UK National Screening Committee (UK NSC)

Note of the meeting held on the 28 October 2020

Virtual meeting held via Microsoft Teams

This meeting provided recommendations on the following:

Fetal Maternal and Child Health conditions:

- Antenatal screening for Asymptomatic Bacteriuria (Rapid Review)
- Newborn screening for Galactosaemia (Rapid Review)
- Screening for Preterm birth in asymptomatic low risk women (Rapid Review)
- Sickle Cell and Thalassaemia programme modification to use NIPT/ NIPT (Evidence map)
- Antenatal screening for Fetomaternal Alloimmune Thrombocytopenia (FMAIT) (Evidence map)
- 2019 Annual call for topic- screening for Dyslexia in school age children (Evidence map)

Adult conditions:

- Screening for Prostate Cancer (Rapid Review)
- Screening for Oral cancer (Evidence map)

Members

Professor Bob Steele	Chair
Dr Graham Shortland	Consultant Paediatrician, Cardiff and Vale University Health Board, Noah's Ark Children's Hospital for Wales (Vice-Chair)
Professor Roger Brownsword	School of Law, Kings College London
Claire Bailey	Lead Clinical Nurse Specialist in breast screening, SW London
Eleanor Cozens	Patient and Public Voice (PPV)
Dr Paul Cross	Consultant Cellular Pathologist, Queen Elizabeth Hospital Gateshead Health NHS Foundation Trust
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 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 at the Health Economics Research Centre, Nuffield Department of Population Health and Professor of Health Economics at the University of Oxford
Dr John Holden	Joint Head of Medical Division, Medical and Dental Defence Union of Scotland

Professor Chris Hyde	Public Health Specialist, University of Exeter
Dr Jim McMorran	GP, Coventry
Margaret Ann Powell	Patient and Public Voice
Dr Anne- Marie Slowther	Reader in Ethics, University of Warwick
Observers;	
Nimisha De Souza	Department of Health and Social Care, Screening Policy Team, Global and Public Health Group
Kaliniecki, Lucjan	Department of Health and Social Care, Screening Policy Team, Global and Public Health Group
Dr Heather Payne	Senior Medical Officer for Maternal and Child Health, Welsh Government
Caspian Richards	Scottish Government
Dr Carol Beattie	Northern Ireland
Professor Niall O'Higgins	Chair of the National Screening Advisory Committee, Ireland
Invitees;	
Dr David Elliman	Clinical lead for Newborn Infant Physical Examination and Newborn Blood Spot, PHE
Mariejka Beauregard	PHE screening fellowship (from Canada)
Catherine Joynson	Nuffield Bioethics on secondment to the UK NSC/PHE
Nick Hicks	National Co-ordinating Centre for HTA
Dr Ros Given – Wilson	Chair of the Adult Reference Group (ARG)
Tasmin Sommerfield	NHS Scotland

Dr Sharon Hillier	Chair of the Fetal Maternal and Child Health Group (FMCH)
Karen Emery-Downing	Public Health England (PHE)
Caroline Vass	Public Health Consultant
Gareth Brown	Director of Screening for Scotland

Secretariat

John Marshall	UK NSC Evidence Lead
Dr Farah Seedat	UK NSC Evidence Review Manager
Dr Cristina Visintin	UK NSC Evidence Review Manager
Paula Coles	UK NSC Evidence Review Manager
Silvia Lombardo	UK NSC Evidence Review Manager
Goda Kijauskaite	UK NSC Evidence Review Manager
Zeenat Mauthoor	Secretariat
Fabrice Lafronte	UK NSC Secretariat officer
Nick Johnstone- Waddell	Public and Professional Information lead

Apologies from members

Prof Alan Cameron	Consultant Obstetrician, The Queen Mother's Hospital, Glasgow

Apologies:

Professor Anne Mackie	Director of Programmes - UK National Screening Committee
Dr Alan Smith	Deputy CMO, Department of Health – Ireland

Professor Louise Bryant	Associate Professor in Medical Psychology, University of Leeds
Kate O'Flaherty	ROI Observer
Morwenna Carrington	Department of Health and Social Care
Joanna Swanson	Scotland
Evette Wade	ROI
Joanne Harcombe	National Lead for Stakeholder Information and Professional Education and Training
Julia Bowen	UK NSC Evidence Review Manager

Introduction and Apologies

1. The Chair, Professor Steele, welcomed all to the UK NSC's October virtual meeting. An extended welcome was offered to the newly appointed Director of Screening for Scotland Gareth Brown.

1.1 The members were asked to provide an update on any new declarations of interest which may be relevant to this meeting. No new conflicts were raised.

1.2 Apologies were received from UK NSC member Dr Louise Bryant as well as Prof Mackie. The Chair confirmed that the meeting was quorate with 16 members present.

1.3 The Chair informed the Committee that Prof Alan Cameron had stepped down from the Committee. Prof Cameron had served the UK NSC for over three terms and have provided useful insight and the Committee wished him well in his future endeavours.

