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Committee

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Screening**

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Science and Technology Committee

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Summary

Health screening is the process of testing a defined population for one of a range of serious diseases or conditions. Usually, its aim is to detect disease among apparently healthy people so that it can be treated at an early stage. Like any medical intervention, screening has its limitations and carries both benefits and risks for participants. These will vary according to the screening programme. Potential benefits include increasing the likelihood of curing, preventing, or delaying the progression of disease; possible risks range from the physical and psychological effects of receiving a false result (either positive or negative) to harms arising from invasive follow-up tests.

Screening is a widely accepted intervention in the UK. Throughout this inquiry we heard that the public perception of health screening was generally positive and expectations of what it could deliver were high. However, such attitudes can make it challenging to convey the types and degrees of harm that may be incurred through screening and much more needs to be done to ensure that both the benefits and risks are clearly, and even-handedly, communicated.

The recently revised breast cancer screening leaflet for the 50-70 age group—with its more explicit focus on helping women to make an ‘informed choice’ about whether, or not, screening is right for them—is an important first step in this process. However, the principles followed to revise this leaflet have not been applied to all the communications developed by other NHS screening programmes. There is also no mechanism in place to ensure that best communication practice is shared across these programmes, potentially leading to inconsistencies in the quality of information materials available to screening participants.

Providing balanced, high-quality information to all potential participants must be a well-resourced and nationally supported priority, not an afterthought undertaken on an ad-hoc basis. We therefore recommend the implementation of a standard process for producing information that facilitates an informed choice to be made about participating in a screening programme. To ensure that valuable health resources are not wasted, we also recommend that the NHS Health Check programme be scrutinised by the UK National Screening Committee, retrospectively, to ascertain its value.

Since 1996, it has been the responsibility of the UK National Screening Committee (UK NSC) to ensure that screening programmes are only offered where there is robust, high-quality evidence that they will do more good than harm, and at a reasonable cost to the NHS. The UK NSC deservedly enjoys an international reputation for excellence and there have been success stories under its watch. If the UK NSC’s decisions are to remain authoritative in the face of demands to introduce new screening programmes, improvements to the transparency and rigour of its processes for reviewing the evidence base are urgently required. In particular, there is a pressing need for the UK NSC to draw on established protocols to standardise the systematic reviews of screening programmes. As the UK NSC approaches its twentieth anniversary, it is also essential that it looks ahead

to the next twenty years and sets out how it will adapt to the rapidly changing landscape of screening while continuing to pursue an evidence-based approach.

Finally, we are concerned that while the UK NSC performs many of the functions of a scientific advisory committee, it is not classified as such. Instead, its formal status, the principles by which it is governed, and its relationship to Public Health England, are all ambiguous. We consider this *status quo* to be potentially damaging to the UK NSC's independence and therefore make a number of recommendations aimed at formalising the operation of the UK NSC to ensure that it can consistently deliver independent, evidence-based advice to Government.

1 Introduction

1. Screening involves systematically approaching apparently healthy, non-symptomatic people to ask if they wish to be tested for a serious disease or condition. Grounded in the principle that prognosis can be improved by intervening earlier, the primary purpose of screening is to improve health outcomes by detecting and treating disease at an early stage.

2. In the UK, screening took off in 1950s with the use of mass radiography to identify tuberculosis in adults and the application of ferric chloride solutions to detect phenylketonuria—a rare metabolic, genetic disorder—in newborns.¹ Today, the National Health Service (NHS) offers screening for a range of conditions and diseases covering all life stages, from antenatal and newborn screening through to adulthood. Each year approximately 11 million people in England are invited to participate in a screening programme² at a total annual cost of around £348 million for the breast³, cervical⁴ and bowel⁵ cancer screening programmes, with an additional £400 million spent on a suite of non-cancer screening programmes.⁶ NHS programmes are characterised by the commitment to guide individuals through each stage of the process, from the test through to referral, further investigations, and treatment for those who require it.⁷

3. Although screening has been described as an “admirable method of combating disease”, debate and disagreement about its practice has never been far away.⁸ Over 45 years ago, following controversies about cervical screening, the World Health Organization commissioned James Wilson (Ministry of Health, London) and Gunner Jungner (Sahlgren's Hospital, Sweden) to set out “the principles and practice of screening for disease in a clear and simple way”.⁹ According to Wilson and Jungner, applying the theory underpinning screening was “far from simple” since it required a delicate balance to be struck between “bringing to treatment those with previously undetected disease and [...] avoiding harm to those persons not in need of treatment”.¹⁰ Such harms include receiving a false positive or false negative result; adverse psychological and behavioural effects; negative impacts on employment and insurance premiums; and over-diagnosis, whereby

¹ Walter Holland and Susie Stewart, *Screening in disease prevention: what works?* (London, 2005), p 1

² Public Health England & NHS England, [Immunisation & Screening National Delivery Framework & Local Operating Model](#), (May 2013), para 1.2.1

³ Public Health England, [How much does the breast screening programme cost?](#), accessed 8 July 2014

⁴ Public Health England, [About cervical Screening: how much does the programme cost and how is it funded?](#), accessed 8 July 2014

⁵ Public Health England, [How much does bowel screening cost?](#), accessed 8 July 2014

⁶ UK National Screening Committee & NHS Screening Programmes, [Annual Report: Screening in England 2011-2012](#), p 10

⁷ NHS0040 [Public Health England], para 2.3

⁸ James Maxwell Glover Wilson and Gunner Jungner, *Principles and Practice of Screening for Disease* (Geneva, World Health Organization, 1968), p 7

⁹ James Maxwell Glover Wilson and Gunner Jungner, *Principles and Practice of Screening for Disease* (Geneva, World Health Organization, 1968), p 7

¹⁰ James Maxwell Glover Wilson and Gunner Jungner, *Principles and Practice of Screening for Disease* (Geneva, World Health Organization, 1968), p 26

abnormalities are identified that would not have become clinically apparent, or caused harm, in the individual's lifetime.¹¹

4. Wilson and Jungner's treatise explaining the complexities of this "deceptively easy"¹² field helped shape the governance and practice of screening across the world.¹³ However, the tension between maximising benefit and minimising harm, identified by the authors in 1968, has persisted throughout the intervening years, most recently in the context of screening for breast cancer.¹⁴ Calls for health screening to be expanded to cover other conditions, on the basis that more people could benefit, have consequently been challenged by those who question the efficacy of existing programmes, the evidence upon which they are based, and the risks they may pose to participants. We therefore decided to conduct a wide-ranging inquiry examining how evidence is used as a base for national health screening programmes, with a particular focus on how effectively the risks and benefits of screening are communicated to the public.

Our inquiry

5. On 17 December 2013, we announced our inquiry on *National Health Screening* and sought written submissions addressing the following points:

- a) What evidence are the national health screening programmes based on, and how regularly is the evidence base reviewed?
- b) Could the evidence base and sources of scientific advice to Government on health screening be improved? If so, how?
- c) How effectively are the potential risks and benefits of health screening communicated to and understood by the public?
- d) How does health screening provided in the UK through the NHS compare with that offered by other countries?

