

Screening in the UK: making effective recommendations

1 April 2016 to 31 March 2017



Public Health England hosts the UK National Screening Committee www.gov.uk/phe
PHE Gateway number: 2017440









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My first year as Independent Chair of the UK National Screening Committee (UK NSC) has been extremely interesting and rewarding. We have come a long way from the early days of health screening, and it is largely due to Sir Muir Gray's vision that the UK NSC provides recommendations that are firmly based on evidence and the balance between benefit and harm.

Our stakeholder event in December 2016 was very successful and it was fitting that it should mark the 20th anniversary of the committee. There was a successful pilot for our annual call for topics, which provides stakeholders the opportunity to submit any new

proposals to UK NSC. The 2017 annual call for topics will run from 6 September to 6 December.

In addition to improving our engagement with stakeholders we are extremely keen to strengthen our approach to ethical issues around screening. Professor Roger Brownsword is providing ethical training sessions and we have engaged with the Nuffield Council on Bioethics. Related to this is our objective that people invited for screening should be provided with information that allows them to make an informed choice. To take this forward, a group has produced guidance that will be made available to screening programmes across the United Kingdom.

Another very important development is the initiation of an Adult Reference Group (ARG) which will complement the Fetal, Maternal and Child Health (FMCH) Group by providing UK NSC with focused expertise in adult screening programmes. This group is chaired by Dr Ros Given-Wilson and we are delighted to welcome her to the UK NSC.

Finally, I should like to pay tribute to Dr Sunil Bhanot who has ably served the committee for many years, most recently as vice-chair. He stepped down in February 2017 but I am glad to say he will continue to serve the committee on the ARG. His enthusiasm, dedication and good humour have become legendary and he will be missed from the main group. I am glad to say that the position of vice-chair has been filled by Dr Graham Shortland and I am very grateful to him for bringing his expertise to this position.

The year ahead holds some exciting prospects as we await unfolding evidence in a number of areas in health screening. We are also looking forward to exploring how existing programmes such as bowel and abdominal aortic aneurysm screening might be optimised.

Professor Bob Steele

Chair, UK National Screening Committee

Screening, in most people's minds, is synonymous with prevention and we all know that prevention is better than cure. It is a rare person indeed who says: "Well, shall we see if in this case cure might be better than prevention"?

The UK National Screening Committee (UK NSC) is an independent scientific advisory committee with the responsibility to make recommendations on all aspects of health screening. In coming to our conclusions we use evidence, stakeholder and public views and expert judgement. We need to do this in a way that is transparent, consistent and credible. We also need to communicate how we do this in a way that is logical and compelling. In our last reports we summarised the conclusions of the House of Commons Science and Technology Committee report and the 2015 review of the UK NSC. This year we have been applying the principles of transparency and consistency to more reviews.

The UK NSC has recommendations on 109 conditions, each one supported by an assessment



of published evidence, consultation and stakeholder responses and the consideration of the committee members. These are reviewed every 3 years. Maintaining this volume of recommendations is a huge undertaking. It becomes even harder when the purpose of the work is to inform policy making. The nature of policy making is that it often has short deadlines and/or objectives that shift as time passes. To ensure the work we do is up to date, sufficiently thorough and can influence policy, we have developed a stepped approach to evidence reviewing.

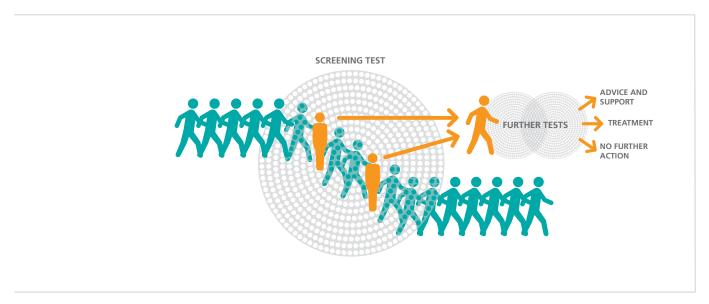
Any proposal to screen for something new, to update our view on a current policy recommendation (the 3-year cycle), to assess whether we should continue or stop an existing programme or make

a major change to a programme, is now defined in a simple stepped process of evidence review. To start with the questions are focused on important criteria. If there is insufficient evidence to support the proposal at that point then the process stops: the resultant report is shared with the public for their view (have we missed something or interpreted the evidence incorrectly?) and then with the committee. If, however, the evidence search and review suggests there is more to be learned or gained from a more in-depth look at some aspect or another type of work then this will done. Examples of further work that we have done include ethical review, economic model, systematic review of a particular question and real life evaluation.

