UK National Screening Committee (UK NSC)

Note of the meeting held on the 12 February 2016

at

PHE Offices- Skipton House

This meeting provided recommendation on the following conditions;

- Varicella Susceptibility
- Organic Acid Oxidisation Disorder (PA &MMA)
- Familial Hypercholesterolaemia
- Stomach cancer

Members

Professor David Walker (Chair)	Medical Director, University Hospitals of Morecambe Bay Foundation Trust
Dr Sunil Bhanot	GP
Professor Roger Brownsword	School of Law, Kings College London
Dr Paul Cross	Consultant Cellular Pathologist, Queen Elizabeth Hospital Gateshead Health NHS Foundation Trust
Dr Hilary Dobson	Consultant Radiologist and Clinical Director of the West of Scotland Breast Screening Service and Honorary Senior lecturer, University of Glasgow
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

Ms Hilary Goodman	Operational Manager of Antenatal Services/Screening at Hampshire Hospitals Foundation Trust
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
Dr Surendra Kumar	GP, Widnes
Mrs Margaret Ann Powell	Patient and Public Voice
Dr Graham Shortland	Consultant Paediatrician, Cardiff and Vale University Health Board, Noah's Ark Children's Hospital for Wales and Executive Medical Director, Cardiff and Vale University Health Board, University Hospital for Wales

Observers;

Dr Stephen Bridgeman	Director of Public Health, Guernsey
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 Heather Payne	Senior Medical Officer for Maternal and Child Health, Welsh Government
Dr Sue Payne	Scottish Government
Ms Jo Taylor	Sexual Health, Screening and Sponsorship Branch Department of Health

Secretariat

Dr Anne Mackie	Director of Programmes - UK National Screening Committee
Mr John Marshall	Evidence Lead, PHE

Miss Zeenat Mauthoor	Secretariat, PHE
Mrs Jo Harcombe	National Education Training Lead

Apologies

Dr Hilary Angwin	Screening & Immunisation Lead, NHS England/PHE Chair of FMCH
Ms Majella Byrne	Acting Director, National Cancer screening service, the Republic of Ireland
Professor Alan Cameron	Consultant Obstetrician at Southern General Hospital, Glasgow
Ms Sam Cramond	NHS representative
Ms Jane Fisher	Patient and Public Voice
Dr Rosemary Fox	Director of Screening Division, Public Health Wales
Dr Nick Hicks	National Co-ordinating Centre for HTA
Dr Dorian Kennedy	Deputy Director, Flu, Immunisation, Screening and Sexual Health, Department of Health
Dr Janet Little	Consultant in Public Health, Northern Ireland

Presenters;

Dr Sophie Whyte	School of Health and Related Research (ScHARR)

Welcome and Introductions

1. The Chair welcomed all to the meeting and a round of introductions was given including;

New member

Ms Hilary Goodman who was recently appointed onto the committee to fulfil the midwifery post

Membership

The Chair informed members that he will be stepping down from the committee, having been appointed in 2013. Recruitment of a new chair is in process and is currently awaiting Ministerial sign off. The post will be advertised on the gov.uk website in the coming weeks. It is expected that a new chair will be appointed ahead of the June meeting, however in the event that a successful applicant is not appointed, Dr Sunil Bhanot has accepted the post of Vice Chair for a year.

The Chair also informed the committee that Dr Surendra Kumar will also be stepping down from the committee at the end of the month, following an long and productive period as a member of the committee.

Members of the committee thanked both Prof David Walker and Dr Surendra Kumar for their dedication and invaluable input onto the committee over the years.

Agenda Item Presenters

Dr Sophie Whyte has been invited to present both the Ovarian screening model following the publication of UKCTOCS mortality data and Bowel Screening Model.

Professor Roger Brownsword will be providing the committee with some training on ethics as proposed by the STC.

Apologies were noted.

Minutes and Matters arising

2. Minutes were confirmed as a true and accurate record

Six action points were identified from the November meeting; the majority of the actions had been completed with only two pending;

Directors update

Interim data on Pulse Oximetry to be shared once available- this will be brought to the June NSC meeting

Dr Mackie to share information from the Inequalities workshop with members and to bring a literature synthesis to the NSC in 2016- it is expected that this will be presented at the October NSC meeting

Director's Update

3. Dr Mackie gave an update on the following

Pulse Oximetry

3.1 The pilot continues to progress well and will be ready to present a formal report to the UK NSC in June. The pilot has so far screened almost 33,000 babies of which around 237 were screen positives; six of which were detected as having a critical congenital heart disease.

