NSC UK National Screening Committee




SCREENING IN THE UK: MAKING EFFECTIVE RECOMMENDATIONS

2015 to 2016





Public Health England hosts the
UK National Screening Committee
www.gov.uk/phe
Gateway number: 2016152

NHS HSC Health and Social Care NHS SCOTLAND NHS WALES GIG CYMRU

I feel very honoured to have been appointed Chair of the UK National Screening Committee (UK NSC).

My involvement with screening started at an early stage of my career when I was working as a surgical trainee for Professor Sir Pat Forrest when breast cancer screening was being introduced. I then worked for Professor Jack Hardcastle during the Nottingham randomised trial of faecal occult blood test (FOBT) screening for colorectal cancer and I was able to observe first-hand the effect of a public health intervention on frontline clinical services. Subsequently, I chaired the executive group that implemented the demonstration pilot for FOBT screening in the UK and I went on to become the Clinical Director of the Scottish Bowel Screening Programme.

Throughout this time I developed a keen interest in screening and I have become very aware of the importance of robust evidence in underpinning the introduction and conduct of any population-based screening programme.

The UK NSC is a unique organisation worldwide and its approach to the rigorous review of evidence is a model of good practice. By chairing this committee, and working with the excellent PHE team headed up by Dr Anne Mackie, I am very much looking forward to helping to facilitate the critical review of ongoing screening programmes and considering the evidence relating to the possible introduction of new programmes.

This is an exciting time for screening, with constant challenges to the status quo, and new ideas and evidence emerging all the time. The new process of calling for proposals and holding an annual stakeholder conference is taking the work of the committee to a new level, and I am greatly looking forward to the next event in December 2016.

Professor Bob Steele
Incoming Chair, UK National Screening Committee

I have been delighted to have had the opportunity to chair the UK NSC for 3 years. We have achieved a great deal during that time, including the review of the committee structure and processes, establishing the annual stakeholder conference and making recommendations for a number of new screening programmes.

The UK NSC now has stronger governance and a greater breadth of experience among its membership. I would like to thank committee members and the secretariat for all the hard work and expert advice they have provided.

I am delighted to be handing over to such an eminent colleague and wish him every success. I hope he enjoys it as much as I have.

Professor David Walker
Outgoing Chair, UK National Screening Committee

It has been a particularly exciting and productive year for the UK NSC. At the start of 2015 we made a commitment to the parliamentary science and technology committee to produce a document explaining how we collect and analyse evidence and consult and make recommendations on screening programmes.

I'm delighted that this culminated in the publication of the new UK NSC evidence review process in October 2015. This document strengthens our evidence process and helps stakeholders understand:

- how we work
- how to feed into our reviews
- how to ask for screening to be considered when we pilot an annual call for new topics in September 2016
- how to request an early update to a topic due to significant new peer-reviewed evidence
- how to suggest a modification to an existing screening programme

Of course, we continue to assess evidence against rigorous criteria for a screening programme's viability, effectiveness and appropriateness. Our new evidence review process also describes the new rapid assessment approach. This will help us filter out topics with poorer evidence bases, identify gaps in evidence that might provide the basis for research or more detailed reviews, and ensure our recommendations reflect the most up to date evidence. Our first UK NSC stakeholder conference in December 2015 underlined just how engaged and committed our stakeholders are and I look forward to seeing what our first annual call for new topics produces when we pilot it in September.

In the following pages you will read about the huge volume and range of topics we reviewed between 1 April 2015 and 31 March 2016. It is particularly pleasing that we were able to make so many positive recommendations, including:

- roll out and evaluation of the use of non-invasive prenatal testing (NIPT) as an additional test for Down's, Patau's and Edwards' syndromes in the current NHS Fetal Anomaly Screening Programme in England
- a change to the test used in the NHS Bowel Cancer Screening Programme – the use of the faecal immunochemical test (FIT) as the primary test for bowel cancer screening should replace the guaiac feacal occult blood test (FOBt)
- a change to the NHS Cervical Screening Programme – human papillomavirus (HPV) testing as primary screening for cervical disease
- a change to the NHS Diabetic Eye Screening Programme – the interval between screening tests for people with diabetes at low risk of sight loss should change from 1 year to 2 years

