UK National Screening Committee (UK NSC)

Note of the meeting held on the 19 March 2015

at

Friend's House 173-177 Euston Road

London NW1 2BJ

Members

Professor David Walker (Chair)	Medical Director, University Hospitals of Morecambe Bay Foundation Trust
Dr Sunil Bhanot	GP
Professor Roger Brownsword	School of Law, King's College
Ms Jane Fisher	Patient and Public Voice

Ex-Officio;

Mr Andrew Anderson	Cancer Screening Communication Team, PHE
Dr Hilary Angwin	Consultant Public Health, PHE
Dr Margaret Boyle	Department of Health, Social Services and Public Safety Northern Ireland
Dr David Elliman	Clinical lead for Newborn Infant Physical Examination and Newborn Blood Spot, PHE
Dr Sharon Hillier	Deputy for Welsh Government (via telecon up to 13.30)
Dr Dorian Kennedy	Deputy Director, Sexual Health, Screening and Sponsorship Team, Department of Health
Professor Julietta Patnick	Director of Cancer Screening Programmes, PHE
Dr Heather Payne	Senior Medical Officer for Maternal and Child Health, Welsh Government (via telecon up to 13.30)
Mr Scott Sutherland	Scottish Government

Miss Jo Taylor	Sexual Health, Screening and Sponsorship Branch Department of Health

Observers;

Mr Thomas Dillon	DH Analyst
Mr Tim Elliott	DH Senior Cancer Policy
Dr Nick Hicks	National Co-ordinating Centre for HTA
Miss Nicole Redhead	Sexual Health, Screening and Sponsorship Branch Department of Health

Secretariat

Mr Nick Johnstone- Waddell	Head of Communications, UK National Screening Committee
Dr Anne Mackie	Director of Programmes - UK National Screening Committee
Miss Zeenat Mauthoor	Secretariat

Apologies

Dr Eric Baijal	Joint Director of Public Health, NHS Borders
Ms Alison Brown	Patient and Public Voice
Professor Martin Buxton	Emeritus Professor of Health Economics
Ms Majella Byrne	Director, National Cancer Screening Service, Republic of Ireland
Professor Alan Cameron	Consultant Obstetrician at Southern General Hospital, Glasgow
Professor Gareth R Evans	Consultant in Genetics Medicine, St Mary's Hospital, Manchester
Dr Rosemary Fox	Director of Screening Division, Public Health Wales
Dr Surendra Kumar	GP
Dr Janet Little	Public Health Directorate, Ireland
Mr John Marshall	UK NSC Projects and Programmes Manager
Mr Terry O'Kelly	Senior Medical Officer, Scottish Government

Welcome and Introductions

1. Professor David Walker welcomed all to the meeting and a round of introductions were given including;

Agenda Item Presenters

Dr Hilary Angwin, newly appointed Chair of the Fetal, Maternal and Child Health Co-ordinating group.

Resignations

The Chair informed members of Moira Morris' retirement. Moira had been on the committee since 2009 as a user representative. The committee agreed that a letter should be sent from the Chair to thank her for her contribution to the committee.

Action; Professor Walker to send letter of appreciation to Moira Morris

Apologies were noted including Mr John Marshall's whose presentation on ante natal screening will be provided by Dr David Elliman.

Minutes and Matters arising

2. The minutes of the last meeting were confirmed as a true and accurate record.

3. There were four actions points identified from the last meeting;

5.2 Review of the UK NSC

Miss Taylor to circulate the final version of the recommendations outlined by the Review group to the UK NSC before submission to the Four CMOs- COMPLETED

5.4 Science and Technology Committee Inquiry

Miss Mauthoor to set up an additional UK NSC meeting looking specifically at the recommendations outlined by the Science and Technology Committee Inquiry- COMPLETED

6.9 Report from the NHS Diabetic Eye Screening Programme

Dr Sherriff to undertake discussions to develop a pilot with the Wales programme (DRSSW) and any other suitable interested areas ,and to provide a more detailed paper on progress to a future meeting – ONGOING and this will be brought to the JUNE meeting as an update.

7. Fetal Maternal and Child Health Screening
(screening in the educational system)

Dr Mackie to discuss possible use of such a resource in schools with the Children's lead in PHE. Mr O'Kelly agreed to help amend see what progress may similarly be made in Scotland- ONGOING with Wales currently developing a screening school vision pathway.

