UK National Screening Committee (UK NSC)

Note of the meeting held on the 29 June 2018

in

Edinburgh, Scotland

This meeting provided recommendation on the following conditions;

- Chronic Obstructive Pulmonary Disorder (COPD)
- Bowel Optimisation

Members

Professor Bob Steele	Chair
Claire Bailey	Lead Clinical Nurse Specialist in breast screening, SW London
Dr Paul Cross	Consultant Cellular Pathologist, Queen Elizabeth Hospital Gateshead Health NHS Foundation Trust
Eleanor Cozens	Patient and Public Voice (PPV)
Dr Hilary Dobson	Consultant Radiologist and Deputy Director of the Innovative Healthcare Delivery Programme, University of Edinburgh

Professor Stephen Duffy	Director of the Policy Research Unit in Cancer Awareness, Screening and Early diagnosis and Professor of Cancer Screening, Centre for Cancer Prevention, Wolfson Institute of Preventive Medicine
Jane Fisher	Patient and Public Voice (PPV)
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
Hilary Goodman	Operational Manager of Antenatal Services/Screening at Hampshire Hospitals Foundation Trust
Professor Chris Hyde	Public Health Specialist, University of Exeter
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;

Natasha Alleyne	Department of Health Screening Team, Emergency Preparedness and Health Protection Policy Global and Public Health Group
Sam Cramond	NHS England

Dr David Elliman	Clinical lead for Newborn Infant Physical Examination and Newborn Blood Spot, PHE
Mrs Karen Emery-Downing	Programme Manager- Bowel Cancer Screening
Dr Ros Given – Wilson	Chair of the Adult Reference Group (ARG)
Rachael Lusk	Scottish Government
Dr Sharon Hillier	Director of Screening Division, Public Health Wales
Dr Heather Payne	Senior Medical Officer for Maternal and Child Health, Welsh Government
Dr Sue Payne	Scottish Government

Secretariat

Professor Anne Mackie	Director of Programmes - UK National Screening Committee
Mr John Marshall	UK NSC Evidence Lead
Zeenat Mauthoor	Secretariat

Presenters

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

Apologies

Members:

Professor Roger Brownsword	School of Law, Kings College London
Professor Alan Cameron	Consultant Obstetrician at Southern General Hospital, Glasgow
Professor Gareth Evans	Consultant in Genetics Medicine, St Mary's Hospital, Manchester
Dr Greg Irving	GP
Dr John Holden	Joint Head of Medical Division, Medical and Dental Defence Union of Scotland
Dr Anne- Marie Slowther	Reader in Ethics, University of Warwick

Observer's apologies:

Dr Nick Hicks	National Co-ordinating Centre for HTA
Charles O'Hanlon	National Screening Service, Republic of Ireland
Mrs Jo Harcombe	National Lead for Stakeholder Information and Profession Education and Training

Four Country Rep apologies:

Sarah Manson	Scottish Government
Dr Carol Beattie	Senior Medical Officer, Northern Ireland
Dr Ailsa Wight	Deputy Director Emergency Preparedness and Health Protection, Department of Health

Welcome and Introductions

1. Professor Steele welcomed all to the meeting. The Chair asked members to provide an update on any new declarations of interest which may be relevant to this meeting. No conflicts were raised.

   Apologies were noted.

   Prof Steele informed the Committee, that it would be seeking to re-appoint a new GP rep onto the UK NSC having recently received Dr Greg Irving's resignation. Dr Irving had accepted a new post at the University of Cambridge and would regrettably not be able to fulfil his role on the UK NSC. The Chair confirmed that a letter of gratitude would be sent out shortly.

   Action 1a: Secretariat to issue letter of service to Dr Greg Irving thanking him for his time on the UK NSC

   Action 1b: Secretariat to arrange for a recruitment campaign to be opened seeking appointments on to the Committee

Minutes and Matters arising

2. The minutes of the February 2018 meeting were confirmed as a true and accurate record and would be uploaded as final on the webpage.