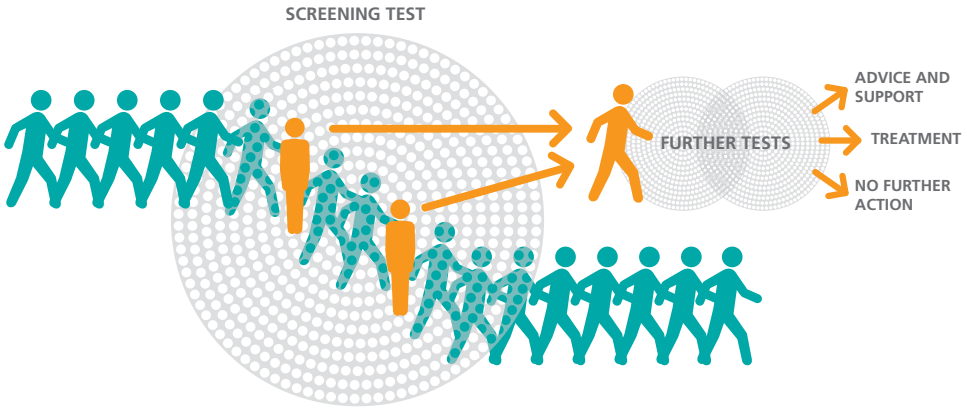
Ministers in each UK country are considering these recommendations. If they become policy then the national screening programmes will take forward their implementation.

We were again unable to support prostate specific antigen (PSA) testing for prostate cancer because of the potential harms of treating men who incorrectly test positive. However, we did publish updated guidance for primary care through the prostate cancer risk management programme (PCRMP) so GPs can advise well men aged 50 and over about the PSA test based on clear, concise, accurate and up to date evidence.

Many thanks to the secretariat, stakeholders and academics, without whom this astonishing amount of high quality work would not have happened.

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.

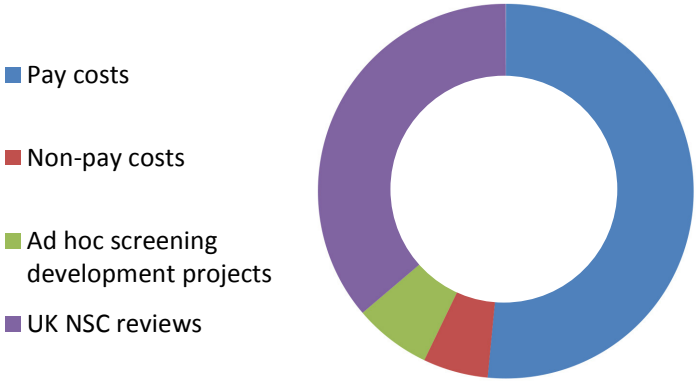


It can be helpful to think of screening like a sieve. In the diagram above a large group of people is invited for the test. The screening test is represented by the sieve. Most people pass through the sieve. This indicates they do not have the condition for which the test is looking.

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 2015 to 2016



	Expenditure (£)
Director's office	
Pay costs	656,400
Non-pay costs	84,900
Ad hoc screening development projects	122,000
Evidence review team	
Pay costs	289,500
Non-pay costs	17,700
UK NSC reviews	664,700
Total expenditure	**1,835,200**

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 David Walker, Medical Director of University Hospitals of Morecambe Bay NHS Foundation Trusts (stepped down February 2016)

