UK National Screening Committee

Review of the UK National Screening Committee (UK NSC)

Summary of Consultation Responses

Published June 2015
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Gateway ref: 2015139

Public Health England hosts the UK National Screening Committee

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Summary of Consultation Responses

Introduction

The UK National Screening Committee (UK NSC) was established in 1996. It advises Ministers and the NHS in all four countries about all aspects of screening and supports the implementation of screening programmes. It assesses the evidence for programmes against internationally recognised criteria, using research evidence, economic evaluation and pilot programmes.

As part of the current governance arrangements for the UK NSC its role, terms of reference and membership are reviewed on a three yearly basis. This regular review provides an opportunity for an in depth structure and process review to ensure that best practice is applied to all aspects of UK NSC business. This includes:

- terms of reference (ToR)
- membership
- the criteria for appraising the viability, effectiveness and appropriateness of a screening programme to ensure the UK NSC continues to operate to the most robust evidence base and criteria available internationally
- the scope of population screening that should be within the UK NSC's remit

This review is being overseen by a working group, which includes representatives from each UK country as well as lay members, external stakeholders and independent public health screening experts. The group was chaired by Professor David Walker, Chair of the UK NSC. The establishment of the working group provides a robust challenge process and scrutiny. A list of working group members can be found at Annex A.

The working group was keen to obtain the views and opinions of a range of stakeholders to help inform its recommendations and therefore a public consultation was held between 15th April 2014 – 8th July 2014. The consultation was undertaken by survey monkey. An e-mail alert was sent to the UK NSC's 250 registered stakeholders requesting their input into the review by answering 22 questions. A link to the consultation was also placed on the UK NSC's website so that it was available to members of the public and other unregistered stakeholder groups to complete. Survey monkey registered 160 responses and we received 3 written responses. After analysis of the survey monkey responses only 94 respondents had answered one or more of the questions following mandatory registration, 66 respondents had simply clicked through the questions without answering any. We have therefore only analysed the responses from the 94 respondents who answered one or more of the consultation questions and the 3 written responses.

This document summarises the responses received. All documents relating to the review, including the full responses, are available for download from: https://www.gov.uk/government/publications/review-of-the-uk-national-screening-committee-2015. The consultation responses will be used to develop the recommendations to the four Chief Medical Officers.

Respondents

Question 1: Who are you completing the survey on behalf of?

The number of stakeholder groups and individuals who completed the survey can be found below.

Organisations	38
Individuals	59

For a full list of stakeholder organisations who completed the survey please see Annex B.

Membership

Question 2: Are any key stakeholder groups or experience areas/areas of expertise missing from the UK NSC membership?

The number of respondents who answered this question is as follows:

Yes:	56
No:	33
Skipped the question	8

Summary

The majority of respondents answered yes to this question. Respondents who felt that key stakeholder groups or areas of expertise were missing from the UK NSC membership suggested the need to include specialists or patients/parents with expertise in or experience of the particular condition under consideration. Examples included representatives from the following medical specialities: cardiology, cytology, epidemiology, gynaecology, inherited metabolic disorders, mental health, microbiology, midwifery, nursing, ophthalmology, pharmacy, radiology, sonography, vascular risk and virologists. Other suggestions included commercial organisations, religious groups, statisticians, voluntary organisations, more patient representatives and umbrella patient groups, as well as additional genetic, ethical and health economic expertise. A number of responses commented on the need for representation from specialists and support groups with expertise in, and experience of, inherited metabolic diseases in order to properly consider newborn screening. Other responses commented on the need for expertise in "screening", knowledge of how to evaluate and assess evidence and a knowledge of delivery impact and harms of screening, for example "over-diagnosis". Others highlighted the need to reflect equality and diversity and the need for fair representation across the countries.

Four organisations with an interest in genetics commented on the particular need to expand expertise to cope with the different sets of issues that arose because of the increased capacity for pre-symptomatic diagnosis and the complexity of testing and interpretation that would arise from the use of genomic technologies (for example interpretation of genomic variation and tests requiring bioinformatics analysis).

There was acknowledgement that, given the wide remit of the UK NSC, it would be difficult for a single committee to have complete coverage of all the issues and practical proposals were for the Committee to seek access to relevant expertise and experience for the conditions under consideration.

Those who answered no did not generally expand on their answers.

Responses included:

Individual:
*"*There is a wealth of expertise within the allied health professionals."

Individual:
*"*Pharmacy have an opportunity to raise awareness and I suspect could also deliver some aspects of screening."

Joint Committee on Genomics in Medicine:
"The potential for new genomic technologies to increase capacity for pre-symptomatic diagnosis mandates an increased representation from clinical genetics, scientists with expertise in bioinformatics and the clinical interpretation of genomic variation. Particular ethical expertise will be required to understand the existing and new technologies, as research into public understanding and attitudes to these technologies occurs"

Primary Immunodeficiency UK:
"Umbrella Patient groups: able to offer what this would mean to parents, children perspective. Essential at a time when the patient voice is deemed as important."

Royal College of Obstetricians and Gynaecologists:
"Gynaecologists are the colposcopists involved in screening and are more relevant to cervical screening than obstetricians. Laboratory services should include cytologists and virologists."

Question 3: Does the UK NSC include the right balance between experts, professionals delivering health care and lay members?