We received 50 written submissions and took oral evidence from 19 witnesses including:

- Academics with expertise in screening and novel screening technologies;
- Representatives from expert medical bodies;
- Patient advocacy groups;

¹¹ Council of Europe Committee of Ministers, [Recommendation No.R \(94\) 11](#) of the Committee of Ministers to Member States on Screening as a Tool of Preventative Medicine.

¹² James Maxwell Glover Wilson and Gunner Jungner, *Principles and Practice of Screening for Disease* (Geneva, World Health Organization, 1968), p 26:

¹³ NHS0013 [Climb]

¹⁴ See, for example: Harald Weedon-Fekjær, Pål R Romundstad and Lars J Vatten, "[Modern mammography screening and breast cancer mortality: population study](#)", *British Medical Journal*, 17 June 2014, BMJ 2014;348:g3701; Anthony B Miller, Claus Wall, Cornelia J Baines, Ping Sun, Teresa To, Steven A Narod, "[Twenty five year follow-up for breast cancer incidence and mortality of the Canadian National Breast Screening Study: randomised screening trial](#)", *British Medical Journal*, 11 February 2014, BMJ 2014;348:g366

- Officials from Public Health England, Public Health Wales, and the UK National Screening Committee;
- The Government, represented by Jane Ellison MP, Parliamentary Under-Secretary of State for Public Health (hereafter “the Minister”) and Professor David Walker, deputy Chief Medical Officer for England, Department of Health and Chair of the UK National Screening Committee.

We would like to thank everyone who contributed to the inquiry.

6. This report focuses primarily on those antenatal, newborn and adult screening programmes that are delivered free of charge by the NHS. Background information on screening in the UK is presented in Chapter 2, while Chapter 3 examines how the evidence base for a screening programme is reviewed and considers if a robust, formal procedure is in place. Chapter 4 looks at how the risks and benefits of screening are communicated, with a particular focus on the design and delivery of public information materials, as well as the use of statistics. Finally, Chapter 5 considers the governance and status of the UK National Screening Committee (UK NSC) and its role in providing policy advice on screening to health Ministers. During the course of our inquiry, the UK NSC announced an independent review of its role, terms of reference and membership to be conducted by a working group comprised of screening experts, including the Chair of the UK NSC. This report therefore identifies matters for the independent review to consider alongside its own findings.

2 Background

National health screening in the UK

7. The process of devolution has effectively created, in administrative terms, four National Health Services within the NHS and provided the National Assembly for Wales, the Scottish Government, and the Northern Ireland Assembly with greater power over health services and public health in their territories.¹⁵ Despite this devolved structure, policy recommendations on screening programmes are made at a UK-wide level by the UK National Screening Committee (UK NSC). Established in 1996, the UK NSC's remit is to “call on sound evidence to inform its advice and recommendations” to Ministers and the NHS in the four UK administrations about all aspects of health screening.¹⁶ This includes evaluating:

- a) “The case for implementing new population screening programmes not presently provided by the NHS within each of the countries in the UK;
- b) Screening technologies of proven effectiveness but which require controlled and well-managed introduction;
- c) The case for continuing, modifying or withdrawing existing population screening programmes. In particular, programmes inadequately evaluated or of doubtful effectiveness, quality, or value; and
- d) Generic issues relating to screening programmes and policy”.¹⁷

The UK NSC is chaired by Professor David Walker, the Deputy Chief Medical Officer for England. Each screening programme also has an advisory committee or group that examines the performance of the programme, suggests improvements or developments, and produces reports for Ministers and the UK NSC.¹⁸

From local to national oversight

8. Prior to 1996, UK-wide screening policy covered: breast and cervical cancer in women; phenylketonuria, congenital hypothyroidism and the physical examination of newborns; and testing for HIV antibodies in all women receiving antenatal care. Individual Health Authorities (as they were then known) also took decisions to introduce screening programmes for additional diseases and conditions “for the benefit of their local populations” and each had its own arrangements and protocols.¹⁹ Speaking in 1994, the

¹⁵ Parliament passed 3 devolution Acts: the *Scotland Act 1998*; the *Northern Ireland Act 1998*; and the *Government of Wales Act 1998*

¹⁶ UK National Screening Committee, '[About Us](#)', accessed 7 July 2014

¹⁷ UK National Screening Committee, '[About Us](#)', accessed 7 July 2014

¹⁸ Public Health England and NHS England, [Immunisation & Screening National Delivery Framework & Local Operating Model](#), (May 2013), para 2.2.4

¹⁹ UK National Screening Committee, *First Report of the National Screening Committee*, (April 1998), p 39

former Chief Medical Officer, and first UK NSC Chair, Sir Kenneth Calman, expressed concern that, in the absence of national co-ordination, different “screening tests” had been implemented across the NHS in an “ad-hoc fashion” and “without the basis of solid research evidence, leading to variations in local practice”.²⁰

9. The establishment of the UK NSC was intended to move screening policy away from a localised, piecemeal approach: in its first annual report, the UK NSC stated that “no further screening programmes should be introduced except where high quality research is used to demonstrate clinical effectiveness”.²¹ Between 1996 and 2014, the UK NSC made over 100 policy recommendations and began a process of bringing the management and organisation of screening under national control. This included providing support for the implementation of its recommendations and, in England, overseeing the introduction, and monitoring the effectiveness and quality, of the non-cancer screening programmes.²² Responsibility for delivering programmes relating to cancer rests with the NHS Cancer Screening Programmes.²³ Table 1 outlines the screening programmes currently recommended by the UK NSC and offered across the UK. Under the NHS Constitution for England, the NHS has committed “to provide screening programmes as recommended by the UK National Screening Committee”.²⁴

Table 1: Overview of the screening programmes currently offered across the UK²⁵

	England	Northern Ireland	Scotland	Wales
Antenatal & newborn				
Down’s syndrome	Yes	No	Yes	Yes*
Fetal anomaly ultrasound scan	Yes	Yes*	Yes	Yes
Infectious diseases in pregnancy	Yes	Yes	Yes	Yes
Antenatal Sickle Cell and Thalassaemia	Yes	No	Yes	Yes
Newborn and Infant Physical Examination	Yes	Yes	Yes	Yes
Newborn Blood Spot	Yes	Yes*	Yes	Yes*
Newborn Hearing Screening	Yes	Yes	Yes	Yes
Young person & adult				
Abdominal Aortic Aneurysm	Yes	No**	No**	Yes
Diabetic Retinopathy	Yes	Yes	Yes	Yes
Breast Cancer	Yes	Yes	Yes	Yes
Cervical Cancer	Yes	Yes	Yes	Yes
Bowel cancer	Yes	Yes	Yes	Yes

* There are some variations in what is offered by these programmes in each country.