Vice Chair

- Dr Sunil Bhanot, GP, Basingstoke

Members

- Dr Eric Baijal, Joint Director of Public Health, NHS Borders (stepped down June 2015)
- Ms Alison Brown, Patient and Public Voice (PPV) (stepped down December 2015)
- Dr Paul Cross, Consultant Cellular Pathologist, Queen Elizabeth Hospital Gateshead Health NHS Foundation Trust (joined November 2015)
- Professor Roger Brownsword, School of Law, King's College London
- Professor Martin Buxton, School of Law, King's College London (stepped down October 2015)
- Professor Alan Cameron, Obstetrician at The Queen Mother's Hospital, Glasgow
- Dr Hilary Dobson, Consultant Radiologist and Clinical Director of the West of Scotland Breast Screening Service and Honorary Senior Lecturer, University of Glasgow (joined November 2015)
- 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 (joined November 2015)
- Professor Gareth R Evans, Consultant in Genetics Medicine, St Mary's Hospital, Manchester
- Ms Jane Fisher, Patient and Public Voice (PPV)
- Ms Hilary Goodman, Midwife, Hampshire Hospitals NHS Foundation Trust (joined February 2016)
- Professor Alastair Gray, Director at the Health Economics Research Centre, Nuffield Department of Population Health and Professor of Health Economics at the University of Oxford (joined November 2015)
- Dr John Holden, Joint Head of Medical Division, Medical and Dental Defence Union of Scotland (joined November 2015)
- Dr Surendra Kumar, GP, Widnes (stepped down February 2016)
- Ms Moira Morris, Patient and Public Voice (PPV) (stepped down March 2015)
- Mrs Margaret Ann Powell, Patient and Public Voice (PPV) (joined November 2015)
- Dr Graham Shortland, Consultant Paediatrician, Cardiff and Vale University Health Board, Noah's Ark Children's Hospital for Wales and Executive Medical Director, Cardiff and Vale University Health Board, University Hospital for Wales (joined November 2015)

Four country representatives

- Dr Margaret Boyle, Senior Medical Officer, Department of Health, Social Services and Public Safety Northern Ireland
- Dr Dorian Kennedy, Screening and Sexual Health Branch, Department of Health
- Mr Scott Sutherland (stepped down August 2015)
- Ms Sarah Manson (commenced August 2015)
- Dr Heather Payne, Consultant Paediatrician, Senior Medical Officer for Maternal and Child Health, Welsh Government

Observers

- Dr Hilary Angwin, Screening & Immunisation Lead, NHS England/PHE Chair of FMCH
- Ms Majella Bryne, Acting Director, National Cancer screening service, the Republic of Ireland
- Ms Sam Cramond, NHS representative
- Dr David Elliman, clinical lead for Newborn Infant Physical Examination and Newborn Blood Spot, PHE
- Mr Tim Elliott, DH senior cancer policy
- Dr Rosemary Fox, Director of Screening Division, Public Health Wales
- Dr Nick Hicks, National Co-ordinating Centre for HTA
- Dr Janet Little, Consultant in Public Health, Northern Ireland
- Professor Julietta Patnick, former Director of Cancer Screening Programmes, PHE (stepped down October 2015)
- Ms Josephine Taylor, Screening and Sexual Health Branch, Department of Health
- Dr Sue Payne, Public Health, Scottish Government

Secretariat

- Dr Anne Mackie, Director, PHE Screening
- Mr John Marshall, evidence manager, PHE Screening
- Mr Nick Johnstone-Waddell, public and professional information lead, PHE Screening
- Ms Zeenat Mauthoor, secretariat expert committee and DH policy liaison manager, PHE Screening

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 during 2015 to 2016:

Amino acid metabolism disorders argininosuccinate lyase deficiency, citrullinaemia and tyrosinaemia type I in newborns

The condition	Tyrosinaemia type I, citrullinaemia (CIT) and argininosuccinate lyase (ASL) deficiency are amino acid metabolism disorders. They are rare conditions caused by altered genes from both the mother and the father. The 3 conditions can disrupt the processes through which amino acids (the building blocks of proteins) are broken down. These disorders lead to a build-up of harmful chemicals that can cause damage to vital parts of the body, such as the liver.
UK NSC recommendation	A systematic population screening programme is not recommended. ✗
Reasons	Babies with CIT often develop symptoms before the results of the screening test would be available. The test would also falsely identify some healthy babies as having the condition. The long-term effects of ASL deficiency, such as liver disease and brain damage, appear to be unaltered by early treatment. The review and public consultation suggested that screening for tyrosinaemia type I may be possible. The UK NSC is undertaking further work to explore the issues raised in the consultation. This includes evaluating the accuracy of the test and effectiveness of the treatment.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/aminoacidmetabolism**

Bladder cancer screening in adults

The condition	Bladder cancer is the seventh most common cancer in the UK, with over half of the identified cases being in people aged 75 and over. Symptoms can include discomfort when urinating and visible blood in the urine.
UK NSC recommendation	A systematic population screening programme is not recommended. ✗
Reasons	No test was identified that would be suitable for use in a screening programme. Blood in the urine remains a poor predictor of bladder cancer. The possibility of improving this by detecting blood in combination with different elements in the urine were explored. These approaches would still result in a large number of people being falsely identified as having cancer. Other potential approaches to screening, for example genetic testing, were identified. These were in the early stages of development and their usefulness for screening had not been established.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/bladdercancer**