   Three action points were identified from the February meeting;

   (action3b) Directors Update- Prostate screening

Members of the UK NSC to email Zeenat M to express an interest in the prostate workshop - *Completed and the first workshop has since taken place*

(action3b) Directors Update- Lung cancer

Prof Mackie to keep the UK NSC up to date with developments with the NHS initiative to offer testing to high risk individuals – *ongoing*

4- Fetal Maternal and Child Health Screening- IPDS Triage review

Secretariat to evaluate the triage process before proceeding to review the evidence for the remaining screening programmes – *in hand*

3. *Matters arising*

***Director's* Update**

Prof Mackie gave an update on the following

Update on Breast Screening Incident

3.1 In May, the Secretary of State (SoS) Jeremy Hunt, announced that the NHS Breast Screening Programme had failed to invite an estimated 450,000 women, aged 68-71 for their final routine mammogram. The cause of this failing was partly due to the basis of invitation relating to date of birth not to age and variable practice by breast screening offices. The UK NSC expressed its sympathy to all those affected, empathising with the deliberation and anxiety women now faced. The Committee stated that it would look forward to receiving the report following the Independent review, expected to be published in November 2018

Update on Screening for Severe Combined Immunodeficiency (SCID)

3.2 At the October 2017 meeting, the UK NSC recommended that screening for SCID should be tried for a period of time in the NHS. DHSC colleagues confirmed that discussion was ongoing with Ministers about this evaluation and would update once decisions had been reached.

Update on NIPT

3.3 As of the end of April, NIPT has been made available in Wales. England and Scotland continue to progress in setting up for the expected roll out in autumn.

UK NSC Member's Appraisals

3.4 Prof Steele thanked all members of the Committee for participating in the annual member questionnaire. Feedback on comments had been duly received and suggestions outlined will be considered and pursued by the Secretariat.

Ethics Update

3.5 The UK NSC has actively engaged in strengthening the consideration of ethical issues in the work of the Committee. Activities have included, the recruitment of ethics member, Dr Anne-Marie Slowther, hosting training workshops for members and the formation of the Ethics Task Group (ETG) chaired by Prof Roger Brownsword.

3.6 The Committee was informed that it has asked the ETG to help develop a structured process to assist the Committee when considering ethical issues relating to screening. The ETG's work has focused on developing a checklist of issues and an outline of the methodology to be used to help address the issues. The ETG also considered scenarios in which the process might be tested.

3.7 The Committee reviewed the circulated working documents and were generally supportive of the work so far. The Committee discussed the relationship of the ETG to the UK NSC. It was noted that the ETG was a time limited task and finish group. It was agreed that the mechanism for input on ethical issues in the longer term needed to be discussed further and that this might be possible at the next meeting when a fuller report of the ETG's work would be presented.

Action 3a: A report on the ETG to be presented at the UK NSC October meeting

Action 3b: A flowchart diagram to be included in the checklist document to outline when an ethical evaluation would be considered

Action 3c: ETG to discuss whether the time limited group requires a more long term position to help assist the NSC

Reflex testing for T21, 18 &13

3.8 In 2017 the UK NSC's reference group, FMCH, received a proposal that "reflex testing" be considered as part of the NHS Fetal Anomaly Screening Programme (FASP). The proposal was that, at the time of the combined test, two samples should be taken, one for use in the combined test and one for subsequent, 'reflexed', non-invasive prenatal testing (NIPT) contingent upon the result of the combined test. The approach differed from the UK NSC's proposed approach to contingent NIPT in that women entering the programme would not be recalled for a discussion about further testing options which include NIPT, invasive testing or no further action. Instead NIPT is performed on some of the woman's original blood sample if the combined screening result falls within a designated threshold.

3.9 The suggestion was that reflex testing provides the mother with a more accurate test result to inform decision making on whether to go on for invasive testing. In addition

it was suggested that reflex testing would be time saving and would reduce anxiety as NIPT is carried out automatically without the need for an additional appointment.