** These programmes are currently in preparatory stages.

²⁰ R Smith, “Government revamps screening policy”, *British Medical Journal*, 5 February 1994, BMJ1994;308:357

²¹ UK National Screening Committee, *First Report of the National Screening Committee*, (April 1998), p 39

²² NHS0040 [Public Health England]

²³ NHS Cancer Screening Programmes, ‘[Homepage](#)’, accessed 2 September 2014

²⁴ Department of Health, *The NHS Constitution for England*, (March 2013), p 8

²⁵ UK National Screening Committee, ‘[Programmes](#)’, accessed 15 August 2014 (table last updated June 2012)

10. Warwick Medical School²⁶ reported that in “only two other countries” (the Netherlands and New Zealand) do screening organisations like the UK NSC have “national responsibility to make and oversee the implementation of screening decisions for all their citizens”.²⁷ Dr Sian Taylor-Phillips, Warwick Medical School, added that screening in the UK is “very well respected internationally”, with other countries looking “to the National Screening Committee processes to inform their own processes”.²⁸ Several witnesses expressed their support for screening delivered via the NHS and nationally managed and quality assured by the UK NSC. The Royal College of Radiologists stated that “NHS-funded screening” provided “a controlled and accessible package available to all”, something that, according to the Academy of Medical Sciences, “few countries achieve”, while the PHG Foundation suggested that this “controlled” approach also helped to ensure “structure and consistency” in UK screening.²⁹

11. Some witnesses, however, told us that the UK NSC’s role inhibited the implementation of new screening programmes. Owen Sharp, Prostate Cancer UK, described the UK NSC as presenting a “barrier” that a screening programme had “to get over” before it could be implemented while Children Living with Inherited Metabolic Diseases (Climb) questioned if the UK NSC was, in fact, “a world-leader at assessing the evidence” since it did not take “the opportunity to screen for many more metabolic diseases”.³⁰ Other witnesses indicated that, despite the establishment of the UK NSC and its focus on evidence-based screening, it may be “politically difficult” to stop a screening programme in response to new evidence about its effectiveness.³¹ Professor Susan Bewley, King’s College, London, stated that the breast cancer screening programme—established in 1988, prior to the creation of the UK NSC—was “supported by political, rather than medical, imperatives”³² while others indicated that screening had become, and remains, a very “emotive” issue.³³

12. 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.

²⁶ Evidence was jointly submitted by four academics from Warwick Medical School: Ms Farah Seedat, Dr Saverio Stranges, Dr Ngianga-Bakwin Kandala and Dr Sian Taylor-Phillips

²⁷ NHS0025 [Warwick Medical School, University of Warwick] para 7

²⁸ Q4 [Dr Taylor-Phillips]

²⁹ NHS0007 [The Royal College of Radiologists]; NHS0018 [Academy of Medical Sciences] para 21; NHS0034 [PHG Foundation] para 2.8

³⁰ Q169 [Owen Sharp]; NHS0013 [Climb]; see also NHS0026 [Muscular Dystrophy Campaign]

³¹ NHS0029 [Institute of Biomedical Science] para 2

³² NHS008 [Professor Bewley] para 7

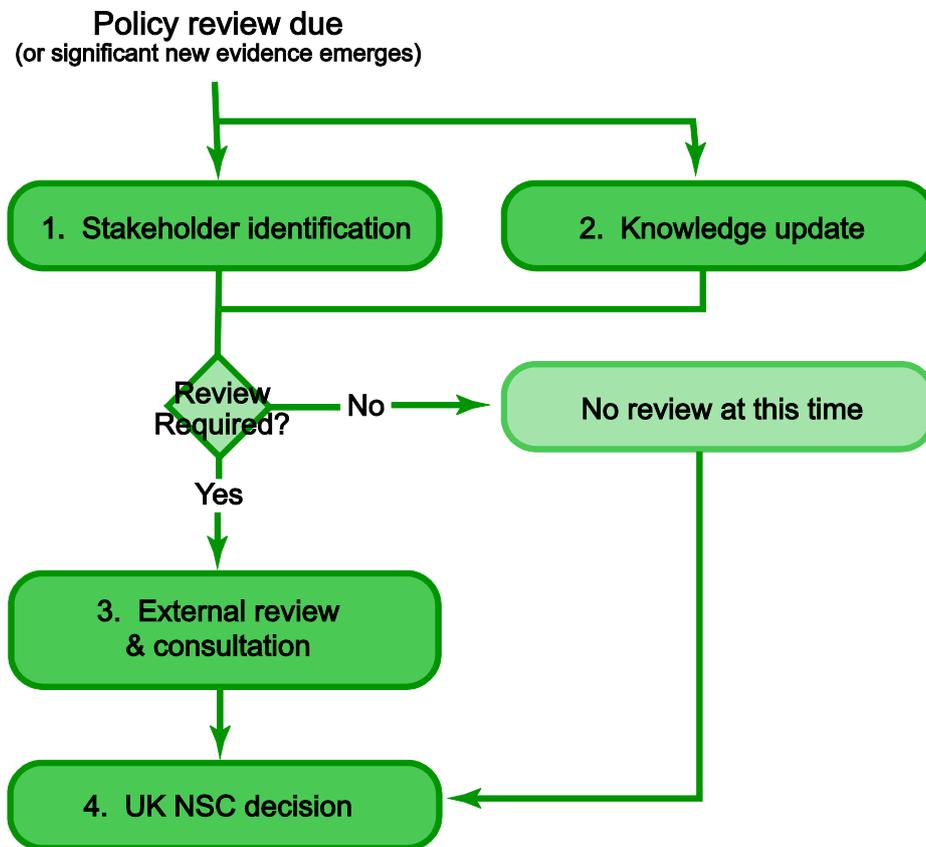
³³ NHS0013 [Climb]; NHS0025 [Warwick Medical School]; NHS0029 [Institute of Biomedical Science] para 3

3 Reviewing the evidence base

The evidence review process

13. Before a new screening programme can be introduced, it must first go through the UK National Screening Committee's (UK NSC) evidence review process. Figure 1 sets out the process and the four main steps. The purpose, according to Dr Anne Mackie, Director of Programmes, UK NSC, is to decipher whether a screening programme is "likely to do more good than harm at [a] reasonable cost".³⁴ This chapter examines what may trigger a policy review, and the UK NSC's approach to evaluating the evidence base for screening programmes, through a discussion of each stage of the process.

Figure 1: UK National Screening Committee policy review flow chart³⁵



Triggering a policy review

14. Figure 1 identifies two triggers for a policy review. For those screening programmes that have previously been the subject of a review and are already "on the books",³⁶ witnesses indicated that subsequent reviews will normally be conducted on a three to four

³⁴ Q202; NHS0040 [Public Health England] para 3.2

³⁵ UK National Screening Committee, 'Policy Review Process', accessed 11 July 2014

³⁶ Q6

year cyclical basis.³⁷ A scheduled review date, however, may be brought forward: Professor Jane Wardle, Academy of Medical Sciences, drew attention to the more “ad-hoc” nature of some reviews, noting that the “appearance of new evidence, trials or suggestions” may prompt the UK NSC to examine a policy recommendation earlier than originally planned.