This might not sound very exciting but it is really quite innovative. The wholescale and consistent use of rapid evidence review processes has not been done very often. This year we continued to implement the process by undertaking evidence review work on more than 40 conditions. The summaries and conclusions of the completed reviews are in the report that follows. The approach was tested with the committee, policy makers and the public and has thus far stood the test of time. It has enabled us to increase the number of evidence products we commission, show the public and special interest groups that we are acting according to a single set of processes regardless of the condition. We are also able to show we are guided by the volume and direction of the evidence when we make a recommendation, or explore an issue further.

The principle of prevention being better than cure runs through all this work.

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.

Expenditure (£)

885,200

75,700

81,000

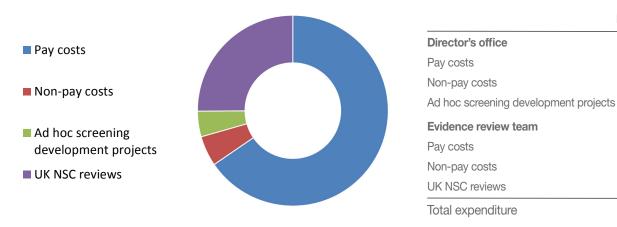
336,300

20,100

468,100

1,866,400

UK NSC central expenditure 2016 to 2017



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 (commenced June 2016), Professor of Surgery and Head of Division of Surgery and Oncology, University of Dundee

Vice-chair

 Dr Sunil Bhanot (stepped down February 2017), GP. Basingstoke

Members

- Dr Paul Cross, Consultant Cellular Pathologist,
 Queen Elizabeth Hospital Gateshead Health NHS
 Foundation Trust
- Professor Roger Brownsword, Professor in Law at King's College London and Bournemouth University
- Professor Alan Cameron, Consultant Obstetrician, Queen Elizabeth University Hospital, Glasgow
- Dr Hilary Dobson, Clinical Director of the West of Scotland Breast Screening Service, 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
- Mrs Margaret Ann Powell, Patient and Public Voice
- Dr Graham Shortland, Medical Director and Consultant Paediatrician, Cardiff and Vale University Health Board
- Eleanor Cozens (appointed June 2016), International Development Consultant, Independent
- Dr Greg Irving (appointed June 2016), Clinical Lecturer in General Practice, University of Cambridge
- Dr Chris Hyde (appointed June 2016), Professor of Public Health and Clinical Epidemiology, University of Exeter Medical School

Four country representatives

 Dr Margaret Boyle (stepped down June 2016), Senior Medical Officer, Department of Health, Social Services and Public Safety, Northern Ireland

- Dr Anne Kilgallen (commenced June 2016),
 Deputy Chief Medical Officer IHI/Health
 Foundation Quality Improvement Fellow, Northern Ireland
- Dr Dorian Kennedy (stepped down September 2016), Screening and Sexual Health Branch, Department of Health
- Dr Ailsa Wight (commenced September 2016),
 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

- Dr Hilary Angwin, Screening and Immunisation Lead, Chair of FMCH
- Charles O'Hanlon (commenced August 2016), Assistant National Director, Head of Screening, National Screening Service, Ireland
- 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 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
- Josephine Taylor (stepped down January 2017), Screening Team, Emergency Preparedness and Health Protection Policy Global and Public Health Group, Department of Health
- Dr Kathryn Callaghan (commenced January 2017), Screening Team, Emergency Preparedness and Health Protection Policy, Global and Public Health Group, Department of Health
- Dr Sue Payne, Public Health, Scottish Government

Secretariat

- Dr 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
- Zeenat Mauthoor, Secretariat Expert Committee and DH Policy Liaison Manager, UKNSC

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 2016 and 31 March 2017:

