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Government Response to the House of Commons Science and Technology Committee Report on National Health Screening



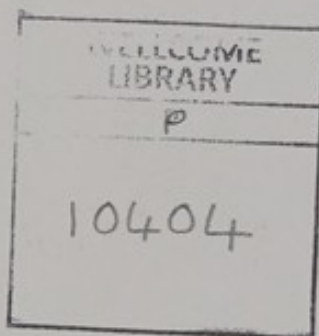
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Government Response to the House of Commons Science and Technology Committee Report on National Health Screening

Presented to Parliament
by the Secretary of State for Health
by Command of Her Majesty

January 2015



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Introduction

This document sets out the Government's response to the House of Commons Science and Technology Committee Report on National Health Screening published on the 29th October 2014. This response has been developed in coordination with the four UK Health Departments and the Secretariat of the UK National Screening Committee (UK NSC).

Health screening is a vital public health tool that saves lives and improves the quality of life through early diagnosis of serious conditions, enabling early treatment and care. Screening programmes offer tests to assess risk or detect early disease and guide people through the whole process – from the initial invitation to attend for screening to the test itself; communicating and interpreting results; advising on options; and referring those who need it for further investigation and diagnosis.

Screening saves many lives and reduces the burden of disability, for example, every year across the UK:

- up to 5,000 deaths per year are prevented by cervical screening¹
- around 2,400 lives are saved through bowel screening²

- 1,300 lives are saved through breast cancer screening³
- around 1,000 babies every year are born without HIV because of antenatal screening
- around 1,100 deaf babies are helped to reach their full educational and social potential following newborn hearing screening⁴
- 400 people with diabetes have sight saving treatment following diabetic eye screening⁵

Great care has to be taken before introducing a new screening programme as some tests cause harm as well as produce benefits. Across the UK, millions of individuals are invited by NHS Screening Programmes to be tested for a range of serious conditions. Some tests may provide misleading results, for example, by giving a negative result when the results should be positive (a false negative result) thereby missing the correct diagnosis; or giving a positive result when the result

1 Peto et al, The cervical cancer epidemic that screening has prevented in the UK, *Lancet* 2004; 364: 249-56
<http://www.ncbi.nlm.nih.gov/pubmed/15262102>

2 Parkin, D.M., Tappenden, P., Olsen, A.H., Patnick, J., Sasieni, P., Predicting the impact of the screening programme for colorectal cancer in the UK. *Journal of Medical Screening*, 2008. 15: p. 163-174
<http://www.ncbi.nlm.nih.gov/pubmed/19106256>

3 The Independent Review on Breast Cancer Screening, The Benefits and Harms of Breast Cancer Screening, October 2012
http://www.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@pol/documents/generalcontent/breast-screening-report.pdf

4 UK NSC – Screening in England 2012/13 Annual Report
<http://www.screening.nhs.uk/getdata.php?id=17453>

5 UK NSC – NHS Diabetic Eye Screening Programme Fact and Figures
<http://diabeticeye.screening.nhs.uk/statistics>

should have been negative (a false positive result). This may result in stress for the individual and possible follow-up treatment that is unnecessary.

For all these reasons, it is important that screening programmes are only introduced when there is sufficient evidence that the benefits outweigh any potential harms, and that people are given all the facts before making an informed decision to take up an offer of screening.

The Government welcomes this report, which rightly recognises the success of the NHS Screening Programmes and highlights the difficulties in balancing benefit and harm that comes with offering large numbers of apparently healthy individuals screening for different conditions.

The Government is pleased that the report recognises the crucial role the UK NSC plays in assessing the evidence base and cost effectiveness of potential programmes before making recommendations to Ministers.

The Government also considers that the Inquiry is very timely as its findings will feed into an ongoing structure and process review of the UK NSC, which is currently considering a wide range of issues including:

- terms of reference
- 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
- stakeholder engagement

The Government has carefully considered the conclusions and recommendations of the Inquiry. Detailed responses to each of the 22 recommendations contained in the Committee's report are provided below.

Recommendation Responses

1. Health screening policy and practice provokes strong reactions among those who argue that the UK should screen for more conditions and in those who question the operation of, and evidence base for, current programmes. Since its establishment, the UK National Screening Committee has discouraged the haphazard growth of localised, unplanned programmes that are not grounded in high-quality evidence and has presented a barrier to entry. We agree that all screening programmes should be grounded in robust evidence and, given the difficulty of withdrawing a programme, support the idea that the evidential barrier to entry should remain high. (Paragraph 12)

The decision to introduce a national screening programme is subject to a rigorous assessment of the evidence in order to ensure that advice to Ministers is based on a robust evidence base. Screening programmes have the potential to do a significant amount of harm as well as deliver life-saving benefits. The Government therefore welcomes the Committee's endorsement to retain a high evidential barrier for the introduction of new screening programmes. We fully support the continuing role of the UK NSC in assessing all the available evidence and providing robust advice to Ministers on whether a screening programme should be introduced or continued.