1.4 The Committee were also pleased to congratulate the UK NSC's vice chair, Dr Graham Shortland on being awarded an OBE in the Queen's Birthday Honours list for services in paediatrics, patient safety and NHS in Wales.

1.Action: Letter to Prof Cameron to be issued; end of service

Minutes and Matters arising

2. The Committee confirmed that the draft minutes from the 15 July 2020 meeting were a true and accurate record of the meeting discussion and would be published as final once clearance had been communicated.

2.1 The minutes and other documents from the UK NSC's July meeting had not been published. This was because the July recommendations are with the Minister for consideration and sign off. The UK NSC will publish such document as soon as clearance had been received.

2.2 Nine action points were identified from the July meeting:

2.2.a. Ethics and engagement at the UK NSC

The UK NSC members who wished to be involved in the ethics work to contact Catherine Joynson —*ongoing*

2.2.b. Ethics and engagement at the UK NSC

Ethics to be added to the October UK NSC agenda as an update — *completed*

2.2.c. NHS Bowel Cancer Screening Programme — Bowel scope

UK NSC and NHSEI to develop a consultation document on BSS cessation — *completed*

2.2.d. NHS Bowel Cancer Screening Programme — Bowel scope

UK NSC to run truncated consultation to targeted UK NSC England focused screening stakeholders— *completed*

2.2.e. NHS Bowel Cancer Screening Programme — Bowel scope

UK NSC to review comments and to take Chairs Action on the final recommendation of BS— *completed*

2.2.f. Adult screening — Thoracic aortic aneurysms (programme modification proposal)
The outcome of the TAA evidence map to be reported back to the submitter— *completed*

2.2.g. Adult screening — Screening for depression
Amendment to be made to the reference of prevalence for depression to be consistent — *completed*

2.2.h. Adult screening — Screening for depression
UK NSC to consider how to handle the next evidence work on depression, a proportionate approach should be taken to consider screening in populations such as over 65 or in young adults — *Ongoing*

2.2.i. AOB 2019 Annual call for topics on pressure reducing carotid stenosis, vascular dementia, regional cerebral hypotension

Recommendation on the evidence map for the 2019 annual call for topic proposal on pressure reducing carotid stenosis, vascular dementia, regional cerebral hypotension to be fed back to the submitter once UK NSC minutes have been published — *Ongoing*

Matters Arising

Director's Update

3.This item was presented by the UK NSC Chair in the absence of Prof Anne Mackie.

COVID-19- restoration of screening programmes

3.1 Since the summer all UK Health Departments have been working to restore screening services that were suspended. However, as expected, programmes were working against a backlog as the programmes resumed.

3.2 Colleagues from Wales informed the Committee that under the two-week break screening would continue. Public Health Wales was aiming to disseminate the message widely to ensure that people who had been invited to be screened and wanted to take up the offer could do so in Wales even under local restrictions.

3.3 The Chair also informed the Committee, that in May 2020, the Age Extension Trial (Age X) which aims to assess the risks and benefits of offering additional screening to women age 47 and over age 70 (who will have been offered routine screening every 3 years from the ages 50-70) announced that further recruitment had stopped. The trial is due to publish in 2026.

Restructure of PHE/ creation of National Institute of Health Protection (NIHP)

3.4 On the 18 August 2020 the Secretary of State delivered his keynote speech on "The Future of Public Health" where it was announced that a new organisation would be formed, The National Institute of Health Protection (NIHP) from 1 April 2021 and would be a new Executive Agency of DHSC.

3.5 In relation to this announcement, the Chair informed the Committee, that the PHE functions and directorates would be transferred to a new organisation. However, details of this reorganisation were still under discussion and no final decision had been taken at the

time of the meeting. Discussions were ongoing also in relation to the future of the screening division. The Committee will be kept informed of future developments.

Update on the UK CMO Single Advisory Body Task and Finish Group — Targeted screening definitions

4. The Chair reminded the Committee, that the task and finish group chaired by CMO England and CMO Wales had been tasked to advise on a single advisory body as part of the response to a number of reviews of screening, this included the Independent Review of Adult Screening Programmes in England (2019).

4.1 The group had met earlier in the month to explore targeted and stratified screening. To support this discussion the UK NSC Secretariat commissioned a review exploring the definitions of targeted screening and the implementation of targeted screening recommendations in the UK.

4.2 The next meeting is due to take place in January 2021 and will focus on the criteria that need to be satisfied for recommending a targeted screening programme and to discuss the terms of reference. Nimisha informed the Committee that the group aims at completing its work before NIHP is established.

Ethics and engagement at the UK NSC

5. Dr Anne- Marie Slowther and Catherine Joynson presented this item.

5.1 Catherine's secondment to the UK NSC aims to explore how the UK NSC considers ethical issues and engagement with stakeholders and the public. Since Catherine started her secondment, several internal workshops have taken place that explored various themes such as; embedding ethics, ethics in practice, public and stakeholder engagement and considerations of a possible case study. Input from colleagues had been well received with members agreeing that a process is needed to enable the UK NSC to consider ethical and social issues consistently and that further stakeholder input was needed to address this.