The number of respondents who answered this question is as follows:

Yes:	47
No:	42
Skipped the question	8

Summary

Responses to this question were contrasted although most respondents felt the balance between experts, professionals delivering healthcare and lay members was right. However, of those who did not there was some difference in interpretation of what was meant by "lay" representation. Most interpreted this as patients, patient organisations and the voluntary sector. Others saw lay representatives as those with a non-medical background, for example, ethicists, health economists and legal experts. As in the previous question a number of people felt that lay representation should be increased to include those with experience of a particular condition, for example, diabetic eye disease or those living with rare disorders or genetic conditions. Again the importance of having access to specialist advice on the specific disorder under consideration was seen as essential. In contrast, other responses were clear on the need for patient representatives to represent the wider community. Some responses highlighted the important role lay members could play in challenging views and ensuring UK NSC business could be understood, in particular, in explaining how and why decisions not to screen were made, and in challenging

views. Some responses highlighted the need for more ethical input, particularly in the light of potential developments in genetic technologies, and the need for knowledge of cost effectiveness. As in responses to the previous question the point was made about the need to take into account the age, ethnicity and gender of the Committee and to balance membership across the four countries. A number of responses were clear about the need to provide support and training to lay representatives.

Responses included:

Individual:
"Can't expect deep knowledge of the various subjects with just 3 lay and 16 expert members. There should be specialist professional and lay members for each of the topics discussed."

NHS National Services Scotland:
"It may be helpful to have a lay representative from each of the 4 UK Countries."

UK Thalassaemia Society:
"There are currently only 2 user representatives on the Committee; this does not seem adequate considering the diverse range of stakeholders in the work of the NSC."

Question 4: In particular, should there be more lay representatives – if so how many, and/or what proportion of the Committee should be lay?

Answered:	62
Skipped the question	35

Summary
This was an open ended question which did not require a yes/no answer. The majority of people who responded to this question felt that lay representation should be increased. Answers ranged from 10% of the Committee being made up of lay members to at least 40% of the Committee being made up of lay members. Several people stated that there should be 3 or 4 lay members. One response requested that the UK NSC should no longer use the term "lay" and use terminology similar to NHS England who use the term "patient and public voice." As in previous questions, some responses reiterated the need to include representatives with experience of the specific issue under consideration. Others highlighted the need for broad consultation and engagement with the public and relevant patient groups to inform considerations. Others queried how lay members were selected, for example, whether it should be somebody with direct experience of screening or treatment and highlighted the need for clear recruitment processes and support for lay members.

Responses included:

Association for Improvements in Maternity Services:
"It is a question of how they are chosen. Establishment organisations almost inevitably choose the voices which are acceptable to them."

Individual:
“I would think that possibly 15% of the committee should be lay representatives.”

Individual:
“No. The balance is similar to that on NICE Guideline Development Groups, which have the same role of assessing evidence and making recommendations.”

Individual:
“Probably two thirds professionals, one third lay.”

Jo's Cervical Cancer Trust:
“I think 3 out of 19 is good but only as long as their experience is relevant to the screening programme being discussed at a particular meeting.”

The Raynaud's & Scleroderma Association:
“Initial thoughts are that each area should have a professional and a lay representative where feasible.”

Question 5: Should the process for appointing members be a formal process with defined stages of application, assessment and appointment?

The number of respondents who answered this question is as follows:

Yes:	77
No:	11
Skipped the question	9

Summary

The vast majority of respondents agreed that the process for appointing members should be a formal process with defined stages of application, assessment and appointment. Respondents emphasised the need for a transparent process. Suggestions included having a person specification and criteria for applicants. It was proposed that individual members should be subject to review periodically to ensure they are still the most appropriate people for the roles on the Committee and members should be on the Committee for a fixed amount of time only. Of those who said no, few expanded on their answer, however, one thought members should be invited to join the UK NSC rather than by personal application as the most appropriate people for the roles may not apply but may accept if invited and another stated that having an application process may put lay people off from applying.

Responses included:

Association for Glycogen Storage Disease UK:
“Whatever process is adopted it should be open and transparent and should invite nominations from a wide field of professional groups.”

Individual:
“It will put people off - especially lay members.”

International Nursing Group for Immunodeficiencies (INGID):
“Sometimes people may not consider applying but may be considered to have much to contribute. There should be the possibility for some individuals to be invited - particularly if representatives of relevant groups.”

Naitbabies:
“Some form of formality would be needed to maintain a balanced and informed membership. The process should be kept simple.”

Social, Ethical and Legal Issues

Question 6: Do you agree that the UK NSC would benefit from including additional ethical expertise?

The number of respondents who answered this question is as follows:

Yes:	73
No:	13
Skipped the question	11

Summary

The vast majority of respondents agreed that the UK NSC would benefit from including additional ethical expertise. Suggestions included seeking additional expertise through a separate reference group to advise on ethical issues, either standing or *ad hoc*, drawing advice from existing expert groups and co-opting additional ethicists on to the Committee when screening reviews required specialist ethical input.

A number of organisations, including provider and patient organisations commented on this from a genetics perspective, noting that this was a rapidly developing field and the ethical issues were only now being worked through in parallel with the technological developments. Public understanding is evolving and not necessarily the same as the perspective of people with rare disease. There was mention of ensuring public trust that the ethical issues around DNA testing had been extensively explored. Key ethical, legal and social issues that may arise in screening as new technologies emerge include discrimination, stigmatisation, employment and insurance as well as issues concerning the privacy, confidentiality, data ownership, and sharing of genetic information.

Others highlighted the need for more legal, clinical and social expertise and input from different ethnic groups. Some responses highlighted that those with experience of the condition could often bring a practical perspective to ethical decision making.

Those who were not in favour of including additional ethical expertise felt there was not currently a need for this or that it could make the Committee unwieldy and noted that ethical expertise could be found from other sources, or members co-opted onto the Committee as necessary. Others thought that additional ethical expertise was not the highest priority.

Responses included:

Individual:
“Suggest a separate members ethical panel (from existing members) concentrating on those areas which prove difficult.’

Individual:
"Public need to be reassured that ethical issues surrounding DNA testing in particular have been extensively explored so they can be confident in consenting to tests."