2. We recognise that the devolved nations have power over public health in their respective territories. However, significant amendments to the delivery of screening programmes by a single nation within the UK (in the absence of a formal recommendation from the UK National Screening Committee (UK NSC)) risk undermining the UK NSC's authority as the body advising all four nations on screening policy. It also generates confusion and uncertainty about current best practice. (Paragraph 17)

The UK NSC advises Ministers and the NHS in all four countries about all aspects of screening. This advice is based on the most robust and up to date evidence base possible. It is, however, for each country to decide how and when this advice is implemented as local circumstances allow. There may, for very good reason, be some differences in delivery across the four UK countries. For example, differences in how the NHS is organised may impact on how a screening programme is delivered; the resource implications may vary or there may be legislation in a country, which may impact on how a screening recommendation from the UK NSC is acted on.

As the Committee has noted, some screening programmes predate the UK NSC so there are some historical differences. However, we are reassured that the direction of travel is to develop a more consistent approach and note the work the UK NSC already has in hand to bring about this consistency; for

example, the recommendation in 2012 on the age range for cervical screening, and we would wish to see this continue.

3. We welcome the UK National Screening Committee's (UK NSC) decision to ensure that any "big change" to an existing screening programme made by one, or more, of the four nations would now prompt the UK NSC to conduct an evidence review and issue a formal recommendation. We recommend that the UK NSC clarifies in its response to this report what constitutes a "big change" to an existing screening programme that would automatically trigger a UK-wide review and policy recommendation. This information should be made available on the UK NSC's website. (Paragraph 18).

A "big change" is considered to be a fundamental change to a screening programme that would affect the balance of good and harm likely to accrue to the programme. Examples would include a change in:

- the eligible age range
- the test
- evidence of altered cost effectiveness or cost
- a shift in understanding of the natural history of screened diseases such that other elements of the pathway needed to be altered (for example, a better understanding of Ductal Carcinoma in Situ leading to a change in diagnostic and treatment pathways)
- evidence of a shift in acceptability
- evidence that primary prevention or treatment are so effective that screening no longer had an important role to play in preventing or reducing the risk of the condition (immunisation for rubella for example)

- evidence that despite good research evidence the programme is simply not able to deliver benefits in practice
- that any stakeholder has good evidence based reasons to request a review.

A clear statement to this effect will be made available on the UK NSC's website. This information will also be included in the UK NSC's Code of Practice with clear governance arrangements for making this assessment.

4. If it is to be effective and trusted, the UK National Screening Committee (UK NSC) must be open to a plurality of perspectives when reviewing the evidence base for its policies. We are satisfied that efforts continue to be made to consult with stakeholders and note that the UK NSC is currently producing updated guidance for stakeholders on "engaging with its policy review process". Engagement, however, should be a two-way process. In addition to being transparent and opening up its policy review process to external input and scrutiny, it is vital that the UK NSC proactively looks beyond traditional, large stakeholder groups and seeks to engage with those smaller – often condition-specific – groups especially where they offer scientific insight. We recommend that the UK National Screening Committee, in its response to this report, details how it will proactively engage with a broader range of stakeholders. (Paragraph 22).

The Government is pleased that the Committee recognises the work the UK NSC has in hand to engage with its stakeholders. We are aware that the UK NSC Secretariat works with a huge range of stakeholders (currently 349 in total). These range from large organisations; such as the Royal Colleges, the NHS and umbrella stakeholder groups,

including Children Living with Inherited Metabolic Diseases (CLIMB), Cardiac Risk in the Young and Prostate Cancer UK to smaller groups, such as Group B Strep Support (GBSS), Vasa Praevia Raising Awareness and the Oliver King Foundation and individuals who have lost family members to disease, for example, cervical cancer, prostate cancer and Severe Combined Immunodeficiency Disorder (SCID).

During 2014, the UK NSC has run consultations on screening for 16 conditions, actively engaging with over 100 stakeholders in the process. Currently, GBSS and CLIMB are actively engaged in the work to assess the evidence for new recommendations and implement the findings of existing ones. However, there is always more that can be done and we are reassured that the UK NSC Secretariat is continuing to work with stakeholders to identify and understand any barriers to their effective engagement with the UK NSC's evidence review process, in order to foster further improvements.

In addition, we are aware that the UK NSC secretariat:

- is trialling new executive summaries of review documents to make them more accessible to non-experts and this is likely to particularly support engagement from the smaller stakeholder groups with less dedicated time to work on their responses
- will introduce monthly alerts to all stakeholders listing current live consultations and any due to start imminently.

The Government also understands that the UK NSC review group is considering stakeholder engagement in some depth and has consulted on this issue. It is likely to make recommendations on how the UK NSC

can further engage with stakeholders in all aspects of UK NSC business.

Reporting Evidence Reviews

5. We consider the consistent conduct and reporting of systematic reviews to high, well-established standards to be of great importance. We recommend that the UK National Screening Committee (UK NSC) draw on established protocols – such as the “Cochrane Handbook for Systematic Reviews of Interventions” – to standardise the steps within, and the reporting of, each systematic review of a screening programme. (Paragraph 27)

The Government agrees that the robust analysis of the evidence base is vital in ensuring the quality of screening programmes.

We would like to clarify in more detail the approach the UK NSC takes to undertaking its evidence reviews. As stated in the evidence, the UK NSC has a filtering process in which a large volume of small reviews are undertaken. These are not systematic reviews, but use systematic searches to identify relevant evidence and apply a rigorous approach to the analysis, summary and evaluation of the included studies. Where systematic reviews are used to inform UK NSC recommendations, for example, by the National Institute for Health Research Health Technology Assessment (NIHR HTA), they are recognised as meeting well established standards and protocols.