5.2 The ethics group would soon be engaging with external stakeholders and members of the public in order to gather views and experiences which would provide options on where, how and what is needed to engage, manage and allow for ethical considerations to be better incorporated into the UK NSC's processes.

5.3 The Committee was informed of two key actions which would soon be taking place. Firstly, that the ethics work would be partnering with Sciencewise and Genomics England to develop a clear approach to engagement on genomic newborn screening. The aim of this is to help development of policies around newborn screening that considers and reflects societal values. Secondly, engaging publicly with stakeholders on the UK NSC values, procedures and opportunities. To understand public needs better, a survey will be undertaken in the coming weeks.

5.4 The Committee thanked Catherine, Anne- Marie and Roger for their work on this so far and were keen to hear the feedback of the work from the survey.

2.Action: Ethics update to be added to March agenda

Adult Screening

ARG Report

6. Dr Given-Wilson provided the Committee with a summary of developments following from the ARG meeting held on the 29 September. The draft evidence review on hereditary haemochromatosis went out for public consultation as well as that on screening for thrombophilia in all ages both due to close on the 15 January 2021.

6. 1 Dr Given- Wilson also updated the UK NSC on the Artificial Intelligence (AI) task group, that is chaired by Professor Steve Halligan, a radiologist and member of ARG. The group convened for the first time on the 27th August and is due to meet again on the 5 November, where the group will discuss the preliminary findings of the reviews on AI in breast screening and diabetic eye screening as well as the methodology paper on standards for tests sets in AI studies.

6.2 The Committee were also informed that NHSX in collaboration with NIHR were overseeing a new project called "Accelerated Access Collaboration"(AAC) which will make £140 million available over the next three years to accelerate the testing and evaluation of the most promising AI technologies that meet the strategic aims set out in the NHS Long Term Plan. Dr Given- Wilson confirmed to the Committee that both NICE and ARG have representation on the group that are overseeing these projects. However, it had been made clear that an award from AAC would not result in an AI technology being automatically approved for use within population screening programmes and that this would need to be submitted to the UK NSC formally for consideration. A statement from the UK NSC would be drafted and circulated to the UK NSC for comments.

6.3 In addition to this the UK NSC was also planning to share the draft manuscript on the UK NSC's approach to reviewing evidence on AI in breast screening for comments. This would then be reviewed and submitted.

3a. Action Zeenat to share the UK NSC statement on the AI Accelerated Access Collaboration statement with the Committee for comments

3b. Action: Zeenat to share the draft manuscript on the UK NSC's approach to reviewing evidence on AI in breast cancer screening. Members are invited to comment on this paper before this is submitted to the BMJ for publication. Deadline for comments will be Wednesday 11 November.

Screening for Prostate Cancer- rapid review

7. Silvia Lombardo presented this item with the accompanying slides

1.Prostate cancer_post consultat

7.1 Prostate cancer is the most common cancer in men and the second most common cause of cancer deaths in men in the United Kingdom, more commonly affecting men of Afro-Caribbean or African descent. Although rare in men under 50, it does become more common as men get older.

7.2 The UK NSC last looked at the evidence to screen for prostate cancer in 2015/16 and, based on a review carried out by Dr Karly S Louie, recommended that a population screening programme should not be offered. This is because the evidence suggested that the harms from prostate cancer screening using prostate-specific antigen (PSA) outweigh the benefits.

7.3 The use of PSA is controversial. PSA tests can incorrectly suggest that there is prostate cancer in men who do not actually have it (a false positive). In addition, the PSA test cannot distinguish between which cancers are aggressive and require treatment and which ones are slow growing and may never cause symptoms. There is concern that population screening for prostate cancer using PSA alone would lead to harm as a result of overdiagnosis and overtreatment.

7.4 The 2020 evidence summary was undertaken by Costello Medical and assessed the quality and volume of evidence published since 2014 on the benefits and harms of PSA-based screening, on risk stratification models to predict clinically important prostate cancer, and on

the effectiveness and harms of various treatment strategies. Expert input from a variety of bodies and medical experts, as well as the evidence gaps from the 2015 UK NSC review, informed the key questions which the 2020 evidence summary focused on. These were:

i. Does screening based on PSA reduce short- or long-term prostate cancer morbidity and mortality and all-cause mortality?
ii. What are the harms of PSA-based screening for prostate cancer and diagnostic follow-up, with particular reference to overdiagnosis?
iii. Is there evidence that screening using risk algorithms or inclusion of markers other than PSA alone can better identify men with clinically significant prostate cancer, or improve screening efficiency?
iv. What are the harms and benefits of currently available treatment approaches for early-stage prostate cancer to reduce morbidity and mortality?