3.10 Since the submission FMCH and ETG have considered the proposal at length comparing the proposed strategy to the current strategy. It was summarised to the Committee that the main discussion points were;

- Both reflex and recall are approaches which offer NIPT on a contingent basis and have the potential to reduce the number of false positives as well as the number of invasive tests compared to current practice,
- Discussion of reflex testing centres around various cut offs such as 1 in 800. The UK NSC was firm in stating that this was not for deliberation stating that the acceptability of the NIPT test at 1/150 was part of the evaluative roll out
- The suggestion that reflex testing is time saving was stated as being inaccurate by FMCH as currently only women who have a high chance result following the combined (3%) have a conversation about NIPT or CVS; a move to reflex testing would mean that all women will need to have a more detailed pre-test discussion about a high chance result with FMCH advising that this may in fact increase anxiety. Several members of the Committee however disputed the comment and stated that all expectant mothers should in fact be aware of the whole screening pathway and potential outcomes.
- The question of whether fewer women would be made anxious through reflex testing was discussed. It was not clear whether this was true nor was it certain that the information given at booking was sufficient to allow informed choice or that there was the midwife capacity to do this well for a much larger group of women.

3.11 The UK NSC noted the comments made by members of the Committee as well as concern that the proposal was looking to modify a recently agreed modification to

the programme which had not yet been implemented or assessed. The Committee agreed that further deliberation was needed which included the need for some research questions to be looked at further. The work would continue to be led by the ETG and would be fed back to FMCH and the UK NSC at the October meeting before any recommendations could be made.

3.12 Welsh representatives at the Committee highlighted that Wales had implemented NIPT since the end of April. Informed choice had been central to the development of materials and as such a video had been produced to assist expectant mothers and parents.

Action 3d: ETG to consider what research questions need to be looked at to address concerns raised

Fetal Maternal and Child Health Screening

FMCH Report

4. Prof Steele provided the Committee with an update on the recent activity of the reference group which looked at the ethical implications of reflex testing for the trisomies as well as reviewing several briefing notes ahead of commission of reviews, as per the UK NSC's evidence review process.

4.1 FMCH reviewed the development of several evidence review documents and agreed that the following review documents were ready to go out for public consultations; Genital Herpes, Hepatitis C in pregnancy, Hypertension in Children and SMA

4.2 The Chair confirmed that an expression of interest would be circulated amongst the four countries in the coming weeks to provide suitable nominees for the independent role of Chair of FMCH.

Adult Screening

Adult Reference Group

5. Dr Ros Given-Wilson, Chair of the ARG, summarised the discussions at the May meeting. The group received the HTA Lung presentation that was shared with the UK NSC in February and discussed both the work on HPV modelling and comments received following the Bowel Optimisation consultation.

HPV modelling work

5.1 This item has been brought back to the UK NSC to note and agree the consultation questions.

5.2 Since the UK NSC's recommendation in 2016 to adopt HPV as the primary screen in the cervical screening programme, replacing liquid based cytology, experts have called for a change in the screening intervals. It is suggested that as we now know more about the course of disease from infection to cancer and the test being more sensitive it would be reasonable to extend the screening intervals. Currently women aged 25-49 years are offered cervical screening every three years.

5.3 The proposal received from the Advisory Committee on Cervical Cancer (ACCS) calls for the programme to consider the following major modifications in light of HPV being implemented:

- HPV negative women to have a screening interval of five years
- HPV positive and cytology negative women to have a 12 month surveillance interval

- Consideration of whether detecting some higher risk sub types of HPV ("genotyping") should be used to guide colposcopy referrals in the surveillance pathway

5.4 However the UK NSC noted that there was no primary research evidence on extended screening intervals to support calls for such modifications. The UK NSC therefore commissioned a review of published cost effectiveness models.

5.5 The UK NSC was now asked whether it was satisfied with the work undertaken to open up a public consultation based on three programme modifications which relate to; changes to screening and surveillance intervals, women aged 64 and over who are exiting the programme and the use of self-sampling as a strategy to address non-attendance in screening. The UK NSC agreed.