The UK NSC considers over one hundred such topics on a three yearly basis and this approach enables it to keep abreast of a high volume of evidence on a wide range of topics. By contrast, systematic review methodologies are procedurally much slower than this type of approach, sometimes taking 2 – 3 years depending on their complexity. They are

more suited to narrow clinical questions and their cost makes the practicality of the approach in every case questionable. For example, a recent NIHR HTA review of screening for domestic violence took three years to complete and cost £140,000. It is an important study, but this approach would be impractical and disproportionate for all reviews. It would also leave policy makers open to the criticism that the evidence was out of date. The current approach makes it possible to identify issues on which a systematic review might be justified in terms of the cost and the knowledge to be gained.

The Government is assured that the approach used by the UK NSC is proportionate to its requirements and the reviews are conducted to a high standard. Rapid reviewing is increasingly recognised in reviewing organisations where resource constraints focus attention on the need for prioritisation of topics for systematic reviewing. Similarly, the importance of rapid reviewing has also been recognised for policy making contexts, which need access to an overview of developments in particular areas and require a quicker turnaround than systematic reviews can offer. It is significant in this regard that the Cochrane Collaboration is developing a methodology for rapid reviews.

We are aware that the UK NSC has work in hand to enhance the consistency of the process, methodology and format of this kind of review and developing the quality of these reviews is the UK NSC's priority. A new format for its rapid reviews has been developed, which takes on board earlier criticisms received from stakeholders. This will be piloted shortly. In addition, there has been discussion with the Canadian 'Knowledge to Action' (KTA) group who lead on the rapid reviewing methodology within the Cochrane Collaboration rapid review group. This is being worked up into a

proposal for joint work with the KTA group. This will consist of a review of a UK NSC recommendation using the KTA process.

This is a complex process and the Government agrees with the Committee's recommendation that the UK NSC should be clear on its approach and set out how it standardises both the steps within and the reporting of each review of a screening programme. We understand that the UK NSC is developing a manual for reviewers, which will make clear that reviews should conform to accepted standards.

6. We note that the Independent Review of the UK National Screening Committee (UK NSC) is currently examining if the existing criteria for appraising the viability, effectiveness and appropriateness of a screening programme need strengthening or amending to take into account the complexities arising from genetic screening. It is also important that the Independent Panel considers if the evaluation of evidence against these criteria is conducted in a rigorous, transparent and consistent manner. Since the UK NSC does not use the same external reviewer for each review, and given the potential for differences in interpretation, we consider it essential that the UK NSC publishes clear guidance on how it assesses the evidence base against its criteria. (Paragraph 33)

The Government acknowledges the comments in the Inquiry about the need for additional clarity regarding how the criteria are evaluated. We understand that this issue has been a key consideration for the group overseeing the review of the UK NSC. A report, 'International Comparison of Screening Policy: A systematic review (Warwick Medical School)' commissioned to support the review, which provides an international comparison of screening policy making, has identified that

the criteria used for evaluation of screening programmes are consistent with those in other countries. However, it also notes that compared to the procedures in the UK, in some countries the procedures within the evidence review are often more formalised. The Government looks forward to the review groups recommendations on this issue.

The Government also agrees with the recommendation that is essential that the UK NSC publishes clear guidance on how it assesses the evidence base against its criteria. As above, we understand that the UK NSC is developing a manual for reviewers which will draw on this experience and enhance the consistency of reporting within the UK NSC's rapid reviews. In addition, guidance will be published on how the UK NSC assesses the evidence base against its criteria.

7. We recommend that the UK National Screening Committee publish a revised version of its 1998 Handbook to clarify and add detail to how the UK NSC evaluates the evidence base against its twenty-two criteria. This should be made available on its website no later than March 2015. (Paragraph 34)

We agree that it is important that the UK NSC should give clarity and detail on how it evaluates the evidence base against its twenty two criteria. As in the recommendation above, this guidance is being developed and will be made available on the UK NSC website by March 2015.

8. Any evidence review process must be flexible enough to accommodate the wide range of screening programmes the UK National Screening Committee (UK NSC) examines and some subjective judgements will be made. However, it is currently unclear what procedures the UK NSC has for reaching decisions about whether to recommend a programme.

In line with the guidance outlined in the Code of Practice for Scientific Advisory Committees, we recommend that the UK National Screening Committee formally agree, and make public, the procedural mechanism by which it will reach decisions and recommendations. (Paragraph 38)

The Government agrees and welcomes the Committee's recognition that there needs to be some flexibility in the evidence review process and the need for some subjective judgements to be made. This is a necessary part of any evaluative practice. The screening criteria (in common with the US and other European and Australasian Committees) include issues such as "is the whole programme acceptable and ethical" and "is the condition screened for important?" These issues are combined with more quantifiable criteria about evidence of effectiveness of treatment, how well the test performs in the NHS etc. These require a degree of judgement to be used alongside an appraisal of the evidence.