Action; Pulse Oximetry to be added to the June UK NSC agenda

Rubella Cessation

3.2 England has agreed that the Newborn Blood spot programme will cease to screen for rubella susceptibility from the 1st April. The programme is continuing to work closely with immunisation colleagues to ensure a smooth transition.

Update from the UK NSC Annual Stakeholder Event

3.2 The event was held on the 9th December with the aim of providing stakeholders with a clearer insight on how the UK NSC makes recommendations and the processes it follows, as well as providing stakeholders with a platform to communicate directly to the people involved. The first half of the day focused on the reviews of the three recommendations followed by a Q&A session as well as providing two presentations of two recent research projects to help outline how the UK NSC engages with researchers. The final part of the day was led by round table discussions which brought all attendees together to help identify the positive workings of the UK NSC as well as highlight areas were improvements could be made.

3.3 The feedback of the event was encouraging and subsequently, Mrs Harcombe informed the committee that a second event will take place in December and will be supported by PHE Events team. The working group will be convening in the coming weeks to commence preparations.

3.4 For those unable to attend, slides of the event are available via the Blog and members of the committee are encouraged to sign up at the subscription page

Annual Call for Topics

3.5 Following the UK NSC structure and process Review, it was recommended that the UK NSC adopts a more formal process when considering new screening topics. The current method used by the committee, allows requests to be submitted throughout the year.

3.6 The UK NSC will be piloting the Annual Call on the 1st September for 3 months. It is anticipated that this method, similar to that used in America and Sweden, will allow the

committee to continue to balance its work load across the year and enable stakeholders and the public to submit topics in a more open and transparent manner.

3.7 An explanation of the process is outlined in the Evidence Review document and more information of the upcoming Annual call will be made available on the website.

Residual Blood spot Consultation

3.8 Dr Elliman informed the committee that this consultation is pending but is cautious of the timing of its publication with the upcoming pre-election period as well as the EU referendum in the summer.

Presentation on Ovarian Cancer Screening Model using data from UK Collaborative Trial for Ovarian Cancer Screening (UKCTOCS)

4. Dr Sophie Whyte presented the findings on the model with the use of the data from the UKCTOCS Trial, looking at both the systematic review and modelling perspective. It is hoped that a more detailed report will be presented at the June UK NSC meeting.

4.1 The committee thanked Dr Whyte for the presentation however aired concern over the lack of data ScHARR had access to therefore hindering them from being able to calibrate the data. This limitation also prevented ScHARR from being able to utilise the history model toolkit and look at various strategies for ovarian cancer.

Action: Sophie Whyte to provide Dr Mackie with a draft letter to write to UKCTOCS asking for data on prevalence

Presentation on Bowel Cancer Screening Model

5. Dr Sophie Whyte provided the committee with a presentation on optimising bowel screening which took into account various combinations of bowel scope and FIT strategies, including altering FIT thresholds.

Fetal Maternal and Child Health

Screening for Varicella Susceptibility

6. Mr John Marshall presented this item to the committee. The UK NSC last reviewed varicella susceptibility in 2009 and recommended that a population screening programme should not be offered due to gaps which surrounded varicella being a health problem and issues relating to the proposed screening test standards.

6.1 The review focused on key questions which related to the condition, test and treatment. Over 95% of the population, who are born in the UK, have had chickenpox in their

childhood. This condition is seen to be more prominent in other ethnicities who are born outside the UK. Furthermore there was no evidence of any studies that indicated the offering screening at an earlier stage would help minimise the severity of the infection.