7.5 The conclusion of the 2020 evidence summary is that the current recommendation, that whole population screening for prostate cancer should not be introduced in the UK, should be retained. This is because;

I. it is unclear how PSA screening impacts prostate cancer outcomes, especially prostate cancer-specific mortality in comparison with no screening
II. in line with the results of the previous UK NSC review, it remains unclear whether benefit gained from PSA-based screening programmes outweighs harms
III. no robust conclusions could be made on whether alternative screening tests perform better than PSA alone. However, magnetic resonance imaging (MRI) (either added to PSA-based screening or alone) and the Stockholm-3 (STHLM3) predictive model represent promising screening methods compared with PSA alone as they may offer greater diagnostic accuracy. Further validation studies are needed to support these findings.
IV. of the treatments currently recommended by the National Institute for Health and Care Excellence (NICE) for the treatment of early-stage prostate cancer, no single intervention could be identified as conclusively superior. This is because better disease progression offered by radiotherapy or prostatectomy, compared to observation, has to be balanced against increased adverse events, particularly in men who may not go on to develop clinically significant disease

7.6 The UK NSC hosted a three-month consultation and made direct contact with 35 stakeholders. Eleven responses were received, including a personal account from a member of the public.

7.7 Six stakeholders (Royal College of General Practitioners, Royal College of Radiologists, Royal College of Nursing, Prostate Scotland, British Association of Urological Surgeons and Cancer Research UK) broadly agreed with the recommendation that a PSA-based screening programme for prostate cancer should not be recommended at the current time. Two stakeholders (a member of the public and a joint response submitted by CHAPS, Tackle Prostate Cancer and Orchid) disagreed with the conclusions of the UK NSC review. Two stakeholders made no direct comments on the review's recommendation. One stakeholder (Prostate Cancer UK) stated that it was not possible to know whether the conclusion reached by the review was the right one.

7.8 Silvia Lombardo summarised for the Committee the main themes that were reflected across the stakeholders' comments. She also outlined the responses for each of the points raised.

One of the themes was that the review should have made more mention of the recent introduction of multiparametric MRI (mpMRI) scanning prior to biopsy and should have included studies, such as PROMIS and PRECISION. It was noted that in their response, the reviewers pointed out that, though studies such as PROMIS and PRECISION did investigate mpMRI, these were not eligible for inclusion in the context of a population-wide screening programme because they only included a preselected population of men who were already known to be at suspicion of prostate cancer, rather than starting with a cohort from the general population. These studies also compared mpMRI with biopsy strategies, rather than with PSA-based screening. In addition, while it was noted that the evidence on mpMRI was promising, the review concluded that the lack of consistency at the moment precludes drawing robust conclusions on the appropriateness of alternative screening approaches for use in a national screening programme and that it would be beneficial to have more evidence on mpMRI to support these initial findings.

7.9 Another theme raised by stakeholders was that consideration should be given to alternative approaches, such as a targeted screening programme for men at increased risk of prostate cancer or a polygenic risk-stratified programme using mpMRI. The UK NSC acknowledges that this is a rapidly evolving area and that alternative approaches to population screening for prostate cancer, such as targeted screening aimed at selected group of men at high risk, are gaining increasing attention in the research community. It was noted that, following the 2019 publication of the Report of the Independent Review of Adult Screening Programmes in England which called for the creation of a single UK wide advisory body looking at both population and targeted screening, work is underway to help define the key criteria that will help support decision-making on recommendations for the introduction of targeted screening programmes or risk assessment programmes.

7.10 Another theme from the consultation comments was that the UK NSC should consider a more pragmatic approach to reviewing evidence for screening, which includes grey literature. It was noted that an analysis of published peer reviewed literature offers some reassurance about the quality of the evidence and is an essential element of the UK NSC rapid review process. It was also noted that the UK NSC approach of evaluating evidence published in peer review journals is in line with the 2014 House of Commons Science and Technology Committee Report on health screening which recommended that the evidential barrier to the introduction of a screening programme should remain high, given that the UK NSC aims to ensure that screening does more good than harm. Prof Evans and Prof Hyde echoed their support to this robust evidence-based approach and expressed concern over the use of grey literature as this would not be appropriate.

7.11. It was also noted that the UK NSC is aware of ongoing modelling exercises which may stimulate discussion on potential screening strategies and the evidence gaps and research questions relating to them. The Committee is happy to be involved in discussions relating to these.

Another point raised by some consultees related to the interpretation of the Protect trial. It was noted that in their response, the reviewers pointed out that the conclusion they reached in the review is aligned with the NICE recommendations to offer all three treatments (radiotherapy, prostatectomy and observation) as an option for those with low- to intermediate-risk prostate cancer.

The Committee reviewed all comments and technical points raised by stakeholders and was satisfied with the updated version of the review provided. A suggestion was made to change the word “benign” in the Plain English summary of the review, as this could be confusing for members of the public. The Committee expressed their gratitude to the member of the public for sharing their personal account and for taking the time to take part in the public consultation.

The Committee was also satisfied with the thoroughness of the responses to the key points raised by the stakeholders during the public consultation exercise.

7.12 Based on the evidence provided, the UK NSC recommended that a systematic population screening programme for prostate cancer should not be introduced.