Individual:
"Not sure...sometimes this takes priority over more important subjects."

PHG Foundation:
"We have particular concern about evidence around ethical, legal and social issues and think that there would be merit in setting up a standing group to advise on individual proposals that would run alongside the NSC: this group could also have an ongoing responsibility to advise on ethical aspects of screening more generally."

Royal College of Nursing:
"There should be the option for the committee to bring additional expertise together to inform the committee and to participate in specific discussions relevant to their area of expertise. This does not necessarily mean they have to be a permanent member of the committee."

Question 7: Do you agree that the UK NSC should on occasion bring together a group of experts in social ethical and legal issues to provide advice? If so should there be a 'reference group' of experts on whom they could draw?

The number of respondents who answered this question is as follows:

Yes:	74
No:	14
Skipped the question	9

Summary

The vast majority of respondents agreed that the UK NSC should on occasion bring together a group of experts in social ethical and legal issues to provide advice. A number of organisations commented that this might be particularly useful in the context of genetic technologies and new screening technologies such as whole genome screening which could lead to new social, legal and ethical issues (some of the key ethical, legal and social issues are outlined in the summary response to the previous question).

While most respondents considered that the input of an expert reference group would be beneficial, there was no consensus on whether this should be a permanent reference group or whether there should be a more *ad hoc* arrangement, drawing on advice from established outside groups. There was some concern about the process for selecting members of a permanent group and also that such a group would be out of date as soon as it was selected. Other responses felt a permanent group

would bring about consistency in decision making. As in previous responses the point was made about the need for experience of and expertise in the ethics associated with specific conditions such as rare diseases.

Some of those who answered no to this question felt ethical, legal and social expertise representation should more appropriately form part of the UK NSC.

Responses included:

Children Living with Inherited Metabolic Diseases (CLIMB):
“Yes, but it should be a permanent group not one that is brought together 'on occasion'.”

Individual:
“Yes to bringing in experts, not sure it should be the same reference group all the time. It probably should differ depending on the subject matter.”

Individual:
“I would expect ethical and legal representation on the committee should be adequate, and would be able to seek external advice where appropriate. The advantage of having ethical and legal representation on the committee is that they will hear everything that is discussed and may wish to interject on something which the committee had not thought to have an ethical or legal dimension.”

Individual:
“But only if they are working to a set of agreed criteria for assessing these social, ethical and legal issues - otherwise the advice could be rather idiosyncratic.”

Nottingham University Hospitals NHS Trust:
“A reference group will be out of date as soon as it is formed, so experts should be identified when needed.”

NHS England (Domain 1)
“ A good idea. Within a few years there will be the potential for genomic tests for all - lots of issues to resolve and risks of inequities between groups.”

Criteria

Question 8: Do you think the criteria should be strengthened or amended in any way?

The number of respondents who answered this question is as follows:

Yes:	49
No	30
Skipped the question	18

Summary

The majority of respondents felt the criteria should be strengthened or amended. Several respondents suggested the criteria needed amending as they were set in 1968 and were no longer relevant, and in particular needed to be updated to reflect advances in genetic and genomic testing. Others felt that they did not reflect the important advances taking place in treatment, or what is valued by patients, families and communities. Another concern was that the current criteria prevented consideration of some screening, for example selective, preventive screening.

Some respondents focused on particular criteria, such as the criterion on treatment, believing that greater consideration should be given to potential new treatments when reviewing screening. Other respondents also supported this view stating that even where a treatment does not exist there are benefits from early diagnosis and the possibility of new treatments. Some felt newborn screening could prompt treatment or care that is not a cure but may help improve a patient's physical or psychological health or delay the onset of more severe symptoms.

Others highlighted the need to recognise that not all potential screening programmes were amenable to randomised controlled trials (RCTs) and allowance should be made for this. One respondent stressed the need for a standardised approach to cost effectiveness to enable screening programmes to be compared with other health care interventions. Another highlighted the need to make the wider consequences or implications of a positive screening result clear.

Some felt that the decision making process was not always clear and a more consistent and transparent approach would be beneficial. There was some concern about how the Committee interpreted the criteria, highlighting the need to consider qualitative data in assessing potential new screening programmes and develop a flexible approach.

Most respondents who said no did not comment but some said they thought current criteria were broadly applicable, thorough and reasonable.

Responses included:

Individual:
"If other countries are already including more detail it would be wise to review and compare the two approaches as this could be an opportunity missed."

Individual:
"Adequate at present and amending could increase complexity."

Jewish Genetic Disorders UK & Jewish Care:
"The UK NSC criteria were set in 1968 and, in our view, are no longer fit for purpose. The criteria desperately need updating to reflect the significant developments in genetics and genetic testing which help us have a much better understanding of the risk of developing a particular condition (both individual risk and population risk), as well as changes in technology and social attitudes."

Question 9: Do you think the criteria should be strengthened or amended in any way to take account of the developments and complexities arising from genetic screening and developing technologies?

The number of respondents who answered this question is as follows:

Yes:	56
No	19
Skipped the question	22

Summary

The majority of respondents answered yes to this question and as in previous responses there were concerns about the criteria relating to the need for an effective treatment and for the emphasis on RCTs and that not all conditions were amenable to such trials.

Two organisations and a patient orientated umbrella group commented that there needs to be a review of the screening criteria with respect to genetics. There was recognition that this would be a major undertaking but nevertheless a necessary and pressing one. It was felt there would also be some specific technical issues arising from genomic testing, including the need for a more sophisticated approach to consideration of criteria in areas such as test performance false positives for disease, uncertainties over penetrance of variants identified and the variability of pathology of copy number variants identified through screening.