6.2 The committee acknowledged the two responses received from the consultation and agreed that screening for varicella susceptibility should not be recommended as a population screening programme as;

- There is very little data relating to the prevalence of varicella susceptibility in the UK or on the number of women who may be susceptible to the virus when pregnant
- There is no agreed cut off for a screening test
- A lack of studies exploring the benefit of offering a screening programme

6.3 It was noted that the JCVI was looking at varicella form their perspective.

Criteria	UK NSC Comments
The Condition	
The condition should be an important health problem as judged by its frequency and/or severity. The epidemiology, incidence, prevalence and natural history of the condition should be understood, including development from latent to declared disease and/or there should be robust evidence about the association between the risk or disease marker and serious or treatable disease.	Majority of people born in the UK have had chickenpox in their childhood and the number of women susceptible to the virus when pregnant is unknown and considered to be a low number. Adverse outcomes in babies born to susceptible women are very rare
The Test	
There should be a simple, safe, precise and validated screening test.	No studies exploring the use of the test as a screening tool in the relevant poplulation
The Intervention	
There should be an effective intervention for patients identified through screening, with evidence that intervention at a pre-symptomatic phase leads to better outcomes for the screened individual compared with usual care. Evidence relating to wider benefits of screening, for example those relating to family members, should be taken into account where available. However, where there is no prospect of benefit for the individual screened then the screening programme shouldn't be further considered.	A lack of studies exploring the benefit of early screening or help predict the severity of the virus

Screening for Organic Acid Oxidation Disorders

7 This item was presented by Dr David Elliman who informed the committee that screening for organic acid oxidation disorders was last reviewed in 2009 which led to the subsequent recommendation and introduction of both isovaleric acidaemia and maple syrup urine disease into the Newborn Blood Spot Programme.

7.1 The two conditions, propionic acidaemia (PA) and methylmalonic acidaemia (MMA) have been reviewed simultaneously as the test is the same. However differences in epidemiology, natural history and treatments differ.

7.2 The review found that the proposed screening test had poor predictive values meaning that the results of the test are not accurate. In terms of screening it would also mean that when screening for PA & MMA, the test would detect other conditions; this would then require the screening offer to be expanded to include additional conditions as well as treating conditions which may not have presented. The committee discussed the implications this would then have ethically and whether screening would be doing more harm than good, especially when there was a chance of overtreatment.

7.3 The committee recognised that both these conditions are rare however noted that more research is needed. Dr Elliman emphasised to the committee that the condition fails to provide any RCT evidence and that this would be impossible to provide as the issue relates to timing. Many babies will have presented with clinical symptoms before the results of the screening test are complete, therefore it is impossible to be able to compare treatment outcomes of babies screened to those who are not screened.

7.4 The UK NSC agreed that a population screening programme for Organic Acid Oxidation Disorder (PA & MMA) should not be recommended as;

- The screening test has a poor predictive value and cannot distinguish between PA & MMA
- The timing of the screening test raises concern with many babies presenting with clinical symptoms before the screening results are completed
- No studies have compared screened and unscreened populations
- There is not enough evidence to be clear that early identification through screening is of benefit
- There are wider ethical, legal and social implications, such as; the screening test identifying other untreatable conditions and parents as unaffected carriers

Criteria	UK NSC Comments
The Condition	
The epidemiology and natural history of the condition, including development from latent to declared disease, should be adequately understood and there should be a detectable risk factor, disease marker, latent period or early symptomatic stage	For PA, there is not a good enough understanding of the condition to accurately predict prognosis
The Test	
There should be a simple, safe, precise and validated screening test.	The Positive Predictive Value is poor and timing to offer the test may be too late with many babies presenting before results are conclusive
There should be agreed evidence based policies covering which individuals should be offered treatment and the appropriate treatment to be offered.	
The Screening Programme	
There should be evidence from high quality Randomised Controlled Trials that the screening programme is effective in reducing mortality or morbidity.	There is no evidence from RCTs to appraise the effectiveness of a general population screening programme in reducing morbidity

Screening for Familial Hypercholesterolaemia

8 Dr Elliman presented this item to the committee and highlighted that the UK NSC has not formally reviewed the evidence for childhood FH. However based upon the review for adult FH and NICE guidance, recommended that universal screening for FH is unlikely to be cost effective and suggests that cascade testing is a more effective strategy.

8.1 The current recommendation is therefore consistent with the NICE Guidance, which recommends screening family members of people identified as having FH to detect more people earlier.