5.6 In regards to practice in the neighbouring health departments, Dr Hillier informed the Committee that Wales would be implementing HPV at a three year interval based on current available evidence. It would then seek to re-examine the change in intervals once evidence supporting this was available and in light of any UK NSC recommendation. Additionally, Dr Sue Payne from Scotland stated that a five year interval would be welcome but any change to screening policy would need to be evidenced.

5.7 The Chair therefore summarised the UK NSC was happy for consultation on the interval changes for HPV to go out for public consultation.

5.8 The Committee was also asked about the management of 65 year old women. It was decided that an agreed consensus was needed in light of an absence in evidence.

5.9 Mr Marshall informed the Committee that calls to look at and use self-sampling within the cervical screening programme were increasing. Initially this had been considered as a tool to encourage young women to participate in screening at their first invitation.

5.10 Dr Sue Payne emphasised to the Committee how in Scotland there was growing support to use self-sampling, but focussed on the use in older women who were persistent non-attendees. It is known that as women mature, cervical screening can become more uncomfortable and also less acceptable. It is suggested that by offering self-sampling in the older cohort may mean screening is more accessible and reduce inequality to those women who do not attend due to the discomfort of the cervical screen test.

5.11 The Committee acknowledged that uptake in older women had declined but that this was also apparent in the younger cohort and so agreed that to minimise inequality for all the offer of self-sampling should be considered to be offered to all rather than to a defined group. Nevertheless the Committee agreed and supported the need for further work to be undertaken to look at self-sampling and the impact that this would have on the programme.

Screening for COPD

5.12 Chronic Obstructive Pulmonary Disease is an umbrella term used to describe various lung conditions which cause breathing difficulties. The condition is more prevalent in middle-aged or older adults who smoke and it is estimated that around 3 million people have COPD with only 1 million being diagnosed as having the condition.

5.13 The UK NSC last reviewed the evidence to screen for COPD in 2013 and recommended that screening should not be offered. This was because;

- There were challenges around the test options for a whole population screening programme
- Limited evidence on whether spirometry prompts people to quit smoking, and
- No RCTs evidence looking at screening for COPD

5.14 The review this time round focussed on the accuracy of the screening tests to detect COPD, the impact screening for COPD would have on people to quit smoking and whether screening is cost-effective by reducing deaths due to this disease and improving people's health.

5.15 The review found that due to a lack of evidence these questions remained unanswered and thus screening could not be recommended; there were still concerns over the number of high false positives that screening would detect and the use of spirometry within a screening programme and the impact screening would have on whether people would in fact give up smoking.

5.16 The Committee noted that the consultation received only two comments, both supporting the recommendation not to introduce population screening for COPD. Comments from the consultation suggested that the review should clearly distinguish between screening and case finding, Mr Marshall informed the Committee that this was taken on board and has since been clarified in the revised version.

The UK NSC upheld its recommendation that a systematic population screening programme for COPD in the adult population should not recommended

Criteria	Met/Not Met
The Test	
4. There should be a simple, safe, precise and validated	Ongoing

screening test. 5. The distribution of test values in the target population should be known and a suitable cut-off level defined and agreed.	concern over the number of high false positives from the risk assessment questionnaire
The Intervention	
9. 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.	Uncertainty about the impact of the spirometry
The Screening Programme	
9. There should be evidence from high quality randomised controlled trials that the screening programme is effective in reducing mortality or morbidity. Where screening is aimed solely at providing information to allow the person being screened to make an "informed choice" (such as Down's syndrome or cystic fibrosis carrier screening), there must be evidence from high quality trials that the test accurately measures risk. The information that is provided about the test and its outcome must be of value and readily understood by the individual being screened.	No RCTs looking at the impact of screening on mortality and morbidity

Bowel Optimisation

5.17 The Chair reminded the Committee that in 2015, it had made a recommendation to introduce FIT as the primary screen test for bowel cancer in the UK. All UK Health Departments and experts welcomed this move and expressed their commitment to offer FIT. The UK NSC had also approved flexible sigmoidoscopy (FS), which is offered in England as a one off screen at 55.