Director's Update

4. Dr Mackie gave an update as follows;

Pulse Oximetry

4.1 The UK NSC has recommended piloting and evaluating a study that looks at the use of pulse oximetry for screening newborn babies to detect congenital heart defects (CHD). Screening pathways and which specific conditions should be screened for have been agreed and a number of English hospitals are signed up to the pilot. Pre and post data be collected and will report to the UK NSC 2016. Dr Mackie invited committee members who would like to be a part of the working group, overseeing the pilot, to contact her directly. Dr Mackie was asked whether home deliveries would be included within the cohort to be offered screening and this could not be confirmed.

Action; Dr Mackie to enquire if pulse oximetry could be used at home deliveries.

Newborn Blood spot Screening Extension

The extension of newborn blood spot screening to include the additional four conditions; Maple Syrup Urine Disease (MSUD), Homocystinuria (HCU), Glutaric Acidaemia Type 1 (GA1) and Isolvaleric Acidaemia (IVA) in England and Wales was officially announced. The work done to support the pilot was very comprehensive and as a result implementation has been reasonably straightforward. A proposal is being drafted to look at the outcome of screening of these rare conditions focusing on Glutaric Acidaemia Type 1 (GA1). Dr Mackie highlighted the increase in interest for other rare conditions to be introduced in the screening programmes and noted the English rare disease registration system, which may help in providing prevalence data and treatment outcomes which would help inform the evidence base for screening.

Duty of Candour

5 This item was brought to the committee following discussions firstly at the Advisory Committee on Breast Cancer Screening (ACBCS) and subsequently at the Bowel Screening Advisory Committee (BSAC) and the Advisory Committee on Cervical Cancer (ACCS).

5.1 Dr Mackie informed the committee that this item relate to a CQC document which is applicable to England only. The Duty of Candour states that "health service bodies are open and transparent…. When certain incidents occur in relation to the care and treatment provided to people who use services in the carrying on of a regulated activity". The Advisory Committee on Breast Cancer Screening (ACBCS) had asked if this is applicable to interval cancers, were there were possible wider implications for screening. The UK NSC agreed that false positives and negatives are expected in screening and these facts should be carefully explained as part of the

offer of screening (to allow informed choice). However there are rare occasions when quality standards have not been followed properly and as a result failings have been made, these are however not intrinsic to the screening offer. The UK NSC was of the view that (Serious Incidents) where quality standards have not been followed should be reported to patients however emphasised that screening is not perfect and will not always capture or predict the development of all abnormalities.

5.2 Dr Mackie has commissioned a piece of work (agreed with Professor Patnick) to be taken to the Screening Programme Board in England. An update would be provided at the next UK NSC meeting.

Action; An update on Duty of Candour to be brought to the UK NSC for information at a later date.

HPV Testing in Cervical Cancer

6 This item was presented by Professor Julietta Patnick and referenced the circulated papers kindly produced by Professor Kitchener and Dr Sue Moss.

6.1 Human Papilloma Virus (HPV) is associated with majority of cervical cancers. The UK NSC approved testing for HPV as a triage to cytology and test of cure in 2014. International work has been underway for some time to assess the effectiveness of using HPV as the first test (primary screen).

6.2 Professor Patnick confirmed that there are now reliable tests for HPV and these are more sensitive than the current cytology test. An absence of HPV means that the woman's risk of developing cervical cancer is very low so a move to HPV testing would also allow for screening intervals to be extended for those who are HPV negative. This move would promote an overall cost effectiveness in the programme, and was illustrated in recent international studies, as well as analysis taken from the expansion of the ARTISTIC follow up. Strategies in which HPV was used as the first test (primary screen) were found to be both cost and life years saving The committee was asked, based on the results from the six pilot sites, whether it would support a consultation on a switch from cytology to HPV as a primary test in order to prevent the spread of cervical cancer.

6.3 Dr Bhanot raised the issue of self-testing and how this could further change the offer of cervical screening. Professor Patnick agreed that self-testing is important and that it was being looked into for those women who do not attend screening. Dr Angwin also raised concern of the call and recall system and the training of staff to input this new data, to which Professor Patnick responded that there will be implementation challenges (should the decision be a positive one) with the main issue requiring a new IT system to support HPV data.