15. The vast majority of policy reviews focus on whether a recommendation should be made to implement a proposed screening programme. However, the UK NSC also reviews existing programmes and considers if their delivery requires any amendments (for example altering the frequency at which people are invited to attend for screening) or if there are grounds for the programme to be withdrawn. Despite this regular review process, inconsistencies can emerge. Public Health Wales (PHW) told us that changes to the “age range and frequency” of cervical screening in England were implemented without the UK NSC first reviewing the programme and making such a recommendation.³⁸ Moreover, PHW noted that the changes in England did not prompt the UK NSC to initiate a review of cervical screening or provide advice to Wales, Northern Ireland and Scotland as to whether they should follow suit.³⁹ According to PHW, “the UK NSC did not examine the evidence for the age range and frequency of cervical screening until 2012, nine years after the English NHSCSP [NHS Cervical Screening Programme] had changed its policy”.⁴⁰ As well as producing differences in the delivery of programmes across the UK, PHW indicated that since “Welsh Government Policy is based on UK NSC advice” the absence of that advice “can lead to uncertainty”.⁴¹

16. Dr Anne Mackie, Director of Programmes, UK NSC, clarified that this particular scenario had occurred because:

cancer screening programmes in England are overseen by a different set of structures⁴², and they have got together some expert advisory committees that have been looking at and continue to look at how they can best improve the programmes. The English committee looked at changing the starting age of cervix screening to 25 quite a long time ago, based on evidence relating to the English population.⁴³

Whether changes to the delivery of a programme in one country should trigger a UK NSC policy review has, according to Dr Mackie, been resolved: “now, any big change in one of the existing cancer screening programmes or in other programmes [...] we would look to bring to the UK NSC”.⁴⁴

³⁷ Q6; NHS0017 [British Association of Urological Surgeons] para 4; NHS0026 [Muscular Dystrophy Campaign] para 7

³⁸ NHS0048 [Public Health Wales]

³⁹ NHS0048 [Public Health Wales]

⁴⁰ NHS0048 [Public Health Wales]

⁴¹ NHS0048 [Public Health Wales]

⁴² See paragraph 9

⁴³ Q219 [Dr Mackie]

⁴⁴ Q220

17. 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.

18. *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.*

Stage 1: Stakeholder identification

19. In some instances an evidence review may be prompted by a request from a stakeholder group. Dr Sian Taylor-Phillips, Warwick Medical School, stated that the UK NSC “say that they will review anything that a significant stakeholder—that is, a stakeholder representing a significant community of people—recommends and can provide a case that it might meet the NSC criteria”.⁴⁵ According to the UK NSC, the stakeholder identification process is “based on the Single Technology Appraisal process guide” developed by the National Institute for Health and Care Excellence (NICE).⁴⁶ Professor David Walker, Chair, UK NSC, told us that the Committee has “a whole range of stakeholders, [...] clinicians, patient groups, charities and [...] Members of Parliament”, any one of which can “ask us to look at any programme at any time”.⁴⁷

20. The Government stated that stakeholders were “involved at every stage” of the UK NSC policy review process while Public Health England (PHE) identified stakeholders as having a particular role during the external review and consultation stage when a detailed, draft report on screening for the condition being considered is shared with “expert stakeholders and the public to consult on for a period of three months”.⁴⁸ According to the UK NSC, the draft report is also made available on its website so that “anyone, including individuals or groups not previously identified as stakeholders” can “provide their feedback”.⁴⁹ Cancer Research UK stated that, in its experience, this process had “been robust and allowed for external input from a range of different stakeholders”.⁵⁰

⁴⁵ Q6

⁴⁶ UK National Screening Committee, ‘[Policy Review Process](#)’, accessed 11 July 2014

⁴⁷ Q301 [Professor Walker]

⁴⁸ NHS0053 [Department of Health]; NHS0040 [Public Health England] para 3.1

⁴⁹ UK National Screening Committee, ‘[Policy Review Process](#)’, accessed 11 July 2014; the UK NSC also issued “interim stakeholder guidance” on its website in February 2014 in advance of updated guidance being published.

⁵⁰ NHS0035 [Cancer Research UK] para 3.7

21. However, patient advocacy groups for newborn screening reported a different experience. Children Living with Inherited Metabolic Diseases (Climb) stated that “patient organisations should be equal and active partners in the health screening decision making processes”, but went on to identify “a distinct reluctance on behalf of the UK NSC to incorporate specialist patient group involvement within their structure” and considered the UK NSC’s engagement with stakeholders to be “at best lackadaisical in this area”.⁵¹ The Save Babies Through Screening Foundation UK stated that the UK NSC’s “existing stakeholder list and [...] method of consultation with stakeholders [was] quite poor”.⁵² The Foundation added that while the ability of stakeholders to request that a policy review take place “may appear to be involving and engaging, [...] very few can attempt the process without the support and time investment of health professionals”.⁵³

22. 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.

Stages 2 and 3: Knowledge update / External review and consultation

23. The second stage of the policy review process—the knowledge update—is used to determine whether a full, external review of a particular screening policy is required. According to Dr Sian Taylor-Phillips, Warwick Medical School, it is a “smaller review where they look at, ‘Is there any big new evidence in this area? Is this going to be a really interesting and important topic?’”⁵⁴ If a further, external review is deemed necessary, Dr Taylor-Phillips suggested that the UK NSC “might farm [it] out to a university” to conduct.⁵⁵ This is broadly in line with the information provided on the UK NSC’s website which states that external reviews are “carried out by a recognised national expert or academic institution in the field, as identified by the UK NSC Director of Programmes”.⁵⁶

24. Group B Strep Support (GBSS) pointed to differences between the theory and practice of conducting evidence reviews of screening programmes. A systematic review of the policymaking processes applied to formulate advice on health screening decisions,

⁵¹ NHS0013 [Climb]

⁵² NHS006 [Save Babies Through Screening Foundation UK] para 18

⁵³ NHS006 [Save Babies Through Screening Foundation UK] para 9

⁵⁴ Q6

⁵⁵ Q6

⁵⁶ UK National Screening Committee, [‘Policy Review Process’](#), accessed 11 July 2014

conducted by academics at Warwick Medical School, found that the UK “was like most other countries” in using “systematic reviewing to synthesise evidence”.⁵⁷ This, however, had not been the experience of GBSS: they told us that antenatal screening for Group B Streptococcus “was not carried out as a systematic review” and that this had been “confirmed” to them “in writing by the [UK] NSC”.⁵⁸ While not commenting on this specific example, Dr Anne Mackie, Director of Programmes, UK NSC, clarified that, in general, the evidence “is brought together by a variety of external organisations” during an external review, adding that “some of that is done in a systematic reviewing way, and some in a literature synthesis way”.⁵⁹ Literature synthesis differs from a systematic review in several ways. A systematic review typically involves a detailed, replicable search strategy that aims to identify, appraise and summarise all relevant studies (usually primary research) on a particular topic. Literature synthesis, in contrast, tends not to rely on a systematic search of the literature but focuses on a subset of studies on the topic area, usually based on availability or author selection.⁶⁰