As the Committee is aware, the review group has also been considering the processes and procedures used by the UK NSC for reaching decisions about whether to recommend a programme. As in recommendations 20 and 21 below, the review has already recognised similarities with other Scientific Advisory Committees (SACs) and the need for consistency in procedural rules. We agree that in line with Code of Practice for Scientific Advisory Committees (CoPSAC), the UK NSC should give a clear explanation of how it uses its criteria to reach decisions and make recommendations, and that this should be published.

9. Interventions that display all the hallmarks of being a systematic, population-based screening programme – like NHS Health Check – should not follow

a “different route” bypassing the UK National Screening Committee’s (UK NSC) evidence review process. To do so risks undermining the UK NSC’s authority and, in the absence of the UK NSC’s scrutiny, may give rise to serious questions about the quality of the evidence upon which the programme is based. We agree with the UK NSC Chair and recommend that, in the future, any programme that “looks like” a screening programme, regardless of the label it is given, should be subject to the UK NSC’s evidence review process. (Paragraph 44)

As indicated by the UK NSC Chair as part of his evidence to the inquiry, there is strong support for ensuring all screening proposals to routinely test for specific conditions are subject to the UK evidence review process. As in recommendations 2 and 3 above, we expect any significant amendments or “big changes” to a screening programme to be reviewed by the UK NSC. We also agree that systematic population based screening programmes should, in the future, be subject to a formal assessment of the evidence by the UK NSC before they can be introduced.

10. We are concerned that there is ambiguity about whether the Government has agreed to the extension of the breast cancer screening programme to cover all women in England aged 47-49 and 71-73. We therefore recommend that, in the Government Response to this report, a clear statement is made about what has, and has not, already been agreed to regarding the extension of the breast cancer screening programme. We ask that this statement also detail the evidential basis for the Government’s position. (Paragraph 47)

The Government welcomes this opportunity to clarify the position. The original plan, as set out in the Cancer Reform Strategy (2007),

was to offer screening to all women aged 47-73 years in England from 2012. However, to gather as much evidence as possible on screening the extended age ranges, the decision was taken for the extension to become a randomised controlled trial. The trial will measure the impact on breast cancer mortality rates and is not due to report until the early 2020s. Public Health England (PHE) has now stated that future decisions about extending routine NHS breast screening outside the age group 50-70 should await the emergence of reliable evidence as to its effects. When evidence emerges, which may well be from the English trial, the UK NSC will be asked to consider the evidence and offer advice to the UK Health Departments.

In order to get a significant result from the trial, the programme will need to invite women in the extended age ranges for at least two more screening rounds. If women aged 71-73 are in the control group, they will be able to self-refer, as women above the upper invitation limit have been able to since the programme began. Women aged 47-49 in the trial control group will also be screened if they ask.

We are investigating extending the programme to women aged 47-49 so that every woman receives her first invitation for screening by her 50th birthday – due to the way the programme works (inviting women in “batches” every three years), some women have to wait until nearly their 53rd birthday until they receive their first invitation. We are investigating extending the programme to women aged 71-73 as the risk of breast cancer continues to rise after the end of routine invitations.

11. The risk taken in not ensuring a policy is evidence based is poor policy that does not achieve its intended aims. We have heard from witnesses

to this inquiry that the NHS Health Check programme may have suffered in this manner. The programme was introduced without an evidence base demonstrating that it could achieve its aims and we are concerned that it could be, as a result, wasting resources. We therefore recommend that the NHS Health Check programme be scrutinised by the UK National Screening Committee, retrospectively, to ascertain its value. (Paragraph 48)

The Government strongly agrees with the principle of ensuring that there is a strong evidence base behind the Health Check programme. However, we feel this work should be carried out by the Expert Scientific and Clinical Advisory Panel rather than the UK NSC to reflect that, in the Government's view, that Health Check programme is a risk awareness, risk assessment and risk management programme rather than a screening programme.

The Government is committed to bringing greater scientific and clinical rigour to the programme. All elements of the programme are strongly evidence based, drawing on established National Institute for Health and Care Excellence (NICE) guidance. In 2013, PHE published a summary of the programme's evidence in 'NHS Health Check: our approach to the evidence', which set out clear actions to support stronger scientific oversight of the programme. Following this, an Expert Scientific and Clinical Advisory Panel, formed of eminent clinicians and academics, was established to scrutinise and advise on the evidence base and facilitate future research and evaluation at a national and local level. A member of the UK NSC Secretariat attends this Panel, along with representation from the NICE.

Two national research projects are due to report next year and PHE has also published

for consultation research priorities, which will further drive the development of the evidence base for the programme. Both projects, one led by Queen Mary's School of Medicine and the other by Imperial College London, are looking at the impact of the programme, in particular, the equity of access to the programme and reduction of risk factors. Both are due to report in early 2015 and will be used to further refine the Health Check programme.

The UK NSC was not asked to scrutinise the NHS Health Check programme in the first instance as it was not designed as a screening programme but a risk awareness, risk assessment and risk management programme. However, the Government is committed to ensuring that the programme is cost effective and evidence based, which is why the Advisory Panel has been put in place and other actions taken. We will keep all evidence under review and will revisit the Committee's recommendation in light of this process.