A number of responses highlighted the need for the committee to reassess the criteria on a regular basis with international benchmarking and that this should be part of its formal governance arrangements and to reassess in the light of new technologies becoming available. One respondent suggested strengthening criteria to reflect the potential for overdiagnosis.

Respondents who answered no to this question, felt the criteria were strong enough already. One questioned the need to distinguish “genetic screening” as requiring separate consideration, noting that newborn bloodspot screening for a number of genetic conditions already meets the current UK NSC criteria and is recommended by the UK NSC.

Responses included:

Individual:
“No criteria should be fixed for life. New technologies and new research bring positive changes and need to be considered and incorporated somehow.”

Individual:
“Probably. Genetic disease is very complex and the impact far reaching. This underlines the need for a mechanism to capture the immediate health consequences as well as the wider impact on family, use of resources, ability to work, ethical issues.”

Save Babies Through Screening Foundation UK:
“Yes I do but there needs to be a real and urgent piece of work done around future implications of genetic screening, genome sequencing and technologies. There is no instant answer on what the criteria or guidance might look like. It is a big piece of work but it needs to be done.”

Society for Mucopolysaccharide Diseases:
“The developing technologies and emerging new therapies make it imperative that regular review of the criteria is undertaken. When a condition is being considered for screening it is essential that all decision makers on the UK NSC are to date on developments, treatments in the condition being considered

Wolfson Institute of Preventive Medicine, Barts and The London School of Medicine and Dentistry, QMUL:
“The guidelines do not need to be altered. However, consideration should be given to merging old and new technologies in a rational way that optimizes screening performance rather than immediately shifting from old to new in one step. For example, this is relevant to DNA screening for Down syndrome in relation to conventional screening of maternal age, ultrasound markers and biomarkers.”

The Scope of Population Screening that should be within the UK NSC's remit

Question 10: Should the UK NSC continue predominantly to consider the evidence for screening large populations selected because of age/sex?

The number of respondents who answered this question is as follows:

Yes:	34
No:	41
Skipped the question	22

Summary

Most respondents answered no to this question and said the UK NSC should not predominantly consider the evidence for screening large populations selected because of age or sex and that there were potential benefits for other populations including those with specific conditions and groups of people such as those defined by ethnicity, genetic risk or lifestyle factors e.g smoking. Other responses suggested the UK NSC should concern itself with the likelihood that the main benefits of new genomic technologies was likely to be in terms of genomic variation influencing outcome of lifestyle choices and particular drug treatment. Others considered that there was an opportunity to consider specific groups in terms of ethnicity because of their susceptibility to rare conditions, for example Gaucher disease in Jewish communities.

Of those responses that answered yes to this question many were unclear how high risk people would be invited for screening, and in addition whether the information records and IT support was available to identify target groups according to other risk factors. Some respondents were concerned about the cost effectiveness of screening population groups who are not defined by age or sex, the potential burden on the Committee's workload, and boundaries with other organisations such as the National Institute for Health and Clinical Excellence (NICE).

Responses included:

Board of Deputies of British Jews:
"Predominantly confining to groups selected by age / sex (except for obvious issues such as prostate and ovary) is not constructive."

Individual:
"If programmes are going to deliver benefits to defined populations then it is these defined populations that should be considered. The NSC should have the remit to consider populations regardless of age or sex to ensure interventions deliver the best outcomes."

Society and College of Radiographers. Representing members of the diagnostic and radiotherapy workforce:
"Consider all new and emerging evidence that might not be solely linked to age/sex."

Question 11: Should the UK NSC include in its considerations an assessment of the benefits and harms of screening large groups of people who are defined by a characteristic other than age or sex?

The number of respondents who answered this question is as follows:

Yes:	63
No:	10
Skipped the question	24

Summary

The majority of respondents agreed that the UK NSC should include in its considerations an assessment of the benefits and harms of screening large groups of people who are defined by a characteristic other than age or sex. Respondents suggested these characteristics should include groups of people who are defined by ethnicity, genetic risk or lifestyle factors.

Many of the respondents who answered no to this question did not expand on their answer. One respondent felt occupational risk screening should be considered.

Responses included:

British Association for Cytopathology:
"If an at risk group can be easily identified and the condition meets the criteria then it is appropriate to consider screening."

Individual:
"Pre-existing conditions/ genetic predisposition etc."

Individual:
"Ethnicity, genetic risk populations."

National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC):
"Yes but this should be clearly constrained to only include situations where certain predefined criteria are met to avoid the NSC becoming distracted from nationally important conditions that apply to the whole population."

NHS England (Domain 1):
"In particular smokers for example."

Question 12: Should the UK NSC include in its considerations an assessment of the benefits and harms of screening large groups of people who are defined by ethnicity or genetic risk?

The number of respondents who answered this question is as follows:

Yes:	62
No:	8
Skipped the question	27

Summary

The majority of respondents felt the UK NSC should include in its considerations an assessment of the benefits and harms of screening large groups of people who are defined by ethnicity or genetic risk. Respondents highlighted that certain ethnic groups are more at risk of some conditions than others. For example the Ashkenazi Jewish population are more at risk of the autosomal recessive disease Tay Sachs than other populations. Therefore a carrier screening programme to be targeted at this population could bring benefits, for example in reproductive choice. Elsewhere concerns were raised that such screening was automatically ruled out from a national screening programme because of small, geographically focused ethnic populations.

Other respondents highlighted that certain groups at an increased genetic risk of cancer should be included in cancer screening and that this should be introduced in a systematic way; for example women with a family history of breast cancer.

Respondents who answered no were concerned about the selection criteria and how people would be invited to be screened, and concern about potential ethical issues.

Responses included:

Joint Committee on Genomics in Medicine:
"Given that populations differ in genetic risk, genetic screening based on ethnicity for some conditions is reasonable, in the presence of meeting appropriate criteria."