4. Action: in the Plain English summary of the prostate cancer review, the word “benign” should be amended to an alternative term such as “slow growing”, “low risk” or "low grade"

Screening for Oral Cancer – evidence map

8. Dr Cristina Visintin presented this item with accompanying slides.


2.ORAL CANCER IN ADULTS UK NSC_28.

8.1 Oral cancer is a cancer that develops in the oral cavity and can also be referred as mouth cancer.

8.2 The UK NSC last reviewed the evidence for oral cancer in 2015. This review mainly looked at the natural history, screening test accuracy and interventions in screen detected individuals. It concluded that population screening should not be offered because: the natural history of the condition was not well understood (it was difficult to know which lesions identified by screening would become cancerous); a reliable screen test was not available; it was not clear what the optimal treatment for the scree detected individuals was.

8.3 An evidence map was undertaken by Solutions for Public Health to assess whether a more sustained review on oral cancer should be commissioned. The 2020 evidence map looked at three key questions similar to the 2015 review;

I. Is the natural history of oral cancer understood (progression from potentially malignant disorders to malignancy)?
II. Are there any accurate screening tests for the detection of oral cancer?
III. Are there any studies looking at the effectiveness of treatment in screen detected (opportunistic or population programmes) oral cancers or potentially malignant lesions?

8.4 It was found that there was a large volume of evidence which relates to the natural history of the condition and therefore and evidence review could be performed for this question. However, very little or no evidence was identified for Q2 and Q3.

8.5 Based on the overall outcome of the evidence map it was suggested that further work should not be commissioned at this time. this is because even if further work would be commissioned for Q1 this would not be sufficient to change the overall recommendation. ARG supported this conclusion.

8.6 Following from three-month consultation of which 26 stakeholders were contacted no comments were submitted. Although no comments were submitted, Dr Visintin informed the Committee that by using google analytics, it was established that the consultation page had received 97 unique views, so, the consultation had generated some interest.

8.7 Prof Hyde asked to update the evidence map publication document to say that: in relation to the screening test the 2015 UK NSC review found a lot of variability in the reported performance of such tests.

8.8 Prof Gray added the document was an interesting read. However, the document would benefit from a clarification on what exactly the term oral cancer refers to. Dr Visintin said that the term oral cancer in this document refers to cancers developing in a part of the mouth, such as the surface of the tongue, the inside of the cheeks, the palate, the lips or gums. This will be added to the publication document.

8.9 The UK NSC agreed to uphold the recommendation that a population screening programme for oral cancer is not recommended in the UK.

Fetal Maternal and Child Health

9. FMCH report

9.1 Dr Sharon Hillier provided the Committee with a brief summary of the FMCH meeting held in September. She confirmed that the public consultation on newborn screening for adrenoleukodystrophy (ALD) was open and is due to close on the 5 January 2021.

Antenatal screening for Asymptomatic Bacteriuria (ASB) – rapid review

3.UK NSC ASB UK NSC_28.10.2020_fina

10. Dr Visintin presented this item to the Committee with the attached slides.

10.1 Currently, the UK NSC does not recommend the implementation of a centrally managed, systematically organised, population screening programme in the UK. However, the recommendation acknowledges that screening is recommended in the clinical practice

guideline covered by NICE (clinical guideline 62: antenatal care for uncomplicated pregnancies).

10.2 ASB is the presence of bacteria in the kidneys, bladder or the tubes that connect them which is identified through a urine sample. In pregnant women if bacteria are detected this is then treated with a course of antibiotics. Clinical concern surrounds the unnecessary administration of antibiotics in pregnancy and how this can affect mother and unborn child.

10.3 The UK NSC last looked at screening for ASB in pregnancy in 2017 and recommended that a population screening programme should not be recommended due to insufficient evidence in relation to the prevalence of the condition, the best way to screen pregnant women, how often and what if any negative side effects on the pregnancy there would be having been given antibiotics .

10.4 The 2020 UK NSC evidence review developed the five key questions following expert input;

I. What is the disease burden associated with ASB? (criterion 1)

II. What is the performance of screening tests for detecting ASB infection in pregnancy? (criteria 4 and 7)

III. What are the benefits and harms of screening compared with no screening for ASB in pregnancy? (criterion 11)

IV. What are the benefits and harms of antibiotic treatment compared with no treatment for ASB in pregnancy? (criterion 9)

V. How benefits and harms of screening and treatment inform women's' decisions to undergo screening for bacterial infections during pregnancy? (criterion 12)

10.5 The 2020 evidence summary concluded that there is still a low volume and poor quality of evidence in relation to most of the research question examined by the review. In addition, most studies were conducted in countries of limited relevance to the UK or did not reflect current practice in antenatal care. Moreover, recent studies in the review place a question mark over the value of screening. Therefore, the evidence currently available is not sufficient to recommend a change in the UK NSC recommendation on an antenatal population screening programme for ASB in pregnancy in the UK.