Adolescent idiopathic scoliosis

The condition	Adolescent idiopathic scoliosis (AIS) is an abnormal curvature in the spine that can develop during puberty. Around 2 or 3 people in every 100 have AIS.
	Serious scoliosis can be identified visually. The Adam Forward Bend Test and a device called a scoliometer can identify less severe cases of scoliosis.
	It is suggested that offering screening, using the Adam Forward Bend Test, would help detect the condition at an earlier stage where treatment may prevent scoliosis from worsening.
UK NSC recommendation	The UK NSC recognises that this is a serious problem but on the balance of evidence was not able to recommend a systematic population screening programme.
Reasons	There is no agreed cut-off for the forward bend test where doctors would agree that treatment is necessary. This means some children would go on to have further tests when they would either get better on their own or the scoliosis was not serious enough to cause any problems.
	The further test is an X-ray examination. This would expose those with positive test results to radiation which can be harmful. It is unclear whether treating people found through screening is better than waiting for symptoms to develop.
	The UK NSC recognises this is a serious problem and would advise professionals to refer to the NICE guidance
Next review due	2019 to 2020
More information	legacy.screening.phe.org.uk/scoliosis

Alcohol misuse

The condition	
The condition	Alcohol misuse occurs when an individual drinks over the recommended number of units.
	Frequent alcohol misuse can increase the possibility of serious health conditions such as heart disease, stroke, liver disease and cancer. It can also affect employment, relationships and can cause anxiety and depression.
	GPs are encouraged to provide support for people who are drinking harmful amounts of alcohol when they have concerns about someone's health. This is different to a screening programme, which would offer a test to everyone over a particular age (general population) whether or not they are drinking too much.
	It has been suggested that offering screening would identify individuals who are drinking over the recommended limits. Early interventions could then be offered to help reduce their intake and risk of alcohol-related harms.
UK NSC recommendation	The UK NSC recognises that this is a serious problem but on the balance of evidence was not able to recommend a systematic population screening programme.
Reasons	The most common tests for alcohol misuse are questionnaires which are unsuitable when used within a whole population screening programme. Thousands of people would be wrongly told they needed follow-on advice when they did not. This would potentially overwhelm services and reduce access for those who could benefit.
	Different people can safely drink different amounts of alcohol, depending on factors such as their age, sex and ethnicity. For a screening test to be reliable it would have 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.
	The review did not find any research evidence that showed a whole population screening programme would help to reduce the harms from alcohol misuse in the long term.
	The UKNSC recognises that this is a serious problem and would advise people to refer to the NICE guidance.
Next review due	2019 to 2020
More information	legacy.screening.phe.org.uk/alcohol

Asymptomatic bacteriuria (ASB)

The condition	ASB is a urinary tract infection (UTI) with no symptoms. This can cause a kidney infection in pregnant women if left untreated. For mothers this can cause fever, breathing difficulties and kidney failure. This can also cause problems for the baby such as being born prematurely, of low birth weight or, in some rare cases, being stillborn. It has been suggested that offering routine screening would help prevent pregnant women developing a kidney infection.
UK NSC recommendation	The UK NSC recognises that this is a serious problem but on the balance of evidence was not able to recommend a systematic population screening programme.
Reasons	Women are tested for ASB in early pregnancy. The benefits of screening over and above the current testing process is uncertain. It is not known how many women and babies are affected by ASB. The best way of screening pregnant women is not known, including when or how often to screen them. Antibiotics can prevent kidney infection but we do not know the best way to treat women, for example with a single dose or short course, of antibiotics.
	The UK NSC recognises this is a serious problem. Women and professionals caring for them in pregnancy should refer to the NICE guidance.
Next review due	2019 to 2020
More information	legacy.screening.phe.org.uk/asymptomaticbacteriuria

Duchenne muscular dystrophy (DMD)