6.4 The committee thanked Professor Patnick and her colleagues for the detailed analysis and report and agreed for Professor Patnick to report back to the ACCS confirming the UKNSC's s interest in the upcoming work of self-testing. Furthermore, the committee agreed for HPV testing as a primary test to be put out for public and stakeholder consultation after the pre-election period.

Action; Dr Mackie to arrange for public and stakeholder consultation after the pre-election period

Review of the UK NSC Role

7 Miss Jo Taylor provided the committee with a verbal update on the UKNSC triennial Review noting that it will now not be published till after the pre-election period.

Update from the Science and Technology Committee (STC) meeting in February

8 Dr Mackie provided the committee with a brief update from the February meeting of the UKNSC, for the benefit of those who were unable to attend as well as to confirm decisions.

8.1 The STC made a recommendation about clarifying governance. This included making the committee a formal scientific advisory committee and therefore adhering to the principles of scientific advice to government and to those elements of the code of practice for scientific advisory committees (CoPSAC) that are relevant to its functions. A Code of Practice for the UK NSC had been drawn up which gives clarity on the Committee's procedural rules, including roles and responsibilities, processes and terms of appointments for members. The Secretariat has reviewed UK NSC documents to ensure that a clear distinction is made between the UK NSC and Public Health England (PHE), clarifying that the UK NSC is a committee provides independent advice to Ministers, and PHE provides Secretariat support to the Committee.

8.2 The STC emphasised that there should be a high evidential barrier to the introduction of screening. The committee did recommend that the UK NSC strive to better engage with stakeholders and more clearly describe the evidence review process. Dr Mackie confirmed that Mr Nick Johnstone-Waddell is leading the work on stakeholder engagement and Mr John Marshall is leading the work on the evidence process. An annual call for screening proposals will be introduced and an annual stakeholder meeting will be held. Work was in hand to ensure that plain English summaries of papers were provided to enhance stakeholder engagement.

8.3 Dr Bhanot raised the issue of cost effectiveness. Dr Mackie responded that at the special meeting the members had suggested that wider societal costs and benefits should be assessed. They also recognised that in order to compare with other interventions such as immunisation or medicines, cost per QALYs should be reported for screening programmes. Dr Mackie reported that DH is taking forward work on this with the involvement from DH, PHE, NICE and the NHS.

8.4 The Chair confirmed that there is an ongoing issue with national programmes that have the hallmarks of a screening programme but are not recommended by the UK NSC. Work to address this is being undertaken, however it a difficult task.

Annual Stakeholder Meeting

9 Mr Nick Johnstone- Waddell provided the committee with a verbal update.

9.1 A working group has been set up to identify topic areas and outline arrangements. The committee discussed which part of committee's work would provide a useful focus for stakeholders. The working group would like committee members to present a topic and request for those interested to make contact with Zeenat.Mauthoor@phe.gov.uk. The group will be meeting at the end of April and will be happy to provide the committee with an update on developments at the next UK NSC meeting.

Action; Committee members who would like to present to contact Miss Zeenat Mauthoor

Fetal Maternal and Child Health Screening

10 Dr Hilary Angwin introduced this item.

10.1 The Fetal Maternal and Child Health subgroup met on the 6th March. The sub group discussed the upcoming reviews coming to consultation.

Screening for Galactosaemia

11 Dr Elliman presented this item.

11.1 The current recommendation is that systematic population screening for Galactosaemia is not recommended. It was reviewed in 1997 by the NIHR Health Technology Appraisal programme (HTA), which found uncertainties surrounding the value of detecting variants of uncertain significance and evidence that long term health outcome reported in clinically presenting Galactosaemia were unchanged in screened populations.

The review noted that a proportion of cases would be detected by screening prior to symptom onset; furthermore the consultation responses suggested that there was a diagnostic delay in clinically detected cases compared to screen detected cases. As such the case for screening might focus on the prevention of acute presentation and the prevention of early mortality from liver failure. However the advantages of this approach compared to a well managed clinical pathway would be uncertain as no papers were found which assessed this strategy, key test performance measures could not be identified by the review, the diagnosis of screen positive cases could be complicated in early presenting cases, current testing options still detected variants of uncertain significance, and a proportion of cases were detected as a by-product finding from the current PKU screening programme. In addition it was unclear whether any guidance was currently available on the management of neonatal liver disease which factored in the possibility of Galactosaemia as suggested in a case review submitted by Genetic Alliance UK. Data suggested that there was a low level of awareness of the condition amongst paediatricians.