10.6 The UK NSC held a three-month consultation which closed on the 22 October. Only one comment was received from the National Guideline Alliance, on behalf of NICE Antenatal Care Guidance Committee which stated that it had noted the UK NSC recommendation and had no comment.

10.7 Dr Visintin informed the Committee that as of 2020, NICE will no longer include recommendations on ASB in the update of their guidance. Consequently, the UK NSC recommendation will be the only national recommendation on screening for ASB in the UK. However, it is to be noted that screening for ASB is a longstanding part of antenatal care packages in some areas and that, recently, delivering this service has become a requirement for CNST cover. The UK NSC discussed this issue and agreed that further work to clarify and explore the issues relating to screening for ASB should be undertaken. This is to ensure that an updated recommendation can be made on the basis of sound evidence. Until the UK NSC has sufficient evidence to make a recommendation on screening for ASB in a nationally managed screening programme, units where ASB screening is an established practice are asked to remain open to participation in research.

10.8 Dr Shortland suggested that a possible stream of work could consider research to find out whether women wish to have this test and what are their thoughts on antibiotics intake. The group also considered the possibility of carrying out a study to identify to what extent the NICE guidance is followed, a possible clinical and cost-effective model or an RCT.

10.9 Dr Hicks suggested that a proposal could be submitted to the NIHR to consider research in this area.

10.10 Mrs Goodman informed the Committee that further work in this area would be of considerable benefit given that the Saving Babies Lives Bundle 2 currently states that Trusts should be offering ASB testing and so further clarification on this vital.

5a. Action: UK NSC to put out a holding statement on screening for ASB

5b. Action: UK NSC secretariat to contact and discuss possible NIHR research into ASB with developments being feedback to FMCH

Newborn screening for Galactosaemia – rapid review

4. UK NSC galactosaemia UK NS(

11. Goda Kijauskaite presented this item alongside the attached slides.

11.2 Galactosaemia is a hereditary metabolic condition which means that some babies inherit a faulty gene which makes them unable to break down certain types of sugar (galactose) found primarily in milk. When the galactose cannot be broken down and digested, it builds up in the tissue and blood in large amounts which can cause feeding difficulties, sickness and liver damage. It can also cause long term complications such a speech difficulties and delayed development. Treatment for this condition would be to avoid foods containing galactose for life.

11.3 The UK NSC last reviewed this in 2015 and recommended that population screening should not be offered because most babies would develop symptoms before the screening process completed and that there was a lack of evidence in relation to early treatment, when compared to current clinical detection.

11.4 The 2020 review looked at three key areas:

I. What is the median age of presentation of classic galactosaemia?
II. What is the accuracy of the available screening tests to detect classic galactosaemia?
III. Does early initiation of treatment for individuals with classic galactosaemia provide better short- and long-term outcomes?

11.5 The 2020 UK NSC review found that:

I. a large proportion of screen-detected cases would be symptomatic by the time screening results are confirmed and diagnosis is made. The delivery of the screening test might not be suitable given that clinical presentation occurs at around 7 days and newborn blood spot screening takes places around the 5th day
II. there was insufficient evidence to establish an optimum screening approach
III. there was insufficient evidence to determine whether early initiation of the treatment, as a result of screening, provide better long-term health outcomes.

11.6 Overall, the 2020 review concluded that the UK should not recommend newborn screening for galactosaemia.

11.7. The UK NSC held a public consultation from June to September and only one comment was received which stated that they had no comment. This ultimately meant that no comments were received on the evidence review to screen for galactosaemia.

11.8 Goda Kijauskaite informed the Committee that through google analytics we were able to learn that the consultation page had 176 hits with the average time spent on the page being

just over a minute. This provides an indication into the stakeholder engagement in that the consultation was viewed, however, it did not warrant a comment to be submitted.

11.9 The Committee discussed that some galactosaemia cases may be picked through the PKU screening, but this information is not recorded consistently in the laboratory notes. Prof Shortland noted that it was imperative for the professional community to understand the need to collect and publish data on this, in order for the UK NSC to take this into consideration. The need for ongoing surveillance was also pointed out in the LCHADD review where published evidence was required to inform future reviews. The UK NSC also noted how there is growing pressure to expand newborn blood spot screening. However, it was stated that data need to be collected and published in order to form part of the evidence base. The Committee agreed that they would welcome such publications.

11.10 Dr Elliman informed the Committee of an outcome project on inherited metabolic diseases that aimed to report and publish its findings on the importance of collecting data in order to present the data required by the UK NSC. The UK NSC expressed an interest in this and requested that this is shared with the Committee at a future meeting.

11.11 Based on the evidence provided the UK NSC agreed that a population screening programme for classic Galactosaemia in newborn should not be recommended in the UK.