Bowel cancer screening in adults

The condition	Bowel cancer remains a significant health problem in the UK. More than 41,000 people are diagnosed with the condition each year and 16,000 people die from it. It is the fourth most common cancer and the second biggest cancer killer in the UK. If the condition is detected early, treatments are more effective and can save or prolong life. The 3 main symptoms of bowel cancer are blood in the stools (faeces), changes in bowel habit (such as more frequent, looser stools) and abdominal (tummy) pain. Eight out of 10 people with bowel cancer are over 60 years old. Screening is routinely offered every 2 years to men and women between the ages of 60 and 74. People over the invitation age range can self-refer. The introduction of the faecal immunochemical test (FIT) into the screening programme provides further opportunities to detect and prevent more cancers.
Programme modification review	The UK NSC reviewed a programme modification to use the faecal immunochemical test (FIT) as the primary test for the bowel cancer screening programme.
UK NSC recommendation	Modification to systematic population screening programme recommended using the faecal immunochemical test. ✓
Reasons	FIT is easier to use and can be measured more reliably by machine than by the human eye. FIT is sensitive to a much smaller amount of blood than the current guaiac fecal occult blood test (gFOBt) and can therefore detect cancers more reliably and at an earlier stage. The increased sensitivity enables FIT to detect more pre-cancer lesions (advanced adenomas). FIT requires a single faecal sample and is more acceptable to invited subjects, which increases participation rates. FIT is a cost effective alternative to gFOBt.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/bowelcancer**

Cervical cancer screening in adults

The condition	High risk human papilloma virus (HPV) is found in 99.7% of cervical cancers. Over three quarters of sexually active women will acquire the infection at some time in their lives. It is most common in women under 35 years. Most infections are transient and are cleared by the woman's immune system. The cervical cancer screening programme is currently offered to women aged 25 to 64 and uses a cytology test, examining cells under a microscope. It only tests for HPV in women who have been found to have a low grade abnormality or have had treatment for an abnormality. Evidence suggests screening for HPV will be a more effective way to let women know whether they have any risk of developing cervical cancer. It will reduce the number of women who would need to go on to have cytology screening to those who are HPV positive only.
Programme modification under review	The UK NSC reviewed a programme modification to use HPV as the primary test for the cervical cancer screening programme.
UK NSC recommendation	Modification to systematic population screening programme recommended using HPV as the primary test. ✓
Reasons	The HPV vaccination offered to girls aged 12 to 13 strengthens the rationale for primary HPV screening. The vaccination will offer prevention of HPV and result in a falling number of women who remain at risk of catching HPV and developing cervical cancer. A primary test for HPV will save more lives by determining a woman's risk earlier. Work to assess extending the screening interval with HPV screening is ongoing and will follow the review of confirmatory pilot data and other international evidence by the UK NSC. If HPV testing finds that a woman does not have high risk HPV then her chances of developing a cancer within 5 years are very small.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/cervicalcancer**

Congenital adrenal hyperplasia screening in newborns

The condition	Congenital adrenal hyperplasia (CAH) is a rare condition caused by altered genes from both the mother and father. The severity of symptoms and the age at which they develop varies. In some cases symptoms never develop. CAH can cause serious illness in babies shortly after birth and as they get older. A child with CAH may lack the hormones (a type of chemical produced naturally) that manage the amount of water and salt in the body. The infant may also have too much of a particular hormone (androgen) that can affect sexual development.
UK NSC recommendation	A systematic population screening programme is not recommended. ✗
Reasons	UK study data suggests around 40 babies are born each year with CAH in the UK. Some evidence suggests CAH is more common in people of an Asian background. However, the information from different studies is conflicting and the role of ethnicity in the condition is uncertain.. Studies suggest the current screening test (using 17-OHP immunoassay) incorrectly identifies a large number of babies as having CAH. Studies also suggest the accuracy of this test is much poorer in babies born early and newborn babies with a low birth weight. This means that affected babies may be missed through screening. There was evidence that screening might not reduce the deaths related to CAH and takes place too late to benefit individuals with some types of CAH.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/congenitaladrenalhyperplasia**