The condition	DMD is an inherited muscle wasting condition that mainly affects boys.
	The condition is most commonly detected around the age of 5 when the muscles become weaker as the child gets older. Physical activities such as running, jumping and climbing become more difficult and falling can become more frequent.
	It has been suggested that offering screening, using the newborn heel prick blood spot to measure the levels of a protein (creatine kinase or CK), might help identify babies with DMD.
UK NSC recommendation	The UK NSC recognises that this is a serious problem but on the balance of evidence was not able to recommend a systematic population screening programme.
Reasons	The suggested screening test misses some babies who have DMD. It also falsely identifies some babies as having the condition, when they do not. Babies and children are currently treated once the condition is diagnosed. It is not clear that earlier treatment (such as would be possible following a newborn screening test) would benefit the child's health.
	There is no clear view on whether parents would want the disease diagnosed in the newborn period. Some would but others would like it to happen later in childhood to allow time with the child without the knowledge that they will become ill.
	The review did find that there are new drugs being tested in boys with DMD. However, research into these drugs was at an early stage. The review also found a report of a new approach to screening, but this too was at an early stage. More information may become available by the time of the UK NSC's next review
Next review due	2019 to 2020
More information	legacy.screening.phe.org.uk/musculardystrophy

Antenatal screening for fetomaternal alloimmune thrombocytopenia (FMAIT)

The condition	FMAIT is a rare genetically inherited condition that prevents a newborn baby's blood clotting effectively.
	A baby inherits blood cells from both mother and father. In a small number of pregnancies, the mother's body starts attacking the unborn baby's platelets (blood cells that help the blood to clot). This is because the mother's body detects platelets which are 'foreign' to her. A drop in the number of platelets can cause serious risk of death or permanent brain damage and long-term disability.
	It has been suggested that offering screening would help identify pregnant women who are at risk of developing the condition. This would help them manage their pregnancy and birth to avoid the possible death of the baby.
UK NSC recommendation	The UK NSC recognises that this is a serious problem but on the balance of evidence was not able to recommend a systematic population screening programme.
Reasons	Population screening for FMAIT is not recommended because:
	FMAIT does not harm all babies and there is no test which can tell which babies will be harmed
	there is no known medical treatment which can prevent FMAIT
	there is no clear evidence to suggest that screening and subsequent treatment would be better than treating women and babies when problems first arise
	The UK NSC recognises FMAIT is a serious problem and would refer professionals to the NICE guidance.
Next review due	2019 to 2020
More information	legacy.screening.phe.org.uk/thrombocytopenia

Antenatal screening for carriage of Group B streptococcus (GBS)

More information	legacy.screening.phe.org.uk/groupbstreptococcus
Next review due	2019 to 2020
	The UK NSC recognises that GBS is a serious problem and would refer women and the professionals caring for them to the NICE guidance.
	The proportion of babies affected by EOGBS in women giving birth at term is similar in the UK to the level reported in countries that have introduced screening.
	It is not clear whether benefits associated with screening outweigh the harms for the majority of the population.
	The treatment for preventing EOGBS in babies is to give antibiotics to the mother during labour. There is serious concern that large numbers (tens of thousands) of women would be offered and would take antibiotics that they did not need to if a screening programme was introduced. The long-term effects of antibiotics for mother and baby are unknown.
	There is no way to predict which babies will be affected by EOGBS and which will be born without complications.
Reasons	Carriage of GBS changes with time. A woman could be found to carry GBS if she is screened at 35 to 37 weeks, but GBS might not be present at labour.
UK NSC recommendation	The UK NSC recognises that this is a serious problem but on the balance of evidence was not able to recommend a systematic population screening programme.
	It has been suggested that offering screening at 35 to 37 weeks of pregnancy will help detect which women carry GBS so that they can be treated with antibiotics at the start of labour to avoid EOGBS affecting their baby.
	The vast majority of affected babies will recover fully. For a few there may be long-term disability. Sadly, some will die.
	GBS in the first 7 days of life is called early onset GBS infection (EOGBS). If the infection occurs after this point it is known as late onset disease (LOGBS).
	GBS can pass from the mother to the baby around the time of labour. This usually causes no ill effects but in a small number of cases it can result in illness.
The condition	GBS is a common form of bacteria. It is present in both males and females and is usually harmless.