25. The methods used to establish the quality of the evidence were a further point of contention. Warwick Medical School noted that “some countries” use “standardised procedures for appraising the quality of evidence for the evidence review”⁶¹: the US Preventative Services Task Force⁶², for example, assesses “the quality of individual studies using objective criteria”⁶³ while other countries use the methods of *GRADE* (Grading of Recommendations Assessment, Development and Evaluation).⁶⁴ However, Warwick Medical School stated that, in the UK, the steps were “tailored to each review”⁶⁵: according to Dr Anne Mackie, Director of Programmes, UK NSC, “the reviewers are expert at saying what the quality of the evidence is” and “only bring together good quality, peer-reviewed evidence” as part of the external review.⁶⁶ HealthWatch⁶⁷ told us that “the quality of evidence available should be subject to greater scrutiny” and suggested that “Cochrane Library systematic reviews” represented “the best available source of quality unbiased information”.⁶⁸

⁵⁷ NHS0025 [Warwick Medical School, University of Warwick] para 9

⁵⁸ NHS0027 [Group B Strep Support]

⁵⁹ Q196

⁶⁰ Pippa Hemingway, Nic Brereton, [What is a systematic review?](#), April 2009

⁶¹ NHS0025 [Warwick Medical School, University of Warwick] para 10

⁶² The US Preventative Services Task Force is an independent panel of experts convened to develop evidence-based recommendations for clinicians about preventative services in primary health care, including screening.

⁶³ David Atkins, “First new screening recommendations from the third US Preventative Services Task Force”, *BMJ USA*, vol 1 (2001), pp187-190

⁶⁴ NHS0025 [Warwick Medical School, University of Warwick] para 10

⁶⁵ NHS0025 [Warwick Medical School, University of Warwick] para 9

⁶⁶ Q196

⁶⁷ HealthWatch describes itself as a UK charity which promotes evidence-based medicine. On its website, it states that it has “no connection” to Healthwatch England.

⁶⁸ NHS0037 [HealthWatch]. Cochrane Reviews are systematic reviews of research in healthcare and health policy that are published in the Cochrane Database of Systematic Reviews. Cochrane systematic reviews follow the protocol set out in the “Cochrane Handbook for Systematic Reviews of Interventions”.

26. GBSS expressed further concerns about the way that the Group B Streptococcus external review had been reported and noted that it did not meet the “PRISMA checklist requirements”.⁶⁹ Warwick Medical School acknowledged that it had not evaluated the “usefulness” of making changes to the methods the UK currently uses when “synthesising the evidence for screening programmes” and suggested tools like GRADE and PRISMA would “need to be carefully evaluated for their applicability in the UK context”.⁷⁰ In her 2013 Annual Report, the Chief Medical Officer for England, Dame Sally Davies, identified the characteristics of “robust reviews”, stating that they should:

use specific research questions, systematic search strategies, strict inclusion criteria, weighted analysis of included studies according to the hierarchy of evidence, a meta-analysis (or at the very least an attempt to quantify effect sizes) and a frank discussion of any inherent biases in the review.⁷¹

In the same report, Dame Sally went on to highlight the “PRISMA statement” and the “Cochrane Collaboration” as two of the “commonly accepted methods for the production of unbiased and transparent reviews”.⁷²

27. 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.

Criteria for appraising the viability, effectiveness and appropriateness of a screening programme

28. When conducting an external review, the UK NSC stipulates that the reviewer(s) must consider the evidence base against its twenty-two criteria for assessing a new programme and, in the resulting report, state whether the proposed programme meets each of those criteria (see Annex).⁷³ Researchers from Warwick Medical School described this approach as standard, with “most countries assess[ing] the evidence collected against health screening criteria”.⁷⁴ The criteria cover the condition, the test, the treatment options and the effectiveness and acceptability of the screening programme. According to the UK NSC’s first annual report, they are based on Wilson and Jungner’s “classic criteria” first

⁶⁹ NHS0027 [Group B Strep Support]. PRISMA stands for “Preferred Reporting Items for Systematic Reviews and Meta-Analyses” and is a process endorsed by a number of clinical journals, including the *British Medical Journal* and the *Lancet*, see PRISMA, ‘[Endorsing PRISMA](#)’, accessed 16 July 2014

⁷⁰ NHS0025 [Warwick Medical School, University of Warwick] para

⁷¹ Sally C Davies, Nisha Mehta, ‘Public mental health: evidence based priorities’ [Annual Report of the Chief Medical Officer 2013 Public Mental Health Priorities: Investing in the Evidence](#), Department of Health, (September 2014), p44

⁷² Sally C Davies, Nisha Mehta, ‘Public mental health: evidence based priorities’ [Annual Report of the Chief Medical Officer 2013 Public Mental Health Priorities: Investing in the Evidence](#), Department of Health, (September 2014), p48

⁷³ UK National Screening Committee, ‘[Policy Review Process](#)’, accessed 11 July 2014

⁷⁴ NHS0025 [Warwick Medical School, University of Warwick] para 13

published in 1968 to guide the selection of conditions that would be suitable for screening.⁷⁵

29. There were divergent views as to whether the UK NSC's criteria remained fit for purpose. Professor Michael Baum, Advocates for Honesty and Transparency in Breast Screening, noted that the criteria had “stood the test of time” but was open to taking “a fresh look at them” while HealthWatch stated that criteria “remain valid to this day” and urged “their continued use”.⁷⁶ The PHG Foundation, however, stated that the UK NSC criteria were developed in the context of “the big common conditions such as breast cancer and cervical cancer” and questioned their suitability for appraising new genetic screening programmes.⁷⁷ According to the PHG Foundation, proposals for genetic screening programmes “bring complexities to the underlying evidence base” and raise “a breadth of ethical, legal and social” considerations, including questions about “informed consent, informed choice and safeguarding autonomy”.⁷⁸ The PHG Foundation therefore recommended that there should be “a review of the suitability of the screening criteria for rare inherited and other genetic conditions” and also suggested “setting up a standing group” to advise on the “ethical, legal and social issues” raised by individual proposals.⁷⁹ Dr Anne Mackie, Director of Programmes, UK NSC, was open to these suggestions and said that both points were being considered as part of “the current UK NSC consultation”.⁸⁰

30. The need for additional clarity regarding how the criteria are evaluated and interpreted was also raised during the inquiry. Cancer Research UK identified the criteria as an “area of concern” on the grounds that they “can be difficult to interpret” and “can lead to controversy”.⁸¹ It singled out item 15 from the UK NSC criteria (that the benefit from the screening programme should outweigh the physical and psychological harm) as posing distinct difficulties, stating that “the magnitude of benefits and harms can be quite difficult to define, and compare, in practice”.⁸² Jessica Kirby, Cancer Research UK, told the Committee that while the criteria were asking the right questions, “it can be difficult sometimes to provide an objective and very clear answer to some of them”.⁸³ For example, there was disagreement as to how the benefits of screening should be measured. Professor Susan Bewley, King's College London, stated that “the proper test of these screening programmes is [reducing] ‘all-cause death’” but Professor Jane Wardle, Academy of Medical Sciences, stated that “it would be impossible to argue that our outcome on the

⁷⁵ UK National Screening Committee, *First Report of the National Screening Committee*, (April 1998), p 27.