Communicating the Risks and Benefits of Screening

12. We support the principle of enabling informed choices to be made about participation in a screening programme. However, we are struck by the lack of clarity over what is meant by "informed choice", how it should be measured and the corresponding dearth of information on whether it is being achieved in practice. We recommend that a definition of "informed choice" is agreed by the UK National Screening Committee, in conjunction with its stakeholders, as soon as possible. The definition should have regard to the legal rights set out in the NHS Constitution, particularly those rights that make reference to consent and informed choice. We also recommend that

this definition is subsequently used as a starting point to evaluate, and compare across screening programmes, whether individuals are being supported to make an informed choice about participating. (Paragraph 54)

The Government supports the principle of enabling informed choice in all aspects of health care. For screening, we understand that a sub group will be established to consider public information and professional development. This will advise on high level principles, such as what is meant by "informed choice". This will have regard to the legal rights set out in the NHS Constitution, although we should point out the NHS Constitution is, of course, only applicable to England.

The Government is reassured by the range of work the UK NSC already has in hand. In 2011, the UK NSC commissioned a report called 'Informed Consent in Antenatal and Newborn Screening'. This used a definition of informed choice as one that is "based on relevant knowledge, is consistent with the decision-makers' values and is behaviourally implemented". The report also acknowledges that, for informed choice to occur, it is not sufficient to just provide information, it must be understood and presented in a way that does not suggest that there is a right and wrong choice. It also assumes that once appropriate information has been provided the course of action should be chosen by the patient rather than the clinician.

These are principles that the UK NSC fully subscribes to and every effort is made to provide public information that supports informed choice as defined above and that, in England, it meets the NHS Constitution commitment "to offer [people] easily accessible, reliable and relevant information in a form [they] can understand". For example, the new booklet on antenatal and newborn

screening programmes in England supports informed choice better than ever before by providing balanced, accessible information. This information makes it clear, which screening programmes are recommended (though still an individual's choice) due to unequivocal evidence of benefit and which should be based on someone's personal values and beliefs (such as antenatal screening, which could result in the choice of termination of an affected fetus). An evaluation of the new booklet will be carried out in 2015 with professionals and the public.

New bowel, breast and cervical screening leaflets were published in 2013 in England as part of 'Informed Choice about Cancer Screening'. Development was led by Professor Amanda Ramirez from King's Health Partners. The learning from this has informed the revised booklet on antenatal and newborn screening (above). Findings from this work are available to other UK countries when they are reviewing and updating their leaflets.

A patient decision aid was launched in January 2014 in England to support men making informed choices about abdominal aortic aneurysm screening. A similar tool is available from NHS Inform in Scotland.

To support health professionals in ensuring people make informed choices, the UK NSC commissioned a training programme called 'Screening Choices' in 2005. This programme rolled out nationally over two years in England and offered all NHS staff the opportunity to undertake training in various formats. This is available to the other UK countries. It was designed "to enhance skills and knowledge needed to ensure women and their families can make informed choices about offers of screening". The electronic resource is freely available to all NHS staff and has been accessed over 10,000 times.

13. Although there are differences between the screening programmes, we are concerned about inconsistencies in the method of developing public information, both within and across programmes. Producing accurate, concise and accessible public information on screening will always be challenging. However, we were surprised that there was no mechanism to share best practice across all programmes and that there was no UK-wide oversight of all NHS screening information materials. (Paragraph 61)

Public information for screening is developed by national screening teams in each country.

There are a number of informal mechanisms in place to share best practice, for example, regular meetings of the four UK Health Departments, and UK wide attendance at National Screening Programme Advisory Committees. These provide opportunities to share new public information and enable a consistency of approach and share best practice. However, as above, the Government is pleased that a new sub group, which will have representation from all four countries, will be established to look specifically at patient information and professional development.

14. We encourage the UK National Screening Committee and NHS to develop, pilot and evaluate approaches to providing screening information that can be accessed at the level of detail desired by individual patients and practitioners. (Paragraph 62)

Screening provides a unique and complex challenge in the need to clearly communicate the benefits of regular screening, whilst ensuring the public understand the potential risks associated with it. This is further complicated by individual patients who want different levels of information; and that a one size fits all approach would not work

with screening programmes that test for different conditions in different groups of the population. We welcome the Committee's encouragement to develop, pilot and evaluate approaches to providing screening information. That is why the standard process for producing information as set out as part of the response to recommendation 15 includes mechanisms for testing and evaluating screening information at all levels. This is done on a programme by programme basis in order to account for the variation in screening programmes and audiences.

In England, an approach is already in development that will provide a core level of information in printed leaflet form to facilitate informed choice for the majority of people offered screening, with more detailed information available online. Online screening information for the public is currently in the process of being transitioned to NHS Choices, which provides an opportunity to review and improve public information and link screening content effectively with symptomatic information. Further work is in hand to consider producing patient experience videos, case studies and stories to enable people to find out more about factors that might affect their decision. Similar principles apply to information for practitioners with training resources for professionals ranging from certified e-learning modules and DVD training, to more detailed training through university modules on screening. Key information about NHS screening is also communicated to practitioners through a regular newsletter, programme specific conference and articles in relevant profession specific publications. The other UK countries can access this information if they wish.

In Wales, all public information on screening is produced in both English and Welsh in accordance with the Welsh Language Act 1993.