6. Action: Reporting on outcomes for IMD to be added as a presentation item for the March UK NSC meeting; Dr Elliman to share details with Zeenat

Screening for Preterm birth in asymptomatic low risk women – rapid review

5.UK NSC preterm
UK NSC_28.10.2020_f

12. Dr Visintin presented this item to the Committee with the attached slides.

12.1 Preterm birth, defined as birth occurring before 37+0 weeks' gestation, is the single largest cause of morbidity and mortality in neonates in the UK with 1 in 12 babies being born premature in the UK. Babies born before full term are vulnerable to health complications and may require special or intensive care in neonatal units.

12.2 The UK NSC last reviewed the evidence to screen asymptomatic low risk pregnant women for risk of preterm labour and births in 2015 and recommended that this should not be introduced.

12.3 The 2020 review aimed to evaluate whether new evidence was available on screening test performance and on the effectiveness of prophylactic interventions. It focused on the four potentially most promising screening tests emerged from the 2015 review to predict preterm labour or associated morbidity and mortality: cervical length measurement, cervicovaginal Fetal fibronectin, tests for bacterial vaginosis and uterine contraction (by home monitoring device). And also, the review looked at several interventions which are aimed at different causes that might prevent preterm birth (Progesterone, cervical cerclage, cervical pessary, antibiotics for bacterial vaginosis and probiotics).

12.4 The conclusion of the 2020 evidence review was that there is a lack of evidence to change the current UK NSC recommendation on preterm birth.

12.5 The UK NSC consultation closed on the 23 October and only two comments from the National Guideline Alliance, on behalf of the NICE Antenatal care guideline committee to indicate that it had noted the UK NSC's recommendations and reviews and had no comments as well as the British Maternal and Fetal Medicine Society, both which did not disagree with the findings of the 2020 evidence review. The British Maternal and Fetal Medicine Society also provided some comments on technical issues which was addressed by the reviewer.

12.6 Dr Visintin informed the Committee that based on google analytics this consultation had received 115 hits with the average time spent being between 2- 3 minutes and these stats clearly shows that there was an interest in the review.

12.7 Having reviewed the evidence and comments submitted the UK NSC recommended that that population screening for preterm birth in asymptomatic low risk women should not be introduced in the UK.

Sickle Cell and Thalassaemia programme modification proposal- evidence map

6.NIPT_NIPD SCT slides for UK NSC_28

13. This item was presented by Paula Coles alongside the attached slide deck.

13.1 Screening for sickle cell and thalassaemia (SCT) is recommended by the UK NSC.

13.2 The UK NSC received a programme modification proposal from the NHS Sickle Cell and Thalassaemia screening programme (NHS SCT) which proposed that non-invasive prenatal testing or diagnosis ((NIPT/ NIPD) could be added to the existing screening pathway in order to detect the condition as an alternative to women opting for amniocentesis or chorionic villus sampling (CVS) since there is no associated risk of miscarriage with non-invasive testing. It is suggested that although proposed as a contingent test the aspiration would be to offer this as a diagnostic test, should the evidence support this.

13.3 An evidence map was commissioned to scope the volume and type of published evidence available as the first step and asked one key question; this was about the test accuracy of NIPD or NIPT for SCT. It was important to note that the proposal used NIPT/ NIPD interchangeably and so both were used as key search terms in the evidence map.

13.4 Although the evidence map generated a result of 15 primary studies and two systematic reviews, these was insufficient evidence to justify further work at this time. This is due to the heterogeneity of the studies, the low applicability to the UK, limited reporting of test accuracy and shortage of studies reporting use of NIPT/NIPD in sickle cell disease.

13.5 The UK NSC were informed however that FMCH were keen to see how this topic develops and would be keeping abreast of developments within the programme. It was noted that the offer of NIPT/D if suitable in other antenatal programmes should be given the same weight as in screening for Down's syndrome, Edward's syndrome and Patau's syndrome.

13.6 The outcome of the evidence map had since been fed back to the SCT Screening Programme who had been engaged with the evidence map process and were content of the findings.

13.7 The UK NSC agreed that based on the findings of the evidence map further work should not be commissioned at this time and that this will be reviewed again in three years or earlier should any significant evidence be published before this.

Antenatal screening for Fetomaternal Alloimmune Thrombocytopenia (FMAIT)- evidence map

7.Antenatal screening for FMAIT UK NSC_28

14. Dr Visintin presented this item with the accompanying slides.

14.1 Fetomaternal alloimmune thrombocytopenia (FMAIT) is a rare condition which affects a baby's platelets. It occurs when a mother's immune system does not recognise the baby's blood and attacks it. If this happens, there is a risk of bleeding in the baby in the womb or shortly after birth. This is very rare but if it happens babies can be at serious risk of brain damage or death.

14.2 The UK NSC last reviewed screening for FMAIT in 2017 and recommended that population screening should not be offered as there was uncertainty about the proportion of FMAIT results in serious adverse outcomes of the fetus/ baby and the lack of evidence about a single optimal management strategy to prevent serious adverse outcomes in the newborn as well as there being no evidence of a reliable predictor that can routinely identify first pregnancies of women at high risk of a baby developing FMAIT leading to disability or death.