⁷⁶ Q80; NHS0037 [HealthWatch] para 5

⁷⁷ Q170 [Dr Burton]; NHS0034 [PHG Foundation] para 2.9

⁷⁸ NHS0034 [PHG Foundation] para 4.3(viii)

⁷⁹ NHS0034 [PHG Foundation] para 4.5

⁸⁰ Q227

⁸¹ NHS0035 [Cancer Research UK] para 4.3

⁸² NHS0035 [Cancer Research UK] para 4.3

⁸³ Q9 [Jessica Kirby]

positive side should be all-cause mortality, just because of the practical difficulty—nay, impossibility—of asking that kind of question”.⁸⁴

31. To improve the overall transparency of the evidence review process Warwick Medical School noted that adding “statements explicitly onto the UK criteria” could clarify the “deliberations and evidence taken into account” by the UK NSC “when judging screening programmes”.⁸⁵ It went on to suggest that the UK NSC “consider uploading a detailed manual on the UK NSC website, detailing how they collect and assess evidence in the policymaking process”.⁸⁶ Jessica Kirby, Cancer Research UK, agreed, adding that the UK NSC could “provide a bit of guidance around how evidence will be used and interpreted within the context of some of the criteria”.⁸⁷

32. This type of guidance has previously been available: the *NSC Handbook of Population Screening Programmes* (“the Handbook”) was first published in 1998 and outlined the “questions that it [the UK NSC] requires [to be] answered when considering a screening programme”.⁸⁸ The Handbook stated that the answers to the questions could be compared to the UK NSC’s criteria and that this would “enable an objective assessment to be made on the balance of benefit to harm to cost for any particular programme”.⁸⁹ The expectation, as stated at the front of the Handbook, was that it would “be updated on at least an annual basis”.⁹⁰ When asked why the Handbook had not been updated and was not available on the UK NSC’s website, Dr Anne Mackie, Director of Programmes, UK NSC, replied that “1998 is an awfully long time ago, and things move on”⁹¹, adding that the UK NSC has “a methods process in development” that describes “fairly carefully how we go about our process”.⁹²

33. 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.

34. 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

⁸⁴ NHS008 [Professor Bewley] para 6; Q18

⁸⁵ NHS0025 [Warwick Medical School, University of Warwick] para 14

⁸⁶ NHS0025 [Warwick Medical School, University of Warwick]

⁸⁷ Q9 [Jessica Kirby]

⁸⁸ UK National Screening Committee, *First Report of the National Screening Committee*, (April 1998), p 30

⁸⁹ UK National Screening Committee, *First Report of the National Screening Committee*, (April 1998), p 30

⁹⁰ UK National Screening Committee, *First Report of the National Screening Committee*, (April 1998), p 27

⁹¹ Q203

⁹² Q204

base against its twenty-two criteria. This should be made available on its website no later than March 2015.

Stage 4: UK National Screening Committee decision

35. The UK NSC meets three times a year to “review current decisions and make recommendations on screening practices”.⁹³ Though the minutes of each UK NSC meeting are published on its website,⁹⁴ it is not clear from these minutes what procedures are used by the UK NSC to ensure that its decisions are robustly and fairly reached. The guidance provided in the Government Office for Science *Code of Practice for Scientific Advisory Committees* (CoPSAC) suggests that Scientific Advisory Committees “should agree on the mechanisms by which the committee is to reach its final position or advice” and that “open and frank discussion should be encouraged”.⁹⁵

36. Dr Sian Taylor-Phillips, Warwick Medical School, told us that her “understanding of how it works in practice is that you would look at all of the NSC criteria, and for it to be implementable as a screening programme it would have to reach a certain level for every single criterion”.⁹⁶ However, when asked if the UK NSC combines and scores the criteria to reach a decision, Dr Anne Mackie, Director of Programmes, UK NSC, confirmed that it does “not score”.⁹⁷ According to the PHG Foundation, the “criteria are subjective; there are no clear cut-off points” and there is “frequently a need to trade-off between them”.⁹⁸ The preamble to a survey that forms part of the Independent Review of the UK National Screening Committee explained that scoring is not used because “not all the criteria can be tested by scientific enquiry and in some cases (comparative research for very rare diseases for example) cannot be fulfilled”. Instead, it states that the UK NSC “brings judgement to bear using the scientific literature, expertise, experience and the views of the public in making a recommendation”.⁹⁹

37. Jessica Kirby, Cancer Researcher UK, suggested that if there were “considerations” that the UK NSC was “using to make these judgments—then it would be good to have knowledge” of them.¹⁰⁰ When asked if, in the absence of “a scoring process”, the UK NSC’s decision was based on “subjective assessments”, Dr Mackie agreed that “inevitably, some bits of it will be so”.¹⁰¹ She added that this was why involving “as many people as possible” in the policy review process was important.¹⁰² The Minister told us that she had “no reason to think” that she was receiving anything other than consistent advice about screening via

⁹³ UK National Screening Committee, ‘[UK NSC Meetings & Minutes](#)’, accessed 19 August 2014

⁹⁴ UK National Screening Committee, ‘[UK NSC Meetings & Minutes](#)’, accessed 18 July 2014

⁹⁵ Government Office for Science, [Code of Practice for Scientific Advisory Committees](#), (November 2011), para 88. The UK NSC’s current use of CoPSAC is discussed in detail in Chapter 5.

⁹⁶ Q15 [Dr Taylor-Phillips]

⁹⁷ Q204

⁹⁸ NHS0034 [PHG Foundation] para 4.1

⁹⁹ Independent Review of the UK National Screening Committee, [Survey](#), (April 2014), p 2.

¹⁰⁰ Q11

¹⁰¹ Q202

¹⁰² Q202

the current policy review process but noted “the different contexts in which programmes are offered”.¹⁰³ The Minister went on to question if it was “possible to achieve perfect consistency because of the very different life stages and differently designed programmes, from the population adult programmes right down to the newborn”.¹⁰⁴

38. 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.*

Policy before evidence?

39. The UK National Screening Committee (UK NSC) is clear that there “should be evidence from high quality Randomised Controlled Trials (RCTs) that the screening programme is effective in reducing mortality or morbidity” before a systematic, population-based screening programme is introduced.¹⁰⁵ During the course of the inquiry, we were made aware of two programmes where screening policy appears to have been made, and in one instance implemented, in advance of data from RCTs becoming available.