15. To avoid inconsistencies in the information provided across programmes, we recommend that the UK National Screening Committee devises and implements a standard process, underpinned by a publicly available set of criteria, for producing information that facilitates an informed choice to be made about participating in a screening programme. The production process should consult with a wide range of stakeholders and should subject information materials to extensive user testing, both before and after implementation. Information materials for all NHS screening programmes should subsequently be revised according to the process and be reviewed at regular intervals. (Paragraph 63)

The Government agrees with this recommendation. We understand that the UK NSC is already developing such a standard process based on the work on 'Informed Choice about Cancer Screening'. A number of principles underpinning communication for screening have been set out:

- the information is based on the "consider an offer" methodology. This approach is designed to respect personal autonomy without overburdening people with unwanted information and decision making tasks. It states that openly explaining the basis for the offer of screening and allowing people to consider the potential bias and trustworthiness of those making the offer will not deter the uptake of effective and personally appropriate screening
- the information is balanced and includes both the benefits and harms of screening
- people have the right to personal choice and it is their right to accept or decline screening and this choice is clearly communicated

- the information is easy to understand, in plain language – conveyed in a variety of formats including text, pictures and diagrams; it is acceptable to the literacy and numeracy levels of an 11 year old; more detailed information online is for people of a higher reading age, but does not assume any medical, scientific or healthcare knowledge
- the information is easily accessible
- information is scientifically accurate
- stakeholders, including members of the public, are involved in the development of the resources. In particular, information is assessed for its general understanding, acceptability, perception of balanced information and its influence on decision making
- the process and resource are evaluated and documented to inform further resource development

This process will be considered by the new sub-committee on patient information and professional development for publication early next year and used for all future publications across all screening programmes. It will have some flexibility according to need as well as core elements, which will ensure that professionals and members of the public are appropriately engaged via focus groups and surveys to seek a wide range of perspectives. All public information materials will be reviewed on at least a three-yearly basis, or earlier if policy or other changes warrant it.

16. In the context of breast cancer screening, we have no reason to doubt the detailed work undertaken by the Independent UK Panel on Breast Cancer Screening in 2012. Its report clearly highlights the assumptions made by the Panel when analysing the data, as well as where uncertainties lie in its estimates of benefits and harms. It is, however,

vital that any uncertainties are also acknowledged in screening information materials and expressed in a clear, accessible way. We consider that the UK Statistics Authority and its executive office, the Office for National Statistics, have a valuable role to play in ensuring the veracity of the statistics used in screening information materials and the models they are based upon. As the independent body with the statutory objective to promote and safeguard the production of official statistics that serve the public good, we recommend that the Office for National Statistics review and validate the statistics presented in NHS screening information materials. (Paragraph 69)

The screening programmes in the UK are committed to producing screening information materials that are as accurate as possible, including the statistics used. There is a balance to be struck on informing people of all possible uncertainties and making the information accessible and understandable and this will be a guiding principle within the standard process described above.

The UK Statistics Authority will independently look into the availability and quality of official statistics on health screening, as well as other numerical information, which might, in future, be handled as official statistics. The Authority will speak to a range of stakeholders, including the relevant statisticians. The Authority will also consider the degree of engagement between statisticians and those producing leaflets and other material for public dissemination containing numerical information and statistics about health screening and related outcomes. The Authority will write to the Committee with a copy of its findings when they are published.

17. Under the NHS Constitution, patients have the right to be given information about the test and treatment options available to them, what they involve, and

their risks and benefits. We are concerned that the rarity of some conditions may lead health professionals to downplay the possibility of participants in a screening programme receiving a positive result and that health professionals can struggle with screening terminology and concepts. We recommend that the Government supports the UK National Screening Committee to step up its education programme and ensure that all front-line health care professionals delivering screening programmes receive regular training to refresh their communication skills, as well as their understanding of available screening programmes and their associated benefits and risks (Paragraph 73).

National Screening Programmes in each of the four countries are responsible for providing health care professionals with the information they need to facilitate informed choice regarding screening. As the Committee notes, in England, this is a right under the NHS Constitution. The Government acknowledges it is a challenge to ensure all staff can access all information needed in an appropriate format. However, we are reassured by the wide range of work already in hand. For example, National Screening Programmes in PHE offer a range of approaches in collaboration with academic institutes, professional bodies, royal colleges and stakeholder groups. In England last year, e-learning resources were accessed by 56,000 users of the Continuing Professional Development (CPD) website resources and approximately 3,500 staff received direct face-to-face teaching from the screening teams. Information from the Royal Colleges, professional bodies that are UK wide is available to staff across the UK.

The above flexible access to regular training is ensured via:

- e-learning modules (freely available, auditable, evidence of CPD, supported by professional bodies, updated continuously in line with findings from QA/ changes to programmes, one is used as annual mandatory training by many NHS providers)
- screening masterclasses (face to face workshops for all staff, focusing on the basics of screening right through to commissioning a quality programme)
- masters level Health Screening Module (in collaboration with Warwick University. Intensive module for those wanting to explore screening in more depth)
- screening Matters, annual reports and programme updates – emailed to all NHS staff groups regularly
- web based resources (detailed information regarding all programmes, for self-directed study and facilitating training at local level, including mapping of professional competencies to resources to maximise use)
- student Midwife Packs (core information in A5 wallet distributed annually to all universities (England))
- resource Cards (pocket sized plastic cards containing hard to remember facts and figures for screening programmes) provided to key groups (eg midwives)
- on-line Induction Resource (core facts and links for all staff)

These resources are kept up-to-date and are inclusive of all level of detail needed by staff, including rare conditions (for example, the new set of Resource Cards and latest e-Learning module contain detailed information regarding the four new rare metabolic conditions to be screened for on the newborn blood spot). Informed choice is underlined throughout training resources.