Individual:
"Probably hardest to do in terms of selection criteria?"

Individual:
"In our very mixed society the question of ethnicity is not always clear cut; we are also not very systematic in identifying people at increased genetic risk and this approach may miss relevant cohorts."

Individual:
"Usually a person is known to be at genetic risk because a family member has the condition. In that case, there will be ethical and practical issues, in particular what are the benefits of early knowledge and how widely do you screen."

Serious Hazards of Transfusion Haemovigilance Scheme:
“Many diseases are more common in some ethnic groups.”

Question 13: Should the UK NSC include in its considerations an assessment of the benefits and harms of screening large groups of people who are defined by a condition with recognised complications?

The number of respondents who answered this question is as follows:

Yes:	65
No:	8
Skipped the question:	24

Summary

The majority of respondents agreed that the UK NSC should include in its considerations an assessment of the benefits and harms of screening large groups of people who are defined by a condition with recognised complications. Many respondents felt that diabetic eye screening which is offered to all people with diabetes aged 12 and over in England, Northern Ireland, Scotland and Wales fell into this type of screening. Several respondents felt that screening for recognised complications of an already diagnosed condition could help prevent morbidity and mortality and may also be cost effective.

Respondents who answered no to this question felt that these groups should be managed by good clinical practice rather than be invited to take part in screening programmes. The cost effectiveness of these types of screening programmes was raised and the resources involved in setting these programmes up. The question as to how these people would be identified and invited to be screened was also mentioned.

Responses included:

Individual:
“Would have thought such groups would be better served by their GP supported by consultants. Also consider would not be cost effective.”

Individual:
“Not unless you can identify all the people affected before you start.”

Individual:
“If there is a cost-effective measure which can be taken to reduce the incidence/severity of complications. Possibly most important/useful "expansion" with the current ageing population?”

NHS National Services Scotland:
“Screening programmes such as eye screening for those with a diagnosis of diabetes are often treated differently but should be delivered to the same rigorous

standard and principles that the NSC recommend for other screening programmes because of the potential to do further harm."

PHG Foundation:
"The NSC should consider the scientific evidence for doing so, and while we believe that it already does to a certain extent (for example, diabetic retinopathy screening), our view that there is scope to expand this in the consideration stage."

Question 14: Should the UK NSC include in its considerations an assessment of the benefits and harms of screening large groups of people who are defined by lifestyle factors? (eg smoking)

The number of respondents who answered this question is as follows:

Yes:	50
No:	17
Skipped the question	30

Summary

The majority of respondents agreed that the UK NSC should include in its considerations an assessment of the benefits and harms of screening large groups of people who are defined by lifestyle factors. Respondents suggested that smokers could be targeted by this type of screening. Respondents felt the UK NSC should take account of research developments such as new screening tests which could benefit certain groups such as smokers. Some felt lifestyle factors should be considered in relation to genetic factors.

Responses from those who said no to this question stated that there were already public health campaigns targeted at these groups and that it may be more helpful to have behavioural change programmes focused at these groups rather than screening programmes. Other respondents highlighted potential difficulties in identifying the cohort programme, for example, there was some concern about the accuracy of self reporting on smoking/alcohol consumption by the public.

Responses included:

Individual:
"I don't know. If one were to do this one might have to look again at the criteria and see if they need strengthening. In particular have all preventative measures been tried and whether screening is the best approach to the problem."

Individual:
"There are a lot of public awareness programmes including TV campaigns. These specifically highlights the harms."

NHS National Services Scotland:
“NSC should take account of research developments about new screening tests such as blood tests to detect lung cancer in smokers/former smokers.”

How to invite people to be screened

Question 15: Should the UK NSC expand its considerations to include an assessment of the benefits and harms of screening large groups of people who are identified and invited opportunistically and then entered into a formal programme?

The number of respondents who answered this question is as follows:

Yes: 54

No: 16

Skipped the question: 27

Summary

The majority of people who answered the question agreed the UK NSC should expand its considerations to include an assessment of the benefits and harms of screening large groups of people who are identified and invited opportunistically and then entered into a formal programme. Several respondents felt that this approach could have significant health benefits and possibly avoid complications of a condition. However, respondents considered it essential that this should be organised as part of a managed pathway with quality assurance rather than the current, often haphazard approach.

Respondents who answered no to this question felt opportunistic screening may widen inequalities by targeting the worried well and it was unclear how people would be able to be properly informed in order to make an informed choice about screening.

***Responses included*:**

Children Living with Inherited Metabolic Diseases (CLIMB):
"People should have access to information regarding the benefits and harms before being entered into any programme."

Individual:
"This may end up with a programme addressed at the worried well. It could well increase inequalities. It may be one of a number of ways of recruiting to a programme, but not the only way."

Individual:
"This will ensure that rigorous assessment is applied to programmes that are currently creeping in through the back door e.g. screening for AF."

UK Thalassaemia Society:
"Opportunistic screening could have significant health benefits and possibly avoid complications/exacerbation of the condition."

Wolfson Institute of Preventive Medicine, Barts and The London School of Medicine and Dentistry, QMUL:
"Opportunistic screening is a euphemism for poor screening. Screening should be part of properly organised programmes focused on populations and involve expertise at all stages of the screening diagnostic and interventional stages."

Screening where the main benefit is to others rather than the person being screened

Question 16: Should the UK NSC expand its considerations to include an assessment of the benefits and harms of screening large groups of people for purposes other than direct health benefit to the screened individual?

The number of respondents who answered this question is as follows:

Yes:	43
No:	32
Skipped the question:	22

Summary

There was a mixed response as to whether the UK NSC should expand its considerations to include an assessment of the benefits and harms of screening large groups of people for purposes other than a direct health benefit to the screened individual. Several respondents who answered yes or no stressed that this was a complex ethical issue that should be given a lot of thought.