Depression screening in adults

The condition	Depression affects people in different ways and has a wide variety of symptoms which vary in severity. These symptoms range from lasting feelings of sadness, hopelessness and anxiety to physical symptoms such as pain or tiredness.
UK NSC recommendation	A systematic population screening programme is not recommended. ✗
Reasons	Questionnaire-based tests used to identify people at risk of depression are not reliable when used in the general population. Many people would be falsely identified as having depression. Although screening would detect people who are at risk of developing depression, there is no clear evidence that treatment would prevent people with mild depression from going on to develop severe depression.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/depression**

Diabetic eye screening

The condition	If a person has diabetes, their eyes are at risk of damage from diabetic retinopathy, a condition that can lead to sight loss if it goes untreated. Diabetic retinopathy is one of the most common causes of sight loss among people of working age. Screening is a way of detecting the condition early before the person notices any changes to their vision. If retinopathy is detected early enough, treatment can stop it getting worse. Everyone aged 12 and over with diabetes is offered screening once a year. The screening test takes about half an hour and involves examining the back of the eyes and taking photographs of the part of the eye called the retina.
Programme modification under review	The UK NSC reviewed a programme modification to extend the screening intervals for people with diabetes who are at low risk of sight loss in the diabetic eye screening programme.
UK NSC recommendation	Modification to systematic population screening programme recommended to extend screening intervals for people with diabetes who are at low risk to 2 years. ✓
Reasons	Following 2 successive diabetic eye screening tests that show no disease, people with diabetes can be classed as being at low risk of developing sight-threatening retinopathy A large observational study showed that it was safe to invite people in this low risk group every 2 years rather than annually. Screening this group less often not only releases capacity, but also lessens the inconvenience for this group of people. The study found that the current screening interval should remain as annual for people who have background retinopathy detected by screening.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/diabeticretinopathy**

Fetal anomaly screening in pregnant women

The condition	The NHS Fetal Anomaly Screening Programme (FASP) in England already offers pregnant women screening for a range of fetal anomalies, including Down's, Edwards' and Patau's syndromes. The combined test, offered from 10 to 14 weeks of pregnancy, involves an ultrasound scan and blood test. The quadruple screening test, involving a blood test only, for Down's syndrome only, is offered if the pregnancy is booked between 14 and 20 weeks' gestation. If the screening test shows that the chance of having a baby with Down's, Edwards' and Patau's syndromes is higher than 1 in 150, this is called a higher-risk result. Currently, women who have a higher-risk result have the option of having an invasive diagnostic test – amniocentesis or CVS. The proposed change to look at the baby's DNA in the mother's blood, known as non-invasive prenatal testing (NIPT), would be offered to women who are deemed at higher risk following the current primary screen. NIPT is not diagnostic and an invasive diagnostic test would still be required after a positive result to receive a definitive diagnosis.
Programme modification under review	The UK NSC reviewed a programme modification to introduce non-invasive prenatal testing (NIPT), as a contingent test for Down's, Edwards' and Patau's syndromes within FASP.
UK NSC recommendation	Modification to systematic population screening programme recommended using non-invasive prenatal testing. ✓
Reasons	An invasive diagnostic test carries a small risk of miscarriage. Evidence suggests that NIPT will reduce the number of women being offered an invasive test. NIPT is very accurate but we do not yet know how it will perform in an NHS screening programme pathway. NIPT will add an extra step in the screening programme for women who choose to have it. We hope to gain a better understanding of the impact of this, and the choices women make at different points in the pathway, through further research. It is therefore recommended that NIPT is implemented as part of an evaluation process to understand these issues better.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/downs** **legacy.screening.nhs.uk/t18andt13**

Familial hypercholesterolaemia screening in children

The condition	People with familial hypercholesterolaemia (FH) have a high amount of a fatty substance called cholesterol. The high cholesterol is inherited from a parent, rather than gained from an unhealthy lifestyle, and can lead to the early development of heart problems, such as coronary heart disease. In the UK, FH is thought to affect about 1 in 500 people. This means approximately 130,000 people may be affected by FH. There is a 1 in 2 (50%) chance that a child, brother or sister of someone with FH will also have the condition. Screening in children has been suggested as it may find FH earlier so that lifestyle changes and other treatments can begin sooner. Earlier treatment may prevent death and serious illness.
UK NSC recommendation	A systematic population screening programme is not recommended. ✗
Reasons	There are no studies that help understand how well a childhood screening strategy would work in practice. No studies have been identified that assessed whether child screening reduces illness or death from FH. There are questions about the acceptability of universal screening at 1 to 2 years old.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/familialhypercholesterolaemia-child**