Hereditary haemochromatosis (HH)

More information	legacy.screening.phe.org.uk/haemochromatosis
Next review due	2019 to 2020
	The UK NSC recognises that HH is a serious problem and would refer professionals to the NICE guidance.
Reasons	Although a faulty HFE gene is known to cause iron to build up, many people with the faulty gene do not experience any ill health. The UK NSC review did not find any evidence that helps improve our understanding of this. Screening would find people who would never have a problem and this might cause unnecessary worry and anxiety. No evidence was found which provided information on the effectiveness of a screening programme.
UK NSC recommendation	The UK NSC recognises that this is a serious problem but on the balance of evidence was not able to recommend a systematic population screening programme.
	It has been suggested that offering screening, by looking for the fault in the HFE gene will help identify individuals who are at a higher risk of developing the condition. The purpose would be to monitor iron levels and reduce them if they get too high.
	Excessive iron levels can cause a number of symptoms such as fatigue, joint pain and stiffness. It can also cause more serious damage to organs such as the liver, pancreas and the heart.
The condition	HH is an inherited condition where a fault in the HFE gene can cause iron to slowly build up in the body. The extra iron can be deposited around the body and its organs over time.

Newborn screening for kernicterus

The condition	Kernicterus is a very rare condition in newborn babies which can damage the brain and spinal cord. It can be life threatening. It usually affects babies who have high levels of a substance called bilirubin in their blood, but this is not always the case.
	High levels of bilirubin can cause jaundice. Signs of jaundice include yellowing of the skin and the whites of the eyes. Jaundice is very common in newborn babies and usually resolves without causing any problems. The National Institute for Health and Care Excellent (NICE) has issued guidance on the management of babies with jaundice.
	It has also been suggested that if screening was introduced it would help to find babies at risk and provide early treatment to reduce bilirubin and prevent brain damage
UK NSC recommendation	The UK NSC recognises that this is a serious problem but on the balance of evidence was not able to recommend a systematic population screening programme.
Reasons	There is no clear evidence that screening would help to find babies at risk of developing kernicterus. The test (bilirubin in the baby's bloodstream) is not a good predictor of whether the baby will develop kernicterus. Many babies might be treated unnecessarily. Current treatment options (phototherapy and exchange transfusion) can reduce bilirubin levels. But it is not known whether these are effective in preventing kernicterus.
	The UK NSC recognises that kernicterus is a serious problem and would refer professionals to the NICE guidance.
Next review due	2019 to 2020
More information	legacy.screening.phe.org.uk/kernicterus

Ovarian cancer

The condition	Ovarian cancer is the 6th most common cancer among women in the UK. It is often diagnosed when the disease has spread from the ovaries and the likelihood of being cured is reduced. The aim of a screening programme would be to find and treat the cancer at an earlier stage to improve outcomes and, in particular, survival rates
UK NSC recommendation	The UK NSC recommends that screening should not be offered except in the context of the Medical Research Council randomised controlled trial.
Reasons	The debate about screening is dominated by the UK Clinical Trial of Ovarian Cancer Screening (UKCTOCS). This is a randomised controlled trial with the primary aim of establishing the impact of screening for ovarian cancer on mortality. The trial outcomes were published in 2015 and did not demonstrate a reduction in mortality after a mean follow-up period of 11.1 years.
	Consequently it was not possible to recommend screening and longer term follow-up is being undertaken. The committee will continue to monitor the outcomes of the UKCTOCS trial to see whether a reduction in mortality from screening is achieved in the longer term.
Next review due	2019 to 2020
More information	legacy.screening.phe.org.uk/ovariancancer

Antenatal screening for toxoplasmosis

More information	legacy.screening.phe.org.uk/toxoplasmosis
Next review due	2019 to 2020
	The UK NSC recognises that toxoplasmosis is a serious problem and would refer professionals to the NICE guidance.
	The number of people who might get the infection in the UK has not been estimated.
	Current treatment with antibiotics does not seem to prevent the infection being passed to the baby. It is uncertain whether treatment reduces the severity of the infection.
Reasons	The screening test has a high false positive rate. This means many women would be wrongly told their baby is at risk.
UK NSC recommendation	The UK NSC recognises that this is a serious problem but on the balance of evidence was not able to recommend a systematic population screening programme.
	Screening has been suggested as a way of preventing babies being affected by these serious complications. This would involve identifying those who are not immune to the infection and monitoring them regularly to identify the infection in its early stages.
	A pregnant mother can pass this infection to her unborn child if she gets it for the first time during pregnancy. Some babies will be unaffected. Others can develop serious complications to their nervous system, heart, eyes and brain.
The condition	Toxoplasmosis is an infection caused by a parasite found in uncooked meats, contaminated soil and cat litter. The infection is common and generally harmless. Many people do not have symptoms, while others may have mild flu-like symptoms.