It was highlighted that antenatal and newborn screening allows families time to come to terms with their child's condition and can help them make personal decisions related to their family life. Several respondents raised the issue of reproductive choice and stated that early knowledge about the cause of ill health in their children can enable couples to choose to avoid the birth of another affected child, if they wished. One organisation commented that, whilst the primary aim should be to benefit the individual screened the benefits and harms for others could be a useful consideration. Where genomic testing is concerned it was noted that the question of effect on others was hard to avoid.

Respondents who answered no were concerned about individual choice and confidentiality of information. Other respondents felt that current screening programmes needed to be fit for purpose before new screening programmes such as these were introduced.

Other respondents who answered yes felt early diagnosis could directly benefit individuals, even if no treatment is available. One respondent felt medical progress could not be advanced if screening was denied just because there was not a treatment or cure for a condition. A respondent believed this type of screening should only be offered where there is a reliable test and this should be reviewed against the UK NSC's criteria so that the benefits and harms have been evaluated.

***Responses included*:**

Genetic Alliance UK:
“Early diagnosis can itself directly benefit individuals and people around them, even if no treatment is available. It provides families with time to come to terms with their child’s condition and can empower them to make better decisions about where they live, what school they choose, or personal choices about the future of their family. Early knowledge about the cause of ill health in their children can enable couples to choose to avoid the birth of another affected child, if they so wish.”

Individual:
“Think previous question "expansions" are more important to establish first and should not stretch remit too far too soon. However if this is possible as a by-product of a programme then it should be considered.”

Individual:
“I think so, but I'd like to see what the ethicist has to say on this.”

PHG Foundation:
“As before, we offer this answer with some contextual justification – for while we believe that the primary aim of screening should be to benefit the person screened, impact on others (eg relatives in genetic screening) also has the potential to play a role (but concerns surrounding this should not automatically preclude implementation of a screening programme). We do in principle believe that the benefits and harms on others could be a useful consideration in the right situation.”

The Raynaud's & Scleroderma Association:
“Generally 'no' as respect for individual choice must be maintained…and the screening relates to a specific time, place and set of conditions. If the individual agrees, information might be shared.”

The role of the UK NSC in making recommendations about possible actions when it has not recommended a national screening programme or a proposed screening opportunity falls outside the scope of a UK NSC recommended screening programme

Question 17: Is there merit in establishing a multiagency group with responsibility for considering alternative actions where the UK NSC says running a formal screening programme is not recommended but evidence or public response shows that other action should be explored?

The number of respondents who answered this question is as follows:

Yes:	55
No:	20
Skipped the question	22

Summary

The majority of respondents agreed that there is merit in establishing a multiagency group with responsibility for considering alternative actions where the UK NSC say running a formal screening programme is not recommended but evidence or public response show that other action should be explored. Respondents agreed that where a formal screening programme is not recommended but there is evidence of a potential benefit from another option such as clinical guidelines these alternatives should be explored. One respondent highlighted that it would be useful for research purposes and improve collaboration between research groups interested in a particular condition or topic.

Those who answered no felt the UK NSC should instead advise appropriate health bodies e.g. Royal Colleges, NHS England's Clinical Reference Groups and NICE so they can develop appropriate clinical guidelines for managing such patients. There was also concern that creating a new group could cause confusion with groups set up by NHS England such as the Clinical Reference Groups and the Rare Disease Advisory Group as well as specialist societies.

Other issues raised by respondents in answer to this question relate to the lack of a process to appeal against and UK NSC decision.

Responses included:

Individual:
"For those populations where no case can be made for national screening it always seems harsh when the response from UKNSC is "no" and yet no one then has responsibility to look at other forms of detection. When the committee says "no"

there should be a recommendation as to the next step that should be taken, even if it isn't the UKNSC that takes it."

Individual:
"But need to ensure that the group has a specific purpose, rather than a group of "important" individuals who pronounce on issues."

Naitbabies:
"Definitely! An alternative process that could be put in place to explore other options would be beneficial to the relevant section of the public and could be beneficial to the UK NSC if a screening programme were recommended in the future."

Society and College of Radiographers. Representing members of the diagnostic and radiotherapy workforce:
"A recent example is the NSC review of vasa praevia. Full population screening was not recommended but further work was recommended on identifying possible pathways for groups at higher risk of the condition. Clear lines of responsibility are important when recommendations for alternative actions are made."

Policy Review Process

Question 18: What could be done to make the policy review process more generally accessible and easy to understand? For example, would it be helpful to provide plain English summaries of evidence reviews and recommendations?

The number of respondents who answered this question is as follows:

Answered	61
Skipped the question	36

Summary

This was an open ended question which did not require a yes/no answer. The majority of respondents who answered this question agreed that the UK NSC should provide plain English summaries of evidence reviews and recommendations. Other suggestions included improving engagement with stakeholders (both small and large stakeholder organisations), publicising reviews more, making the UK NSC website easier to use, ensuring evidence reviews are published, making the consultation template easier to understand and answer, publishing consultation responses in full rather than summaries, including a public fora for upcoming recommendations and streaming meetings over the internet.

Responses included:

AF Association:
"Yes, and more widely publicised. Be proactive in engaging with groups and individuals who could and should be included in the response."

Genetic Alliance UK:
"A combination of increased transparency in the processes of the UK NSC and improved communications, including plain English, would make the policy review process more accessible and easy to understand. It is important that the UK NSC engage with all patient groups that may have an interest in a particular programme. There may be more than one patient group, and some patient groups may have very little resources. It is therefore important to look continuously and thoroughly for relevant patient groups, and to give as much warning as possible that a review is planned. Publishing the external review on the website and allowing anyone to comment, increases the accessibility of the consultative process. Nonetheless, some valued viewpoints made by various smaller patient groups may be overlooked because only those that the UK NSC identifies as stakeholders are considered, with other comments considered more circumspectly. While the online publication of the summarised comments by the stakeholders on the external review report is very useful, the complete version would increase transparency."