Fatty acid oxidation disorders VLCADD and CTD screening in newborns

The condition	A person with a fatty acid oxidisation disorder has problems breaking down certain types of fat to produce energy. In very long-chain acyl-CoA dehydrogenase deficiency (VLCADDD) this is caused by a missing or faulty enzyme (a chemical found naturally in the body) that is responsible for breaking down certain fats. In carnitine transporter deficiency (CTD) a fault in the chemical compound carnitine prevents transport of certain fats into areas of our cells so that they can be used for energy. Fatty acid oxidisation disorders can affect children in different ways. Children with VLCADD and CTD 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, babies can develop heart problems, go into a coma and the disorders can cause death. 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	It is not clear how accurate the screening test is for identifying those with the condition. In addition, there is no way to identify those who will be severely affected and those who will not. The test will identify those who have one copy of the altered gene but the way this will affect their health is not understood. There are treatments for those with symptoms but it is not clear which babies detected by screening would need treatment or what the best treatment would be.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/fattyacidoxidation**

Fragile X screening in pregnancy

The condition	Fragile X syndrome results in a spectrum of intellectual disabilities ranging from mild to severe. More severe learning disabilities are thought to be rarer and the syndrome is more common in boys. People affected by Fragile X can get on easily with others. However, the condition can also result in social and behavioural problems. These include an inability to concentrate for long periods, over-activity and anxiety in unfamiliar social situations. The development of speech and language skills can be delayed and can continue into adulthood.
UK NSC recommendation	A systematic population screening programme is not recommended. ✗
Reasons	There are problems with the accuracy of the pre-natal genetic test, which would not give enough information about whether a baby would go on to develop Fragile X symptoms or not. The test is labour intensive and therefore unsuitable for a screening programme. There are alternatives, including specially designed kits, but the evidence for these is very limited. There is no good evidence that screening during pregnancy would mean that treating or managing the condition in the infant would improve compared to a diagnosis in childhood. There are no curative or preventative treatments that could be offered to those identified through screening.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/fragilex**

Galactosaemia screening in newborns

The condition	Galactosaemia is an inherited condition which causes excessive amounts of galactose, a type of sugar, to accumulate in the blood and other tissues. Too much galactose can be toxic and can cause long-term problems, including cataracts, learning difficulties, growth restriction, speech and behaviour problems and premature menopause in women. Galactosaemia can also cause illness such as vomiting, diarrhoea, liver failure and infection. In rare cases it can be fatal for newborn babies.
UK NSC recommendation	A systematic population screening programme is not recommended. 
Reasons	Screening and treatment do not prevent the long-term problems caused by galactosaemia. Screening tests will identify babies with different forms of the condition who may never experience any symptoms or who may only develop milder symptoms. A special diet has been shown to reduce the severity of symptoms in the baby's first month. However, the contribution of screening would be limited as some babies who are severely affected would develop symptoms before the screening test result was available. Others with the disease are already identified through tests within the current newborn blood spot screening programme.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/galactosemia**

Glaucoma screening in adults

The condition	Glaucoma is the name given to a group of eye conditions that can lead to blindness if left untreated. In affected people the eye may seem fine and work normally, but vision is being damaged very slowly. It is estimated that 67% of glaucoma cases are not detected and just over 2 people in every 100 have the condition. The risk of getting glaucoma increases with age, by being diabetic, of African ethnicity or having an affected close family member. The UK NSC reviewed the most common type of glaucoma, open angle glaucoma. It considered whether a national screening programme would be effective in reducing the burden of the disease by preventing further damage to the eyes and preserving eyesight.
UK NSC recommendation	A systematic population screening programme is not recommended. ✗
Reasons	There are no tests that can accurately predict who is going to develop the disease. Many people diagnosed with early glaucoma will never suffer visual impairment in their lifetime. There is no good-quality evidence demonstrating treatment to be better than no treatment. Available treatments can cause harm. The effectiveness of a screening programme has not been studied. There is therefore no evidence to suggest screening would reduce the burden of the disease to the UK population.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/glaucoma**