5.18 The UK NSC commissioned The School of Health and Related Research (ScHARR) to produce a model which explored the various options for FIT and FS. The modelling work using real time data and taking into account current endoscopy and workforce constraints, developed strategies seeking out the most cost effective and feasible means to offer FIT; this included looking to offer FIT exclusively to 50 – 74 year olds at a threshold below 93 µg/g and decommissioning (or not starting) FS or to offer FIT alongside FS at trial uptake level.

5.19 The UK NSC had actively engaged with the modelling work, having been presented with the initial model and given the opportunity to discuss any queries or concerns with the researchers at its previous meetings. The Committee expressed that this input was incredibly useful allowing all members to gain a more detailed insight on the matter at hand by being able to breakdown information and work through the intricate details of bowel screening. A further two specialist workshops were also set up and attended by various experts from the NSC, ARG and the bowel screening programme to discuss and explore the modelling work in detail.

5.20 The consultation opened for a three month period which closed on the 7 April. A total of 36 responses were received. The Committee had copies of all the comments. In addition for the benefit of the Committee, the comments were presented in themes outlining the main issues to a fruitful discussion on each matter. It was noted that the majority of the comments favoured option B as outlined in the consultation, which is to offer FIT to 50-74 year olds at a lower threshold and decommission FS. The Chair however highlighted that although the majority of the comments favoured this option there was also support for FS. The argument to maintain FS was based on FS having been introduced based on RCT evidence which demonstrated a reduction in colorectal cancer mortality (CRC) and that this should not be overlooked. Furthermore the Committee acknowledged that the roll out of

FS had been challenging. It is currently being offered at a lower age than initially trialled at (60 years).

5.21 The Committee discussed the comments received at length and concerns about the modelling were addressed by Dr Sophie Whyte, in particular the use of the data for FS was raised. Dr Whyte informed the Committee that the data had been thoroughly scrutinised, however some data (especially for FS) would interact with sensitive FIT tests was imputed and not based on empirical data.

5.22 The UK NSC agreed with the majority of comments, supporting a recommendation to introduction a biennial FIT to 50-74 year olds, specifying that this is carried out at as low a threshold as possible down to 20ug/g taking into account current available endoscopy resource. With FIT being a more sensitive and acceptable test the UK NSC stated it was important that thresholds were flexible and should be adjusted in light of service delivery. The Committee recognised that although this is the aspiration, detailed and careful planning would need to be undertaken to ensure that the programme could manage the very significant extra demand.

5.23 In regards to FS, the Committee discussed and supported the suggestion that FS is still to be offered where currently available and to consider decommissioning FS once FIT was more fully implemented in England. The Committee made a recommendation for research pilot to look at the combined strategy of offering FS at 60 alongside FIT in order to help provide real life data on the combination of the two offers. The Chair stated that it is hoped that such a pilot will enable the Committee to have better a better understanding of whether FS and FIT together find and prevent more cancers than FIT alone.

5.24 The Chair informed the Committee that since FIT had been rolled out in Scotland a 10% increase had been reported in uptake. The Scottish health system had set up a

system of monitoring and feedback to allow adjustments to the threshold (and therefore the numbers of people requiring colonoscopy) in light of service delivery.

There is work going on in the UK to see if FIT can be used to rule out the possibility of cancer without the need for colonoscopy and this too would reduce pressure on the services.

5.25 The UK NSC made the following recommendations;

i. To offer biennial FIT to 50- 74 year olds at an adjustable threshold with an aim to move to 20ug/g, when capacity allows. Roll out of FIT would be phased taking into account current constraints
ii. To consider decommissioning of FS once FIT has been rolled out to a greater range of ages
iii. To set up a small research pilot to gather evidence of the combined strategy in action; offering FIT at 50-74 years alongside FS at 60 years

Updates

NIHR NETSCC Update (for information)

The Committee noted the updates

SIGN Update (for information)

The Committee noted the updates

AOB

i. Pulse Ox

Prof Mackie informed the UK NSC that a workshop was held at the start of June. A write up of the work is being carried out and is hoped to be brought to the October NSC meeting

Action 5a: Pulse Ox to be added to the UK NSC October agenda