Individual:
"Yes and to always include the latest evidence used during the process."

Individual:
“Evidence reviews and recommendation in the current formats are inaccessible to patients and lay persons, including the consultation documents. Plain English summaries are definitely needed. The consultation response questions and form are too rigid, and biased in the language and tone towards the position of the UK NSC.”

Prostate Cancer Support Federation:
“That would certainly help. Also, public discussion fora where upcoming recommendations are discussed and can be questioned by laymen. NICE already do something along these lines.”

Question 19: Would the process for requesting reviews for screening be improved by a regular formal call for proposals?

The number of respondents who answered this question is as follows:

Answered	63
Skipped the question	34

This was an open ended question which did not require a yes/no answer. The majority of respondents agreed there should be a regular call for proposals. There was a varied response as to how often a call should take place, this ranged from every three months to annually. Respondents felt that having a call for proposals would make the process more transparent and help engage with stakeholders.

Those respondents who weren’t in agreement with a formal call for proposals felt the UK NSC would be overwhelmed with responses if a call for proposals was set up and would not have an appropriate level of staff to handle all of the enquiries within the timescale. Some highlighted the need for criteria for considering requests in order to make the process manageable.

Responses included:

Individual:
“Yes but would be useful to continue to accept proposals at any time whilst making it clear that they will be reviewed at the next formal call.”

Individual:
“Call for proposals at a defined point eg annual would be transparent and also ensure better planning and use of resources.”

Individual:
“No, you'd get swamped. The current systems seem to work well enough.”

NHS National Services Scotland:
“This could perhaps be done twice per year and would make the work of the NSC more transparent to pressure groups, NHS clinicians and the general public.”

PHG Foundation:
"It is our view that unless a more regular call is in parallel supported by more designated NSC personnel, there is a danger that it could simply create a larger administrative burden and actually slow down the process in the long run. If, however, there is adequate support envisaged, we would of course welcome such a proposal."

Stakeholder Engagement - Annual Meeting

Question 20: Do you think this is a useful way of engaging with stakeholders?

The number of respondents who answered this question is as follows:

Yes: 57

No: 17

Skipped the question: 23

The majority of respondents agreed that an annual meeting between stakeholders and officers and members of the UK NSC to discuss and take questions on the work of the Committee over the preceding year would be useful. Respondents felt this would make the UK NSC more outward facing and would help build working relationships with stakeholder organisations. Concerns were raised over the venue for such a meeting as this could disadvantage stakeholder groups depending on where they are based geographically. It was suggested that online conferencing could be made available for delegates who could not attend in person. One respondent felt that an annual meeting should be open to individuals as well as stakeholder organisations.

Respondents that answered no felt that annual meetings were out dated and social media and enquiry lines were the way forward for engaging with stakeholder organisations. One respondent felt it may become a lobbying forum for stakeholder organisations unhappy with a UK NSC recommendation and another respondent felt that the money involved in hiring a venue for an annual meeting could be better spent elsewhere.

Responses included:

Individual:
“Many people have no direct contact with the Committee and it would be useful to have a targeted venue for building relationships.”

Individual:
“This sort of public engagement is increasingly important for all public bodies.”

Individual:
“More valuable to put info on website with FAQs and an enquiry line/email.”

Individual:
“Annual meetings, invariably in London, are outdated and inequitable to most of the population. Use the new media options to reach a bigger audience.”

Joint Committee on Genomics in Medicine:
“This would be useful, but attendance will of necessity be limited to those with job flexibility. If this occurs, a rotating venue and city is important.”

Question 21: Are there any other ways the UK NSC could improve stakeholder engagement and understanding of the work of the Committee?

The number of respondents who answered this question is as follows:

Yes:	55
No:	9
Skipped the question:	33

Summary

The majority of respondents agreed that the UK NSC could improve stakeholder engagement and understanding of the work of the Committee. Suggestions included improving publicity of the UK NSC and its up-coming reviews, consulting with stakeholder organisations before and during the review process and co-opting stakeholder organisations onto the UK NSC when screening for a certain condition is being reviewed, an annual meeting, a better publicised annual report, employing a stakeholder engagement officer, better use of social media, e-mail updates, articles in medical journals, inclusion of recommendations on other NHS facing websites such as NHS Choices, open meetings and online conferencing.

The majority of respondents who answered no did not expand on their answers. However, one respondent said that the processes covered in this consultation appeared to be quite comprehensive and promoted openness and understanding.

Responses included:

Society for Mucopolysaccharide Diseases:
"Appropriate representation at UK NSC meetings; relevant patient org to contribute to the discussion around a particular screening test."

Individual:
"Social media, email updates."

Individual:
"Much greater transparency of the workings of the UK NSC is required. At present only very limited draft minutes are provided 4 weeks after meetings take place. The UK NSC should adopt the approach by the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children (DACHDNC) in the USA where agendas, presentations and audio transcripts are shared publically. It is to be noted that NHS England shares in advance its Meeting Agendas, Board Papers and streams Board Meetings over the internet and provides them in archive."

National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC):
"Possibly feedback to relevant groups through written feedback and summary of the reasons for the decision not to recommend screening."

Wolfson Institute of Preventive Medicine, Barts and The London School of Medicine and Dentistry, QMUL:
"It could issue regular summaries of what they are doing and considering in a professional journal such as the Journal of Medical Screening."

General

Question 22: Are there any other points you would like the review working group to consider?