NHS Health Check programme

40. The NHS Health Check programme was described by Public Health England (PHE) as a “national risk assessment, risk reduction and risk management programme”¹⁰⁶ that aims to help prevent heart disease, stroke, diabetes, kidney disease and certain types of dementia through inviting everyone between the ages of 40 and 74, who has not already been diagnosed with one of those conditions, to have a health check every 5 years to assess their risk.¹⁰⁷ Roll-out of the programme in England formally began in 2009. Under the *Local Authorities Regulations 2013*,¹⁰⁸ local authorities are mandated to offer a health check to every eligible person in their area, with PHE providing “oversight and implementation support”.¹⁰⁹ There is some evidence to indicate that the programme has had an impact on prescribing behaviour. A study examining the relationship between the uptake of the NHS Health Check Programme and the prescription of statins (medicines that can help lower

¹⁰³ Q297

¹⁰⁴ Q297

¹⁰⁵ UK National Screening Committee, [‘Programme appraisal criteria’](#), accessed 15 August 2014

¹⁰⁶ NHS0040 [Public Health England] Appendix 1 para 3

¹⁰⁷ NHS Health Checks, [‘Home page’](#), accessed 6 August 2014

¹⁰⁸ The Local Authorities (Public Health Functions and Entry to Premises by Local Healthwatch Representatives) Regulations 2013 (SI 2013/351)

¹⁰⁹ NHS0040 [Public Health England] Appendix 1 para 9

the level of low-density lipoprotein (LDL) cholesterol in the blood) found that 19.4% of patients with a high risk of cardiovascular disease (CVD)¹¹⁰ were prescribed statins before the introduction of the Health Check, while 43.1% of high risk patients were prescribed statins after the Health Check was introduced.¹¹¹ When asked about conflicting reports in the press regarding the safety of statins, Professor David Walker, Chair, UK NSC, pointed to “a scientific consensus that statins are valuable for people who are considered to be high risk” but acknowledged that there is a “serious debate at the moment” about “where that cut-off should be”.¹¹²

41. Several witnesses raised questions about the evidence base for the NHS Health Check programme. Professor Jane Wardle, Academy of Medical Sciences, told us that the programme was not “based on rigorous randomised controlled trial data”¹¹³ while Dr McCartney, a GP from Glasgow, stated that the programme was “launched without an evidence base”.¹¹⁴ The Academy of Medical Sciences also highlighted concerns about the evidence for systematic health checks in general. Pointing to the findings of the *Inter99* trial¹¹⁵ published in June 2014, the Academy noted that the trial found “no reduction in mortality from ischaemic heart disease, stroke or total mortality [...] in those who participated in the screening and lifestyle counselling, compared to the control population”.¹¹⁶ Professor Walker was clear that the Health Check programme had “not been through the NSC process” and that, because it was “was implemented through a different route”, the UK NSC had not conducted “the rigorous evidence review that [it] would normally do before implementation of this kind of programme”.¹¹⁷

42. A report published by PHE in July 2013 acknowledged that the NHS Health Check programme was “being implemented in the absence of direct randomised controlled trial evidence” but maintained that “the existing relevant evidence” provided “compelling support for the programme”.¹¹⁸ Speaking to the Health Committee about NHS Health Check in November 2013, Professor Kevin Fenton, Director, Health and Wellbeing, PHE, stated that PHE was “really committed to instilling evidence in the programme” and that “from 1 April [PHE] would ensure that science—evaluation and research—underpinned the evaluation of the programme”.¹¹⁹ When we asked if this meant the NHS Health Check programme had been implemented without conclusive evidence of its effectiveness, Jamie Waterall, National Lead NHS Health Check, stated that while there was “strong evidence

¹¹⁰ High risk was defined as “patients presenting with an elevated CVD risk factor, or at greater than or equal to 20% risk of developing CVD in the next 10 years”

¹¹¹ Macide Artac et al, “Uptake of the NHS Health Check programme in an urban setting”, *Family Practice* vol 30 (2013) pp 426-435

¹¹² Q285

¹¹³ Q49 [Professor Wardle]

¹¹⁴ NHS0004 [Dr Margaret McCartney] para 8

¹¹⁵ A large, Danish randomised controlled study into population screening and lifestyle intervention for cardiovascular risk factors.

¹¹⁶ NHS0050 [Academy of Medical Sciences]; see also Q147 [Dr Middleton]

¹¹⁷ Q246

¹¹⁸ Public Health England, ‘[NHS Health Check: our approach to the evidence](#)’, July 2013, paras 15 & 17

¹¹⁹ Health Committee, Eighth Report of Session 2013–14, ‘[Public Health England](#)’, HC 840, Q67

for individual risk factor management”, there was a need for “better evidence around treating them as a collective”.¹²⁰

43. The Minister told us that the Health Check programme was “proceeding on a reasonable evidence base” that would be “built on”, noting that results from two evaluations commissioned by the Department of Health would be available in the autumn.¹²¹ The Minister also stated that NHS Health Check “was not strictly a screening programme”; according to Professor David Walker, Chair, UK NSC it was “more of a vascular risk management programme than a screening programme”.¹²² Nonetheless it was his own “personal view” that “for every programme that looks like a screening programme it would be useful to put it through the [UK] NSC” process.¹²³ He was hopeful that this approach would be followed in the future.¹²⁴

44. 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.

Extending the breast cancer screening programme

45. All women who are registered with a GP and are aged 50-70 are currently sent an invitation every three years to attend for breast cancer screening. Public Health England told us that the NHS Breast Screening Programme was conducting a randomised control trial (RCT) on the screening of women aged 47-49 and 71-73 to examine whether “screening in the extended age ranges is effective or not”.¹²⁵ Cancer Research UK described RCTs as the “gold standard” of clinical evidence” while Breakthrough Breast Cancer and Breast Cancer Campaign stated that “facilitating robust research into the risks and benefits of screening older women [would] ultimately lead to an improved screening programme based on the best possible evidence”.¹²⁶ Witnesses, however, disagreed whether a decision had already been taken to extend the age range of the breast cancer screening programme prior to this “internationally important” RCT reporting its findings.¹²⁷ According to the Cancer Epidemiology Unit, University of Oxford (the “co-investigators” of the age

¹²⁰ Q200

¹²¹ Q248 [the Minister]

¹²² Q247 [the Minister, Professor Walker]

¹²³ Q247 [Professor Walker]

¹²⁴ Q247 [Professor Walker]

¹²⁵ NHS0040 [Public Health England] Appendix 3 para 11

¹²⁶ NHS0035 [Cancer Research UK] para 3.3; NHS0036 [Breakthrough Breast Cancer and Breast Cancer Campaign] para 3.1.5

¹²⁷ NHS0040 [Public Health England] para 3.8

extension trial), Government “policy is to extend the age range for routine screening of all women from 50-70 to 47-73 in 2016”; however, the Unit added that “reliable mortality results” from the trial were “not expected until the early 2020s”.¹²⁸ HealthWatch echoed these points, stating that the extended age range would “be implemented nationally in advance of [the RCT] being completed or the results being analysed”.¹²⁹

46. In contrast, Professor Walker, Chair, UK NSC, told us that:

we have not decided to implement the age extension, although we support the trial to see whether we should be implementing it. Once the trial is complete we will make a recommendation.¹³⁰

Writing in the *British Medical Journal*, Professor Susan Bewley, King’s College, London, stated that Professor Walker’s comments to us represented “a dramatic policy U-turn, as hitherto it has been the Government’s stated intention to extend”.¹³¹ In subsequent correspondence with Professor Bewley, Professor Walker clarified that his comments “were made on behalf of the UK NSC, not Government”, noting that “the UK NSC does not implement policy”. In the same letter, he added that, from a “Government perspective, Public Health England is responsible for funding the trial and say no final decision on the extension will be made until the trial results are known”.¹³² Professor Walker also pointed to the Government’s 2011 *Strategy for Cancer*, which, he said, “made clear that full roll-out to women aged 47-49 and 71-73 was expected to be completed after 2016”.¹³³

47. 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.

