening programme, would look for babies with low numbers of white blood cells as a sign that they may have SCID. Early detection can improve the success of the transplants. This is because doctors can help the baby to avoid infections before the transplant if they know the baby has SCID.
UK NSC recommendation	Following a review of the evidence against strict criteria, the UK NSC recommends that screening for SCID should be evaluated in the NHS. ✓
Reasons	The UK NSC found that screening for SCID is likely to be effective in increasing the number of babies who survive before and after transplant. But the evidence is uncertain in some areas. For example, it is not known: • how many healthy babies might be told they are ill when they are not (false positives) • what care and treatment to offer babies with other conditions that cause low numbers of white cells • how many babies are born in families who already know they have SCID • how the laboratory and treatment services will cope with new tests and more ill babies These and other issues can only be evaluated by trying screening for SCID in a large number of babies. The UK NSC is organising an evaluation to help inform its decision whether screening should be recommended as part of the newborn blood spot screening programme.
Next review due	2020 to 2021
More information	legacyscreening.phe.org.uk/scid

Thrombophilia in newborn babies and adults

The condition	Thrombophilia increases an individual's risk of developing a blood clot. Clots can be dangerous if they break away and block blood flow (and oxygen) to important organs such as the heart, lungs or brain. This can be very serious, resulting in a stroke, heart attack, deep vein thrombosis and death. Thrombophilia can either be inherited or develop later on in adult life. Routine screening in newborn babies and adults might help to identify which individual could benefit from treatment in order to prevent blood clotting.
UK NSC recommendation	Following a review of the evidence against strict criteria, the UK NSC does not currently recommend screening for thrombophilia in pregnancy. 
Reasons	The review did not find any research on screening programmes, nor was there evidence about how good the treatment is for people found through a screening programme. Therefore, there is not enough evidence to suggest that a screening programme for thrombophilia in newborn babies or adults would offer more benefit than current practice. There are clinical practice guidelines from the National Institute for Health and Care Excellence (NICE) for the diagnosis and management of diseases related to thrombophilia in adults and the role of thrombophilia testing.
Next review due	2020 to 2021
More information	legacyscreening.phe.org.uk/thrombophilia

Thrombophilia in pregnancy

The condition	Thrombophilia is a broad term that covers a number of conditions where the blood clots easily. It may be hereditary or it may develop during a person's life. During pregnancy, women with thrombophilia may be at increased risk of: • blood clots in leg veins (deep vein thrombosis also known as venous thromboembolism or VTE) • other complications such as high blood pressure • birth of a preterm or small baby Routine screening in pregnancy might help to identify women who could benefit from treatment, as this may improve the baby's health.
UK NSC recommendation	Following a review of the evidence against strict criteria, the UK NSC does not currently recommend screening for thrombophilia in pregnancy. 
Reasons	Pregnant women who are at higher risk of thrombophilia, through inherited disease or other risk factors, are already assessed for VTE risk factors. These include previous VTE, increased age, obesity, smoking, and obstetric risk factors such as preterm birth or pre-eclampsia. A national screening programme for thrombophilia in every pregnant woman is not recommended by the UK NSC because: • there is no evidence to suggest that universal screening of all pregnant women would offer more benefit compared with current practice • there are inconclusive findings on the safety and effectiveness of treatment
Next review due	2020 to 2021
More information	legacyscreening.phe.org.uk/thrombophilia

Thyroid dysfunction in adults

The condition	The thyroid gland, located at the front of the neck, is responsible for the production of 2 hormones which regulate energy levels. Thyroid dysfunction occurs when these hormones are out of balance. Thyroid dysfunction can lead to many health problems. These include tiredness, heart disease, thinner bones and stroke. But many people with thyroid dysfunction do not suffer any symptoms. The aim of a screening programme would be to identify people with undiagnosed thyroid dysfunction. They could then be offered treatments to prevent symptoms and reduce the risk of health problems.
UK NSC recommendation	Following a review of the evidence against strict criteria, the UK NSC does not currently recommend a national screening programme for thyroid dysfunction in adults. ✗
Reasons	A national screening programme for thyroid dysfunction is not recommended in the UK because: 1. Different people can safely have different levels of thyroid hormones, depending on their age, sex and ethnicity. For a test to be reliable it must be able to consider these factors by defining test 'cut-off levels'. We didn't find any agreement on what these levels should be in the diverse UK population. 2. Some people with abnormal levels of thyroid hormones will return to good health without the need for any treatment. This is because hormone levels naturally fluctuate in life. We are unable to identify which people would actually need treatment. 3. We did not find reliable evidence showing that treatment would benefit patients identified through a screening programme. Further research is needed in this field.
Next review due	2021 to 2022
More information	legacyscreening.phe.org.uk/thyroid