11.2 The UK NSC agreed not to recommend screening for Galactosaemia as;

- The evidence continues to suggest that the long term outcomes of Galactosaemia are unaffected by screening
- The gains to be made from screening in terms of the management of acute neonatal presentation were uncertain

Action; This recommendation will be considered further by the UK Health Departments

The committee noted that work in the following would help inform the debate.

- Identification of the number and / or proportion of Galactosaemia cases detected through PKU screening,
- consideration of the need for guidance within the screening programme for cases detected in this way by NHS Screening Programme
- a review of current guidance on neonatal liver disease to ensure that the requirements of clinically presenting Galactosaemia is appropriately considered.

Action: UK Health departments to consider

Screening for Fatty Acid Oxidisation Disorders

12 Dr Elliman presented this item.

12.1 The UK NSC currently does not recommend screening for the following fatty acid oxidisation disorders;

- Carnitine uptake defect
- Long chain hydroxyacyl CoA dehyrogenease deficiency
- Trifunctional protein deficiency
- Very long chain acyl CoA dehydrogenase deficiency

12.2 The most recent evaluation of expanded newborn screening resulted in a recommendation to not screen for long chain hydroxyacyl CoA dehydrogenase deficiency / trifunctional protein deficiency. The review therefore took into account the evidence for very long chain acyl CoA dehydrogenase deficiency (VCLADD) and carnitine transport deficiency (CTD). There was no reliable way to predict phenotypes/prognosis through the screening and diagnostic process and there was uncertainty over the performance of the respective tests due to biological processes associated with the conditions. False negatives and false positives had been reported in studies of conditions. In addition there was uncertainty around which cases identified through screening would require treatment.

12.3 The committee agreed that screening for very long chain acyl CoA dehydrogenase deficiency (VCLADD) and carnitine uptake defect (CTD) should not be recommended as;

- The test performance was questionable in both conditions with uncertainty about treatment of screen detected babies.
- The natural history of heterozygotes was not well understood

Screening for Amino Acid Metabolism Disorder Diseases

12.4 Dr Elliman presented this item to the committee looking at three newborn amino acid metabolism disorders; Tyrosinaemia Type 1, Argininosuccinic acidaemia and Citrullinaemia.

12.5 The current policy recommends that screening for these additional disorders should not be included in the newborn blood spot programme.

12.6 The reviews noted that there were uncertainties surrounding the epidemiology of all three conditions. The reviews also noted ongoing concerns about the proportion of cases of Argininosuccinic acidaemia and Citrullinaemia which presented prior to screening.

12.7 In the case of Citrullinaemia the withdrawal of screening programmes had been reported in the literature. In the case there were additional concerns about the effectiveness of the treatment even if metabolic decompensation was avoided in the neonatal period. However Tyrosinaemia Type 1 appeared to be a stronger candidate for screening and further work might address some uncertainties highlighted by the review and the consultation. For example papers published after the literature search cut off and submitted by the Royal College of Paediatrics and Child Health (RCPCH) addressed concerns about European epidemiology and the long term outcomes from treatment with Nitisinone (NTBC). In addition it had been suggested that the review should focus on studies using succinyl acetone as the screening marker rather than combining studies of this marker and tyrosine, a less specific marker. As with Galactosaemia, a proportion of Tyrosinaemia cases were identified as a by product finding from PKU screening and further information was required on this.

12.8 The Committee agreed that screening for Tyrosinaemia Type 1 is not recommended but that the decision should be revisited on completion of a review addressing the issues in the future.

12.9 Screening for Argininosuccinic acidaemia and Citrullinaemia is not recommended as;

- There are uncertainties over the epidemiology of this condition in the UK
- Concerns raised over the reliability and timing of the respective tests.

Adult Screening

Screening for Depression

13 The item was presented by Dr Anne Mackie.

13.1 The UK NSC last reviewed screening for depression in 2010 and systematic population screening for depression was not recommended.

13.2 The review identified that the natural history to screen for depression is poorly understood. There are various tests but they have poor predictive value and can therefore create a lot of false positives.

13.3 The committee discussed and recognised that there has been a shift in the perception of depression with this becoming more acceptable within society and more people discussing this condition

13.4 Dr Bhanot provided the committee with a GP perspective of treating depression and importance placed on communication with patients and noted that depression is dealt in various ways indirectly. The use of anti-depressants has risen in general practices both in the UK and in the US with many overcoming depression a lot quicker.