Regular uptake of the above CPD is encouraged and maximised by incorporating recommendations into programme standards and service specifications. In addition, work is in hand with professional bodies to influence pre-registration curricula as appropriate. An example of this is the incorporation of a competency related to 'informed choice for screening' into pre-registration midwifery education.

By establishing an effective relationship with Health Education England (HEE), work is in hand to align the screener training programmes (for newborn hearing screeners, aortic aneurysm screeners and diabetic eye screeners) with other non-professional NHS staff groups. In addition, the NHS Screening Programmes' e-learning modules will migrate to HEE's platform in 2015.

Similar arrangements to those described above are in place in Scotland, Wales and Northern Ireland.

We are reassured that the new sub group of the UK NSC will provide an opportunity to develop high level principles and enable more formal sharing of best practice. This will incorporate evaluation to ensure that all front-line health care professionals delivering screening programmes receive regular training to refresh their communication skills, as well as their understanding of available screening programmes and their associated benefits and risks.

Private Health Screening

18. We recommend that the Government clarifies, in its response to this report, where responsibility rests for ensuring that the information materials and advertisements produced by private providers of health screening are held to the same evidential standards as those produced by the NHS and that

they enable people to make an informed choice about participating. We also recommend that the bodies regulating the conduct of health professionals, including the General Medical Council and the Nursing and Midwifery Council, review the effectiveness of their processes for ensuring that those operating in the private sector are providing patients with good quality, balanced information. (Paragraph 78)

There are a number of ways in which private health screening is regulated in the UK. However, these regulations do vary from country to country.

In England, private providers are captured under the provision of the Health and Social Care Act 2008 where they are providing services included in the regulated activity of Diagnostics and Screening Procedures. Providers delivering this regulated activity are required to register and meet the requirements of registration with the Care Quality Commission. This includes provisions to provide service users with appropriate information and encourage them to understand the care or treatment choices available.

Computerised Tomography (CT) scans and other diagnostic procedures, which use radiation, magnetic resonance or ultrasound for the purposes of determining disease, disorder or injury, are activities, which fall within the regulated activity of Diagnostic and Screening Procedures. Screening services not covered by regulation, includes (but is not limited to) the taking of blood samples via pin prick tests; fitness screening procedures; hearing aid needs assessments; baby scans for the purposes of other than determining disease; disorder and injury and 12 lead electrocardiography.

Private providers must comply with the Consumer Protection from Unfair Trading

Regulations 2008 (CPRs), which prohibits traders from engaging in unfair commercial practices (mainly marketing and selling techniques) against consumers. The Regulations apply across all business sectors and set out a framework for how businesses must deal with consumers.

Under the CPRs, traders must provide consumers with the information necessary to make informed decisions. In particular, the CPRs require traders not to omit or hide material information, which the average consumer needs according to the context to make an informed choice, and as a result this causes or is likely to cause them to make a different choice. Nor must they provide such information in an unclear, unintelligible, ambiguous or untimely manner. Enforcement of these regulations is by local authority trading standards services and carries criminal penalties.

There are also nine regulatory bodies responsible for regulating 32 professions across the health and social care sector in the UK – consisting of approximately 1.44 million professionals. The primary purpose of professionals' regulation is to ensure public safety. To be able to legally practice in the UK, for example as a nurse, a doctor or dentist, the individual must be registered with their profession's regulatory body. This is applicable to individuals working in both the NHS and the private sector.

Each regulatory body has the same overarching functions, which are as follows:

- setting the standards of behaviour, competence and education that professionals must meet
- dealing with concerns from patients, the public and others about professionals who are unfit to practise because of poor health, misconduct or poor performance
- keeping registers of professionals who are fit to practise and setting the

requirements for periodic re-registration (and in some cases revalidation) for each profession

This is not a simple landscape, with a number of bodies responsible for ensuring the information materials and advertisements produced by private providers are appropriate. However, there is a role for the UK Health Departments and the UK NSC in lending its expertise in producing information that facilitates an informed choice in relation to the offer of screening. The UK NSC already offers guidance to people who are considering taking up an offer of private screening and for GPs who may have been approached by private screening providers who wish to offer screening to their NHS patients.

Innovations in Screening

19. Throughout this inquiry we have heard about the potential benefits, and concerns about the possible harms, arising from participation in a screening programme. The Committee welcomes the current, ongoing research that aims to improve the targeting of screening programmes towards those in higher risk groups. We have previously documented the NHS's resistance to change and therefore consider it imperative that the UK National Screening Committee (UK NSC) and the NHS set out how they will ensure proven developments in screening risk stratification are supported, and where recommended, implemented, as well as how best practice is to be disseminated. We also recommend that the UK NSC is supported by the Department of Health and the Government Office for Science to develop its capacity for "horizon scanning" and to embed it in its operations. (Paragraph 83)

The Government recognises that the targeting of screening through improved risk stratification and the advances in technologies that enable this, offer the opportunity to change the way screening is carried out and bring about many benefits. We believe the UK NSC is already demonstrating the capacity to adapt to these changes; for example, abdominal aortic aneurysm screening has in place a risk stratification approach to its surveillance programme, where the size of aneurysm determines the frequency of follow up scans. Antenatal screening for sickle cell uses a family origin questionnaire to target those at risk. We are also encouraged that the report 'International Comparison of Screening Policy: A systematic review (Warwick Medical School)' commissioned to support the review of the UK NSC has found that the four UK countries are the most prepared of countries for the genomic era. We are also confident that the UK NSC has embedded horizon scanning into its operations.