Triage process to review evidence of existing programmes

The UK NSC has designed and agreed a new process for 'triage reviews' which are made publically available for comments. This was in response to the independent review of the UK NSC's structure and function and the Science and Technology Committee's review of health screening.

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 the programme. Triage reviews have a surveillance function and are not intended as comprehensive reviews.

This process was piloted in the newborn bloodspot programmes. Further information on the triage process can be found at www.marvellousprocess.org.uk

The UK NSC will consider the experience of these reviews before finalising the method used to regularly review the evidence relating to ongoing national screening programmes.

Triage review of newborn blood spot screening for 5 conditions

The condition	The first triage review pilot considered 5 conditions currently included in the newborn blood spot screening programme: PKU phenylketonuria Congenital hypothyroidism Medium chain acyl-CoA dehydrogenase deficiency Sickle cell disease Cystic fibrosis.				
UK NSC recommendation	Newborn blood spot screening for these 5 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				
Next review due	2019 to 2020				
More information	legacy.screening.phe.org.uk/screening-recommendations				

Annual call for topics

Following the UK NSC's Independent Review it was recommended that the UK NSC should consider establishing a more formal route of submitting requests to the UK NSC to consider.

The previous practice permitted anyone to submit a request using an approved form available online. The stakeholder and screening sub-groups both agreed that a single port of entry to requests consideration for a topic would be of benefit. A pilot call was held in September 2016 and 4 submissions were received.

Submission 1: newborn screening for childhood Cerebral Adrenoleukodystrophy (cCALD)

UK NSC	The recommendation is that a further review is not justified at present.				
recommendation Reasons	The evaluation established a number of issues relating to screening for which there is an absence of evidence. These include:				
	1. The screening test is still experimental. Case control type studies are the mainstay of accuracy estimates and its use in a population setting is currently being evaluated in the New York State newborn screening programme.				
	2. The test will identify a number of boys with the genetic mutation who will not develop cCALD. In addition, the test will identify babies with conditions, other than ALD, for which there are no interventions.				
	3. There is uncertainty on the ability of the diagnostic pathway to distinguish those requiring HSCT from those who do not.				
	4. There is uncertainty on the balance of long-term benefits and harms of treatment with HSCT.				
Next steps	The UK NSC has agreed to add cCALD to its list of conditions to review.				
Next review due	2019 to 2020				
More information	legacy.screening.phe.org.uk/screening-recommendations				

Submission 2: screening for hypercholesterolaemia in children

UK NSC	This topic is already on the list that the UK NSC reviews and it was reviewed in 2016. The submission				
recommendation	was prompted by the publication of a study of screening in children aged 2. It is proposed that this				
	topic should be handled as an early update request.				
Next steps	To be looked at as an early update and follow the evidence review process.				
More information	legacy.screening.phe.org.uk/screening-recommendations				

Submission 3: screening for prostate cancer

UK NSC recommendation	Prostate cancer is already on the list of topics and was reviewed in 2016. The proposal is to add MRI as a risk refinement test following the identification of eligible men using a risk calculator. The risk calculator is based on the outcomes of the STHLM3 study. This study was considered in the last UK NSC review.
Next steps	It is proposed further consideration of this approach should be deferred until the next review of prostate cancer screening. The proposed strategy should be considered in the scoping work at the beginning of the review project
Next review due	2018 to 2019
More information	legacy.screening.phe.org.uk/screening-recommendations

Submission 4: screening for anal cancer

UK NSC recommendation	Anal cancer is already on the list of topics and is due for review in 2017 to 2018. A document is being prepared on whether the topic should be retained on the list. This is because the condition is confined to high risk groups and may not be within the remit of the UK NSC.				
Next steps	It is proposed that this topic should not be taken any further as it falls outside the UK NSC's remit.				
Next review due	2017 to 2018				
More information	legacy.screening.phe.org.uk/screening-recommendations				



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Published:

PHE publications gateway number: 2017440