13.5 The committee agreed that population screening programme for depression is not recommended because ;

- The natural history of this condition is not fully understood
- The tests have poor predictive value when used in a general population leading to a high number of false positives
- A lack of Randomised Controlled Trials
- Limited literature surrounding evidence on follow up and benefit of early intervention preventing major depression.

13.6 The committee acknowledged that depression is a major public health problem, and agreed that a link to the national clinical guidance on depression in both high risk groups and subsets of the population should be signposted alongside the recommendation on the UK NSC website

Screening for Bladder Cancer

14 Dr Mackie presented this item to the committee. The review concluded that there was not a useful screening test.

14.1 Dr Mackie confirmed that the general response to the consultation concurred that screening for this would not be advisable as a reliable screening marker could not be identified.

14.2 The committee agreed to not recommend a national screening programme for bladder cancer as there is no reliable screening markers that meet the UK NSC criteria to offer a safe, precise and valid test.

Screening for risk of Sudden Cardiac Death

This item will be forwarded for discussion at the next UK NSC meeting in June.

Updates

NIHR NETSCC Update (for information)

15 The committee noted the updates

SIGN Update (for information)

16 The committee noted the updates

NHS English Cancer Screening Programmes

17 Professor Patnick presented this item to the committee with thanks to Julia Thompson, Senior PHE communication lead, for providing the circulated paper.

17.1 The NHS Breast Screening Programme is hoping to report in 2020 on the age extension trial. There has been media interest into whether the trial has ethics approval and the programme has confirmed it does. Routine screening screens around 2 million women a year and the programme is now almost 100% digital.

17.2 The NHS Bowel Cancer Screening Programme has successfully carried out a pilot study of faecal immunochemical testing (FIT), which the programme hopes to present at the UK NSC June meeting.

17.3 Bowel Scope Screening met the Secretary of State's commitment to be rolled out in 60% centres by the 31 March 2015, with 100% centres signed up by April 2016.

17.4 NHS Cervical Screening Programme report that although cervical screening uptake is falling particularly in the number of women aged 30 and under. This is consistent with the international overall downward trend over the last ten years in this age group. Professor Patnick

was asked whether the low uptake could be demographically mapped to see if this was due to inequalities in service. Professor Patnick responded stating that the data collected could not be broken down demographically for either the cervical and breast cancer screening programmes, however inequality based on age could be looked into but highlighted that this would be the responsibility of NHS teams to ensure equal access to services.

17.5 HPV as a primary test is being piloted in six sites across England as previously discussed.

17.6 There is continued media interest in the extremely rare cases of younger women being diagnosed with cervical cancer, and Professor Patnick has reaffirmed the position that to screen under the age of 25 would do more harm than good. Professor Patnick and the ACCS have encouraged GPs to look at the cervix of a young women who presents with symptoms and to follow the guidance produced by the ACCS in 2009; http://www.cancerscreening.nhs.uk/cervical/publications/doh-guidelines-young-women.pdf

NHS Screening Programmes

18 Mr Nick Johnstone- Waddell provided the committee with a verbal update on current work and noted that the 2013/14 Annual report was now available on the website. http://www.screening.nhs.uk/publications

18.1 It was noted that once the pre-election period has ended, information on screening programmes will now be available on the gov.uk website.

18.2 Screening undertaken in FASP for T13/18 will commence in the first area in England imminently with national roll out over the coming years.

AOB

19 Dr Mackie raised Genetic Alliance UK concerns that the UK NSC does not have patients affected by rare conditions being discussed at the UK NSC. Members noted that patients are able to input into the consultation. The committee discussed and reaffirmed that patient and public voice is important and already part of the process of decision making, however any practical ways to improve this should be explored. The Secretariat will discuss and identify ways to provide this. Jane Fisher has agreed to help.

19.1 Dr Kennedy raised the issue of rubella to the committee. Dr Mackie reiterated the committee's position of screening for rubella susceptibility and noted that work is being undertaken with PHE immunisation colleagues in PHE to look into how this could be halted in England. Work is being developed and Dr Mackie confirmed that she would be happy to update the committee once more was known.

Date of the next meeting

Thursday 18th June - Edinburgh


NSC
UK National
Screening Committee