Hearing loss screening in adults

The condition	Hearing loss is a common problem that often develops with age and has a significant impact on those affected. It is a major health problem.
UK NSC recommendation	A systematic population screening programme is not recommended. ✗
Reasons	The evidence is too limited to establish: • the best type of test to be used • the level of hearing loss to target • the age at which people should start to be screened and the amount of time between screening tests There is also a lack of evidence about the acceptability of the available treatments. Despite the high prevalence of hearing loss and many options for amplification, a significant proportion of those with hearing loss do not use hearing aids for any length of time. Research also reports a lack of evidence on the benefit from long-term use of hearing aids.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/hearing-adult**

Mucopolysaccharidosis type I screening in newborns

The condition	Mucopolysaccharidosis type I (MPS 1) is a rare, inherited condition that prevents the body's cells processing molecules such as proteins, carbohydrates and fats. The right levels of these are essential for the development and functioning of organs such as the heart, lungs, skin and bones and tissues such as blood vessels and tendons. MPS 1 causes problems with the enzyme that makes it possible to maintain the right levels within the body's cells. As a result, the build-up of 2 carbohydrates called glycosaminoglycans to high levels can cause a wide range of health problems. There is a great deal of variability of symptoms among those with MPS 1, often making diagnosis difficult. Generally, severe MPS 1 will present within the first year of life, while less severe forms present later in childhood.
UK NSC recommendation	A systematic population screening programme is not recommended. ✗
Reasons	For a newborn screening programme to be recommended there must be evidence that a test can reliably find babies with MPS 1 before they become ill and that effective treatment would lead to better outcomes following screening. There was not enough evidence on these 2 points to say screening should be introduced. A very small study explored the attitudes of parents towards an early diagnosis. This pointed to broad support. However, some parents expressed concerns about the loss of a carefree period in which they could bond with their child. This was a very small study and it was not possible to draw clear conclusions from it.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/mps1**

Neuroblastoma screening in children

The condition	Neuroblastoma is one of the most common forms of cancer in children under 5. The cancer is a form of tumour (an abnormal growth of tissue) found in particular parts of the body. Neuroblastoma tumours may sometimes reduce in size or disappear with or without treatment. However, they can also continue to grow and may progress to life-threatening disease. Screening has been suggested as it may find cancer earlier and allow treatment before it becomes lifethreatening.
UK NSC recommendation	A systematic population screening programme is not recommended. ✗
Reasons	There is no evidence of a screening test that would only detect individuals with neuroblastoma needing treatment. Some low quality studies suggest screening at a later age may ensure only children who would benefit from treatment are detected. However, no high quality studies have assessed the effect of screening at 18 months. This is either compared to no screening or to screening at 6 or 12 months. No studies have addressed the main concern that screening could lead to treating more people who would not have needed treatment. There is no evidence that screening would reduce deaths from neuroblastoma.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/neuroblastoma**

Oral cancer screening in adults

The condition	Oral cancer is uncommon in the UK. It develops from a tumor in the mouth, most commonly on the surface of the tongue, mouth, lips or gums. The main risk factor is smoking, which is linked to more than two-thirds of cases in men and more than half of cases in women. The most common type of oral cancer is called squamous cell carcinoma, which accounts for 9 out of 10 cases. Over half of these cases are diagnosed when the cancer has spread to other areas of the body.
UK NSC recommendation	A systematic population screening programme is not recommended. ✗
Reasons	Oral cancer develops from growths in the mouth, most often in the form of visible white lesions. Although these growths are indicators, only 5% of them will become cancerous. It is not yet known how to tell the cancerous from the non-cancerous growths. A reliable test has not been identified. There is no evidence to determine how well existing tests would perform in the general UK population.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/oralcancer**

Screening for the organic acid oxidation disorders MMA and PA in newborns

The condition	These 2 rare conditions are both passed on from parents and mean the child's body is unable to break down parts of proteins called amino acids. This leads to a build-up of chemicals that can cause damage. The severity of symptoms and the age at which they develop can vary.
UK NSC recommendation	A systematic population screening programme is not recommended. ✗
Reasons	The quality of evidence from studies is not high enough to understand whether screening is of long-term benefit. Not enough is known about PA to identify those who will be severely affected and those who will not. It is also unclear from the guidelines how to treat babies who are detected with PA and MMA at screening and show no signs of being ill. The screening test for PA and MMA detects other conditions that may not be suitable for screening.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/organicacidmetabolism**