Tyrosinaemia type 1 in newborns

The condition	Tyrosinaemia type 1 (TYR1) is a very rare, inherited condition which prevents the body breaking down an amino acid called tyrosine from food. This leads to the build-up of toxic substances in the blood. If these are left untreated they can cause damage, particularly to the liver, kidneys and the nervous system. TYR1 can occur as: • early onset, within the first months of life • chronic, which is slower to develop The treatment for TYR1 is a drug called nitisinone combined with a strict diet. A liver transplant is performed in patients who do not respond to nitisinone or who develop liver cancer. Newborn screening has been suggested to identify babies with TYR1 before they become ill in order to give early treatment.
UK NSC recommendation	Following a review of the evidence against strict criteria, the UK NSC does not currently recommend screening for tyrosinaemia type 1. ✗
Reasons	The most recent evidence review showed that the screening test finds most babies with TYR1. But there is not enough information available to know if the test misses affected babies. Treatment with nitisinone results in improved outcomes in TYR1 cases. But there were a number of problems in how the research had been carried out which made it difficult to be sure that there was more benefit from early rather than late treatment. The UK NSC is continuing to work with stakeholders to understand more about these issues. The Committee will commission a modelling exercise to estimate whether screening is more beneficial than prompt treatment of babies with nitisinone following the start of symptoms.
Next review due	2020 to 2021
More information	legacyscreening.phe.org.uk/tyrosinaemia

Vasa praevia in pregnancy

The condition	Vasa praevia is a rare but serious condition. It happens when the umbilical cord lies across the cervix (the entrance to the womb) during pregnancy. When this happens as the baby is born it can damage the blood vessels in the umbilical cord. This can lead to heavy bleeding and sometimes to the death of the baby. If vasa praevia is found during pregnancy this allows planning of a caesarean section. This may increase the chance of survival for the baby. This is why it has been suggested that screening all pregnant women for vasa praevia could be useful in finding which women might benefit from a planned caesarean section.
UK NSC recommendation	Following a review of the evidence against strict criteria, the UK NSC does not currently recommend screening for vasa praevia in the second trimester of pregnancy. ✗
Reasons	A national screening programme for vasa praevia is not recommended by the UK NSC because: • there is not enough information about the number of babies affected by it in the UK • vasa praevia can be found by ultrasound testing but it is not clear how accurate the test is and so some women may be advised to have an unnecessary early caesarean section, which brings risks to the baby There is also a concern that ultrasound screening of the placenta and its blood vessels would find other, more common, conditions. For example, velamentous cord insertion (VCI) is a condition where the umbilical cord does not attach properly to the placenta. It is not known whether these would be a problem for the baby and doctors are not agreed on what advice to give women. This could lead to a larger number of pregnancies considered at risk, making women and their family very anxious. It could also increase the number of unnecessary early caesarean sections.
Next review due	2020 to 2021
More information	legacyscreening.phe.org.uk/vasapraevia

Triage review of evidence on existing programmes

Triage reviews are high level reviews which scan the literature to identify any 'red flags' that suggest it might be necessary to further explore reasons to cease an existing screening programme. Triage reviews have a surveillance function and are not intended as comprehensive reviews.

The aim of these triage reviews is to establish if there is published evidence addressing:

- screening programme cessation
- the harms of screening for the condition in question
- the balance of harms and benefits of screening for the condition in question

Triage reviews were first piloted the previous year in the newborn blood spot programme. The UK NSC will consult stakeholders to determine if more work needs to be done to improve the process.

Infectious diseases in pregnancy screening

The condition	This triage review considered evidence for antenatal screening for HIV, hepatitis B, or syphilis, which make up the infectious diseases in pregnancy screening (IDPS) programme. A 3-month consultation was hosted on the UK NSC website.
UK NSC recommendation	Infectious diseases in pregnancy screening for these 3 conditions should continue. ✓
Reasons	No red flags were identified and the UK NSC concluded there is no evidence to suggest that programme cessation should be considered. All submissions supported the continuation of the IDPS programme. Two submissions suggested that screening for hepatitis C should be included in the IDPS programme in future. A review of this topic has been initiated as part of the UK NSC 3-year cycle.
Next review due	2021 to 2022
More information	legacyscreening.phe.org.uk/hiv legacyscreening.phe.org.uk/hepatitisb legacyscreening.phe.org.uk/syphilis

Annual call for topics

The UK NSC held its second annual call for new topic proposals from 6 September to 6 December 2017. We advertised the call for topics via the PHE Screening blog.

A total of 4 submissions were received.

1. Screening for early keratoconus in children and young adults with Down's syndrome

The evaluation group agreed that this proposal falls outside the UK NSC's remit of whole population screening programmes. Therefore the proposal was sent to the Down Syndrome Medical Interest Group and NICE to consider.

2. Screening for increased risk of stroke in children aged 2 to 16 with sickle cell disease

The evaluation group agreed that the proposal to diagnose children with sickle cell disease (SCD) who are at a higher risk of stroke and to offer early intervention was outside the remit of the UK NSC but was part of the care pathway for children diagnosed with SCD. Although no further action was required by the UK NSC it was agreed that the issue would be escalated to NHS England and NICE.

3. Screening for Auditory Neuropathy Spectrum Disorder as an extension to the NHS Newborn Hearing Screening Programme (NHSP)

The evaluation group agreed to review the proposal for an additional hearing condition as a programme modification.

4. Screening for endometrial cancer

This submission was handled as a new topic as the UK NSC had not looked at the evidence to screen for endometrial cancer before. A scoping exercise was undertaken which revealed that screening is not recommended. It was therefore agreed that this would not to be added to the UK NSC list of conditions to screen for.

UK National Screening Committee

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