8.2 The review revolved around four key areas; the test, evidence of an effective screening programme, acceptability of screening and treatment to patients as well as the cost effectiveness of offering a universal screening programme as opposed to the current practice of cascade testing. The committee discussed the condition and noted that it was one which develops gradually and does not present until much later in life when change is irreversible. The committee considered the possible outcomes of a positive result and concluded that a positive outcome for a small child would focus upon better eating habits and awareness of food content, however highlighted that this should be an ongoing practice which should be taken throughout one's life regardless of levels of cholesterol.

8.3 Discussion then moved onto ages and acceptability of when to offer screening. The proposal was that the test could be done at the same time as childhood immunisations. The ethics of offering screening at the time of a child's immunisation when treatment wouldn't start for years was discussed.

8.4 Responses from the consultation recognised that there was a significant lack of evidence relating to test, timing, feasibility and cost effectiveness. The committee noted that some responders were optimistic about the prospects of childhood screening. However it agreed to the recommendation to not offer a population screening programme for familial hypercholesteraemia in children because;

- a suitable and feasible strategy for general population screening has not yet been identified
- there are no studies which assess whether children screened helps to reduce the illness or possible death from FH
- there is no published cost-effectiveness study in screening children between the ages of 1-2 years old
- there are numerous unanswered questions which draw upon ethical issues and acceptability to screen children between the ages of 1-2 years, as well as the management of screen detected cases

Criteria	UK NSC Comments
The Test	

There should be a simple, safe, precise and validated screening test.	There are no studies of a universal screening programme in practice and there is no information to indicate when the best time to screen would be. The Wald et Al study helps to address the acceptability of the test but does not address the outcome and treatment pathways.
The Screening Programme	
There should be evidence from high quality Randomised Controlled Trials that the screening programme is effective in reducing mortality or morbidity.	Lack of evidence
There should be evidence that the complete screening programme (test, diagnostic procedures, treatment/intervention) is clinically, socially and ethically acceptable to health professionals and the public.	

Adult Screening

Screening for Stomach Cancer

9 Dr Mackie presented this item to the committee and highlighted that in the 2009 review, the committee recommended not to offer screening for stomach cancer as it was not clear that the benefits outweighed the harms. The test and treatment were both poor and invasive with the likelihood of causing more anxiety and worry to a population who would be at a relatively low risk of developing the condition. Furthermore the treatment was seen as being very radical and would not be cost effective within a population screening programme.

9.1 The current review focused on three key areas; the natural history, the test and the treatment for stomach cancer. The review also sought to find data on mortality and morbidity looking at existing screening programmes in both Korea and Japan.

9.2 The conclusion of the review was that there was no evidence on a suitable screening test for stomach cancer. H.pylori; which is a risk factor to stomach cancer, is a poor disease marker when used, as it provides low specificity; this would result is a high number of false positives being reported causing unnecessary worry and exposing many to aggressive treatments which can involve radiation. The committee agreed that such a

test may cause more harm than good. Furthermore the review could not identify any RCT evidence to demonstrate a reduction on mortality and morbidity. The data provided from Korea and Japan was limited and had inconsistencies therefore was not robust enough to be used and generalised to the UK population. The committee also noted that Korea and Japan both have a higher incidence rate of stomach cancer when compared to the UK.

9.3 The UK NSC recommended against a universal screening programme for stomach cancer as;

- a suitable test had not been identified and the use of using H.pylori as a marker would cause a large number of false positives
- alternative testing options are invasive and would not be cost effective in a screening programme
- a lack of RCT evidence to demonstrate a reduction in mortality and morbidity

Criteria	UK NSC Comments
The Test	
There should be a simple, safe, precise and validated screening test.	A suitable test has not been identified and the use of H.pylori is not suitable
The Intervention	
There should be an effective treatment or intervention for patients identified through early detection, with evidence of early treatment leading to better outcomes than late treatment.	There is a lack of peer reviewed evidence and no RCTs to determine the benefit of screening
There should be evidence from high quality Randomised Controlled Trials that the screening programme is effective in reducing mortality or morbidity.	

10 Ethics Training

Members of the committee were kindly provided with a training session on ethics kindly provided by Professor Brownsword. The session provided committee members with an overview on the development and various theorists of ethics.

11 Updates

NIHR NETSCC Update (for information)

The Committee noted the updates

SIGN Update (for information)

The Committee noted the updates

AOB

None noted

Date of the next meeting

Wednesday 15 June- Wales


NSC
UK National
Screening Committee