We are aware that the UK NSC is a principle customer for the National Institute for Health Research Horizon Scanning Centre, which provides timely information about emerging health technologies that may have a significant impact on patients or the provision of health services in the near future. The UK NSC also has well established networks, which inform its horizon scanning, for example, it is represented on the Joint Committee on Genomics in Medicine (JCMG). It also works closely with those in the research community on up and coming technologies in screening, for example, work is in hand with the Institute of Child Health, University of London on non-invasive prenatal diagnosis for Down's syndrome. The UK NSC also seeks regular updates from a range of research bodies about screening trials and activities on screening in other countries, for example:

- through a regular article alert service the UK NSC is updated on screening developments from international screening committees, including Canada, the US Preventive Services Task Force and New Zealand
- the National Institute for Health Research Health Technology Assessment, Medical Research Council and Scottish Intercollegiate Guidelines Network provide updates to the UK NSC on their screening related research and evidence synthesis
- The National Institute for Health and Care Excellence diagnostic and technology groups contact the UK NSC secretariat about new screening tests

There is also a close working relationship with the NHS on preparing for future challenges on screening. For example, in England there is a comprehensive governance process in place that brings together officials from the Department of Health (DH), PHE and NHS England to consider issues on screening. Incorporated into this process is a regular update and review of possible future developments on screening, so they can be appropriately planned for.

However, we are not complacent and recognise that there is always more that can be done and officials in the DH will work closely with the Government Office for Science to develop the UK NSC's capacity for "horizon scanning" and to embed it in its operations.

We are also pleased to learn that the UK NSC plans to have a meeting specifically to discuss all the recommendations from the Science and Technology Committee. In addition, this meeting will provide an opportunity for the UK NSC to horizon scan and prepare for the many challenges ahead.

Screening Policy and Advice

20. From the evidence we have taken, the UK National Screening Committee (UK NSC) broadly performs the functions of a Scientific Advisory Committee, yet it is not classified as such. A compelling reason for the status quo was not offered. It is of concern to us that the UK NSC Director of Programmes did not know what code of practice the UK NSC worked within. This suggests that the UK NSC's "procedural rules" are not informing its day-to-day work. (Paragraph 90)

While we are confident that the UK NSC's current procedural rules do inform its day to day work, we agree that there should be greater clarity around this and to how the UK NSC adheres to relevant guidance and good practice. Actions to address this need for clarity and the issue of the UK NSC as a Scientific Advisory Committee (SAC) are outlined in the response to recommendation 21.

21. The Code of Practice for Scientific Advisory Committees (CoPSAC) reflects the authoritative guidance on providing independent scientific advice to government departments. It was intended to apply to advisory committees regardless of their specific structure and lines of accountability. We are, therefore, at a loss to understand why efforts are apparently underway to develop a distinct code of practice for the UK NSC that "draws on" CoPSAC, rather than adhering to CoPSAC in full. We recommend that the UK National Screening Committee adopts, and adheres to, the Code of Practice for Scientific Advisory Committees in its full and unchanged form. (Paragraph 91)

The Government is committed to ensuring it has access to, and that policy makers are able to draw on high quality, wide ranging,

most up to date and robust evidence to enable informed decision making and therefore welcomes these recommendations. As above, there could be greater clarity in how the procedural rules operate and relate to guidance and best practice. Current arrangements, which inform the day to day work of the UK NSC are set out in an agreement between the four UK Health Departments. As the Committee has acknowledged, the UK NSC is currently undergoing an in depth structure and process review. As part of this, discussions are underway between the DH and relevant partners to ensure that appropriate guidance and best practice is applied to all aspects of the UK NSC's business and that arrangements are in place for the DH to ensure the robustness of the evidence provided to it on screening. The UK NSC has been added to the list of DH SACs, but it is appropriate to note that the term SAC is a description of form and function, rather than a classification. Measures will be put in place to provide assurance that the UK NSC advice to the DH adheres to the principles of Scientific Advice to Government and to those elements of the Code of Practice for Scientific Advisory Committees, which are relevant to the function of the UK NSC.

22. There is a worrying lack of clarity regarding the relationship between Public Health England and the UK National Screening Committee (UK NSC). It is essential that the two parties formally define their working relationship and identify the safeguards in place to ensure the UK NSC's continuing independence. We recommend that a memorandum of understanding between the UK National Screening Committee and Public Health England is promptly drawn up and placed in the public domain no later than December 2014. (Paragraph 95).

The Government agrees there is a need to clarify more formally the working relationship between PHE and the UK NSC. This will be set out in the UK NSC's Terms of Reference and Code of Practice.





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