14.3 The 2020 evidence map was undertaken by Solutions for Public Health and asked two key questions:

i. What are the most effective screening tests to identify pregnancies at high risk of serious adverse outcomes due to FMAIT?
ii. What is the optimal intervention for anti-Human Platelet Antigens type1a (HPA-1a) women to prevent serious adverse outcomes in the newborn?

The conclusions of the evidence map were that due to the limited volume and type of the new evidence identified it was unlikely that an evidence review looking at the above key questions would provide the evidence to charge the current UK NSC recommendations on antenatal screening for FMAIT. The UK NSC consultation ran from the 28 July 2020 to 20 October 2020. It was circulated to 21 stakeholders and received one response from the Royal College of Paediatrics and Child Health who did not disagree with the findings of the 2020 evidence map

14.4 The Committee agreed that further work should not be commissioned at this time and screening for FMAIT should be reconsidered in three years' time.

2019 Annual call for topic: Screening for Dyslexia in school age children — evidence map

8.DYSLEXIA UK NSC_28.10.2020_fina

15. Dr Visintin presented this item to the Committee along with the slides.

15.1 Screening for Dyslexia in school age children was a proposal from the 2019 annual call for topics. It was the first time the UK NSC has looked at screening for dyslexia in children. As suggested by the UK NSC evaluation group for annual call topics and consequently discussion at the UK NSC meeting in Feb 2020 it was agreed that an evidence map should be undertaken to scope the volume and quality available of screening tests for dyslexia.

15.2 The 2020 evidence map identified 13 studies which met the eligibility criteria however only one specifically focused on screening children for dyslexia. All other studies looked at dyslexia in combination with other learning difficulties or delays in learning and this highlighted the difficulty in screening for dyslexia as a single condition as it is typically looked at within a range of other conditions. As a consequence, there is very little to guide discussion on the use of a test which is targeted at dyslexia and which might be used to increase the detection rate in school age children.

15.3 The findings of the evidence map had been shared with the submitter at DHSC who complimented the work as being thorough and accepted the findings.

15.4 The UK NSC agreed that based on the findings of the evidence map further work should not be commissioned at this time and agreed that this should be formally communicated with the submitter.

7. Action: The UK NSC to issue a formal outcome letter on the 2019 annual call for topics to screen for dyslexia to be sent to the submitter.

NIHR NETSCC Update

16.The UK NSC noted the document

AOB

17.

Newborn hearing Screening programme modification

The Committee were informed that the consultation on the programme modification proposal for newborn hearing screening to detect auditory neuropathy spectrum disorder (ANSD) had recently closed.

The Chair informed the Committee that for brevity and not to delay a recommendation on this, the recommendation would be signed off under Chair's Action in order for this to be

published within the usual six-week timeframe. However, should there be significant opposition to the findings this would be deliberated at FMCH.

Comments and responses would be shared with Committee for information with a two-week deadline for comments on the suggested recommendation.

This would then be an addendum to the October minutes and published alongside this.

Next UK NSC meeting; Friday 5 March 2021

UK National Screening Committee (UK NSC)

Chair's Action

Following the 28 October 2020 (virtual) meeting

NOTIFICATION OF CHAIR'S ACTION ON BEHALF OF THE COMMITTEE

Action Number	Item to be addressed	Initial status	Reason for Chair's Action	Decision
1.	Newborn Hearing Screening Programme (NHSP) Modification Proposal- on whether Auditory Neuropathy Spectrum Disorder (ANSD) should be added to the screening programme using the automated Auditory Brainstem Response (AABR) test	During the 2017/18 UK NSC's annual call for topic a proposal was submitted by the National Deaf Children's Society (NCDS) asking the UK NSC to consider adding AABR to the existing screening programme in addition to the Otoacoustic Emissions (OAE) test. It was agreed that the submission fell within the UK NSC remit but that the proposal should be handled as major programme modification.	As the public consultation closed on the 19 October, there was not sufficient time to review and respond to the consultation comments before a final recommendation was presented to the UK NSC. The Committee were informed at the meeting, under AOB, that the evidence summary, undertaken by Bazian Ltd, would be circulated in the coming week to provide members with a two-week	Based on the evidence provided the UK NSC supports the recommendation that the programme modification proposal to add ANSD to the existing NHSP should not be introduced. This was because there is limited evidence on the incidence of ANSD. It is thought that via the current screening programme in England 4 out of 6 per 100,000 well-babies with ANSD

		An evidence summary was undertaken which looked at three key questions. A public consultation was then held for three months from the 27 July to the 19 October.	timeframe/ opportunity to review and comment on the documents and proposed recommendation. Following a two-week period two comments were received which supported the findings of the evidence review. No members or officers contested the proposed recommendation.	may be missed and that as it may only affect one ear it is unclear how this will affect their hearing and development overall. There was also not enough applicable evidence on the time, resource or cost implications on including AABR into the well-baby protocol. A future annual call submission for this would be welcomed should published evidence addressing the gaps identified in this evidence summary become available.

I confirm that I have taken Chair's action in relation to the decisions recorded above.