The number of respondents who answered this question is as follows:

Answered the question: 43

Skipped the question: 54

Summary

There was a wide range of responses to this question. Some respondents complained about the length of the survey and the fact that there was not an option to click 'don't know' or 'not applicable'. A number of respondents focused their response on screening for a particular condition. Several respondents stressed the need for better stakeholder engagement. A number of respondents focused on the accountability of the UK NSC and requested that the UK NSC's oversight, reporting mechanisms, appointments and decision making processes are clarified. Some responses concentrated on the criteria and the evidence needed to meet the criteria such as RCTs and appropriate treatment. Other responses requested that the UK NSC continues to be a four nations Committee with improved implementation of screening programmes in each country.

Below are a selection of the responses received. For all other responses please see the full list of consultation responses.

Responses included:

Individual:
"Aye where are the representatives or professionals from Northern Ireland or Scotland this is a loaded table with unfair heaviness from England."

Individual:
"Consequences of identifying diseases for which there are no current treatments or none envisaged in the near future - the role of anxiety and anticipation in screening programmes."

Individual:
"Competency within the UKNSC to deliver its aims and objectives. Regular monitoring of the effectiveness of existing screening programmes."

Individual:
"1.Regulation of the private sector screening programme. 2.Whether other related parts of the NHS screening programme (eg GPs) have the capacity to do their part. Where resources are stretched, there is anecdotal evidence that screening may not be a priority. Is there more robust evidence of this?"

Individual:
“More clarity about how the UK NSC reaches its decisions.”

Joint Committee on Genomics in Medicine:
“The accountability of the NSC needs to be clarified, including oversight, reporting mechanisms, scrutiny and duration of appointments and decision making processes.”

Society and College of Radiographers. Representing members of the diagnostic and radiotherapy workforce:
“Screening programmes should be subject to regular review with regards to whether they are continuing to meet the NSC criteria for screening. Whether suitable staffing and resources are likely to be available should also be part of the considerations. There should be local consultation with management and staff prior to commencing a screening programme as only they can give assurance that point 19 can be applied or not.”

Annex A

Membership of the Review Group

Name	Role
Professor David Walker (Chair)	Former Deputy Chief Medical Officer for England, Chair UK NSC
Professor Kevin Fenton (Vice-Chair)	Director, Health and Wellbeing Public Health England
Mrs Jane Allberry (up to April 2014) Dr Dorian Kennedy (from April 2014)	Deputy Director Sexual Health, Screening and Early Diagnosis Department of Health
Dr Margaret Boyle	Senior Medical Officer Department of Health, Social Services and Patient Safety, Northern Ireland
Ms Alison Brown	User representative
Dr Hilary Burton	Director PHG Foundation
Dr Jennie Carpenter (up to April 2014)	Consultant in Public Health Department of Health
Professor Aileen Clarke	Professor of Public Health & Health Services Research Director of Warwick Evidence Head of Division of Health Sciences
Dr Simon Cuthbert-Kerr (up to July 2014) Mr Scott Sutherland (from July 2014)	Health Protection Team The Scottish Government
Mr Greg Fell	Consultant in Public Health City of Bradford Metropolitan District Council Public Health Department
Ms Jane Fisher	Director ARC (Antenatal Results and Choices)
Dr Rosemary Fox	Director of Screening Services Public Health Wales

Professor Liddy Goyder	Professor of Public Health and Deputy Dean of the School of Health and Related Research (ScHARR)
Dr Sharon Hopkins	Director of Public Health Cardiff and Vale University Health Board Headquarters
Ms Fiona Jorden	Consultant in Public Health Screening and Immunisation Lead South Yorkshire and Bassetlaw Area Team
Dr Anne Mackie	Director of Programmes UK National Screening Committee
Dr Heather Payne	Consultant Paediatrician, Senior Medical Officer for Maternal and Child Health Welsh Government
Dr Sue Payne	Public Health Consultant NHS Lothian
Dr Angela Raffle	Consultant in Public Health Bristol City Council
Ms Farah Seedat	PhD student, Division of Health Sciences, Warwick Medical School, University of Warwick
Professor David Weller	James Mackenzie Professor of General Practice Centre for Population Health Sciences University of Edinburgh

Annex B

Stakeholder organisations who responded to one or more of the consultation questions

AF Association
Association for Glycogen Storage Disease UK
Association for Improvements in the Maternity Services
Barnet & Chase Farm NHS Trust
Board of Deputies of British Jews
British Association for Cytopathology
Cardiac Risk in the Young
Children Living with Inherited Metabolic Diseases (CLIMB)
Genetic Alliance UK
Hep B UK
International Nursing Group for Immunodeficiencies (INGID)
Jewish Genetic Disorders UK & Jewish Care
Joint Committee on Genomics in Medicine
Jo's Cervical Cancer Trust
Mid Yorkshire NHS Trust
Muscular Dystrophy Campaign
Naitbabies
National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC)
NHS England (Domain 1)
NHS England NCD team
NHS National Services Scotland

NHS Pathology Laboratory
Nottingham University Hospitals NHS Trust
PHE
PHG Foundation
Primary Immunodeficiency UK
Prostate Cancer Support Federation
Royal College of Obstetricians and Gynaecologists (RCOG)
Royal College of Nursing
Save Babies Through Screening Foundation UK
Serious Hazards of Transfusion Haemovigilance Scheme
Society and College of Radiographers. Representing members of the Diagnostic and Radiotherapy Workforce
Society for Mucopolysaccharide Diseases
SVT
The Raynaud's & Scleroderma Association
The Royal College of Ophthalmologists
UK Thalassaemia Society
Wolfson Institute of Preventive Medicine, Barts and The London School of Medicine and Dentistry, QMUL