Prostate cancer screening in adults

The condition	The prostate is a small gland that lies below the bladder. It helps produce healthy sperm. Prostate cancer happens when some cells start to grow out of control. Slow-growing prostate cancers are common. They may not cause any symptoms or shorten a man's life. The risk of developing prostate cancer increases with age and is more common in men aged 50 or over. It is also more common in black men, those who have a family history, are overweight or obese. Prostate cancer is a major public health problem. It is the second-leading cause of cancer-related deaths among UK men. In 2011, there were 41,736 new diagnoses and 10,793 deaths from the disease.
UK NSC recommendation	A systematic population screening programme is not recommended. 
Reasons	Evidence suggests prostate specific antigen (PSA) testing could reduce prostate-cancer related mortality by 21%. Despite this, the major harms of treating men who incorrectly test positive still outweigh the benefits. The PSA test is a poor test for prostate cancer and a more specific and sensitive test is needed. The PSA test is unable to distinguish between slow-growing and fast-growing cancers Current evidence does not support a population screening programme using any other test. Evaluation is currently taking place which could have the potential to improve the accuracy of PSA testing to identify men at greater risk of fast-growing prostate cancers.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/prostatecancer**

Stomach cancer screening in adults

The condition	Around 7,000 people are diagnosed with stomach cancer each year in the UK. Causes of stomach cancers are thought to include diets high in salt and preservatives, smoking, and infections caused by a particular type of bacteria.
UK NSC recommendation	A systematic population screening programme is not recommended. ✗
Reasons	As yet, there is no initial test that is both reliable and harmless which could be used in a population screening programme. Diagnostic tests can confirm the presence of cancer but are too invasive and potentially harmful to be used on everybody as an initial screening test. It is not known how and when to treat suspicious signs of cancer.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/stomachcancer**

Sudden cardiac death screening in adults

The condition	There are a number of causes of sudden cardiac death (SCD). Hypertrophic cardiomyopathy is the most common. The chances of sudden heart attacks in apparently physically fit young people are very small but they can be fatal. SCD usually occurs when a healthy young person's heart suddenly stops beating, with little or no warning, after a period of physical activity.
UK NSC recommendation	A systematic population screening programme is not recommended. ✗
Reasons	There are a number of uncertainties over the test, the conditions that can cause SCD, and the overall benefit of identifying those at risk when weighed against the potential harms. There is very little research into the reliability of the tests for identifying those at risk of SCD. The UK NSC therefore cannot recommend its use in a screening programme There is no agreed treatment or care pathway for supporting those who have been identified as at risk of SCD. Someone who is identified as having a high risk of SCD may become anxious about their physical activity and stop regularly exercising, which can be detrimental to their overall health.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/suddencardiacdeath**

Varicella susceptibility screening in women

The condition	Varicella zoster virus (VZV) is the virus that causes chickenpox. In the UK, chickenpox mostly occurs in children less than 10 years of age, causing a mild infection. In the UK, approximately 90% of women of childbearing age are protected (immune or have immunity) against chickenpox. This is because infection in childhood produces immunity from infection in later life. Chickenpox acquired for the first time during pregnancy can result in serious maternal illness. It can also adversely affect the fetus. The risk of this happening depends upon the point at which maternal infection is acquired. This remains very rare. Susceptible women who come into contact with chickenpox can be treated with an injection of varicella immune globulin (VZIG) within 10 days of contact with the infection. This temporarily boosts the immune system, helps reduce the severity of the infection and is thought to reduce the risk of harm to the baby. Screening has been suggested as a way of providing women with information on whether they are susceptible to chickenpox. It has been suggested that this would improve the timeliness of prescribing VZIG.
UK NSC recommendation	A systematic population screening programme is not recommended. ✗
Reasons	There is very little data on susceptibility to chickenpox in the UK or on the number of susceptible women who come into contact with the virus during pregnancy. Current tests have not been evaluated for use in a screening programme There was no research looking at whether a screening programme improved the delivery of VZIG, so there is uncertainty over whether a screening programme would be of benefit.
Next review due	2018 to 2019
More information	**legacy.screening.nhs.uk/varicella**

UK National
Screening Committee

UK National Screening Committee
Floor 2, Zone B
Skipton House
80 London Road
London SE1 6LH

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