48. 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

¹²⁸ NHS0019 [Cancer Epidemiology Unit, University of Oxford] paras 3&4

¹²⁹ NHS0037 [HealthWatch] para 16

¹³⁰ Q283

¹³¹ Susan Bewley, Les Rose, “[Did the Deputy Chief Medical Officer mislead MPs about the breast screening age extension trial?](#)” *British Medical Journal* vol 349 (2014)

¹³² Correspondence from Professor David Walker, Deputy Chief Medical Officer for England to Professor Susan Bewley, King’s College, London, July 2014, <http://www.parliament.uk/business/committees/committees-a-z/commons-select/science-and-technology-committee/other-work/parliament-2010/general-correspondence/> accessed 15 September 2014

¹³³ Correspondence from Professor David Walker, Deputy Chief Medical Officer for England to Professor Susan Bewley, King’s College, London, July 2014, <http://www.parliament.uk/business/committees/committees-a-z/commons-select/science-and-technology-committee/other-work/parliament-2010/general-correspondence/> accessed 15 September 2014

recommend that the NHS Health Check programme be scrutinised by the UK National Screening Committee, retrospectively, to ascertain its value.

4 Communicating the risks and benefits of health screening

49. As Chapter 1 highlighted, screening—like any clinical intervention—has the potential to do harm as well as good. Exploring how effectively the possible risks and benefits of screening are communicated to, and understood by, the public formed a substantial part of this inquiry. Professor David Walker, Chair, UK National Screening Committee (UK NSC), identified “two big” communication “problems”: “one is what information we should be trying to pass on and what the messages are that we need to be giving. Secondly, how good are the processes for transmitting that information?”¹³⁴ This chapter examines the content of the message and its delivery. Particular consideration is given to where responsibility for communication lies and whether consistent communication across programmes is possible.

Public perceptions

50. Witnesses repeatedly told us that the overall public perception of screening was positive. In the case of cancer screening programmes, Professor Jane Wardle, Academy of Medical Sciences, suggested that “enthusiasm” for the programmes arose, “at least partly,” because they signalled that “something is being done [...] to help”.¹³⁵ According to Public Health England, the generally positive attitude towards screening can make it a “challenge” to explain to the public “that there is a balance of risk and benefit”.¹³⁶ Public Health Wales stated it had “found a resistance amongst [the public] to information regarding risks of screening”¹³⁷ adding that, in its opinion, the risks and benefits of screening remain “poorly understood by both professionals and the public, with benefits typically being over-estimated, and risks under-estimated”.¹³⁸ Other witnesses indicated that such positive perceptions of screening led to high, and perhaps unrealistic, expectations. According to Síle Lane, Sense about Science, the “expectations people have about screening are not matched by what screening programmes can deliver”.¹³⁹

Delivering information

51. There was some suggestion that, in the past, clinicians may have actively avoided publicly discussing, and documenting in public information materials, the possible risks of screening. Recounting his time as “a director of public health in a primary care trust”, Dr John Middleton, UK Faculty of Public Health, identified “the complicit idea”, which he and “many” of his “colleagues may have had”, that “if you tell people the whole truth,

¹³⁴ Q249 [Professor Walker]

¹³⁵ Q25 [Professor Wardle]

¹³⁶ NHS0040 [Public Health England] para 3.10

¹³⁷ NHS0048 [Public Health Wales]

¹³⁸ NHS0048 [Public Health Wales]

¹³⁹ Q104 [Síle Lane]; see also NHS0029 [Institute of Biomedical Science] para 3

getting them into the screening programme will somehow be jeopardised”.¹⁴⁰ He added that providing people with a “much more sophisticated, honest and open set of information” was necessary in order “to enable them to make informed choices”.¹⁴¹ The concept of “informed choice” was highlighted throughout the inquiry as the goal which information on screening should strive to achieve. Rather than encourage a “blanket promotion”¹⁴² of screening, witnesses explained that informed choice materials were designed to provide potential participants with “clear, unbiased information”¹⁴³ to enable them to “assess the offer of screening”¹⁴⁴ and decide “whether to accept or decline” it.¹⁴⁵ Recognising that choices may be influenced by personal circumstances and values, and that “some people will choose one particular set of risks compared with another”, Public Health England noted that informed choice materials should also make “it clear that not taking it [the screening test] may be a reasonable choice”.¹⁴⁶

52. Information on the risks and benefits of taking part in a screening programme is provided to potential participants via a number of routes and media. The method of delivery, and its timing, appears to be largely dependent on the programme in question and its point of engagement with the individual. As the Minister explained:

If you take the population cancer screening programmes, you have a very different communication challenge there from the programmes being offered to newborns. There, you have someone who is already very much in the health system and at a point where the messages are being discussed with clinicians. They are in a different setting from trying to bring people in for breast cancer screening.¹⁴⁷

In the case of bringing people into the health service for cancer screening, written evidence indicated a reliance on enclosing information materials, particularly leaflets, with the letter inviting the individual to attend.¹⁴⁸ In the case of newborn screening, by contrast, we received evidence that engagement with parents began during the antenatal period.¹⁴⁹ For example, Robert Meadowcroft, Muscular Dystrophy Campaign, told the Committee that there was “no reason why one would not start a dialogue at [the first antenatal visit] to make sure there is ongoing discussion about newborn screening and what it might mean for the parent”.¹⁵⁰ However, he added that, in the case of Duchenne muscular dystrophy, 82% of parents surveyed:

¹⁴⁰ Q98 [Dr Middleton]; see also Q55 [Professor Baum]; Q157 [Dr Burton]

¹⁴¹ Q98 [Dr Middleton]

¹⁴² NHS0049 [UK Faculty of Public Health] para 1.2.7

¹⁴³ UK National Screening Committee, *Annual Report. Screening in England 2011-12*, p 10

¹⁴⁴ NHS0040 [Public Health England] Appendix 3 para 13

¹⁴⁵ NHS0047 [Royal College of Midwives]

¹⁴⁶ Q108; NHS0040 [Public Health England]

¹⁴⁷ Q263 [the Minister]

¹⁴⁸ For example: NHS0036 [Breakthrough Breast Cancer and Breast Cancer Campaign] paras 4.2 & 4.3; NHS0003 [Elizabeth Dawson]; NHS0010 [Pamela Redding]

¹⁴⁹ Q54 [Steve Hannigan]; NHS0047 [Royal College of Midwives]

¹⁵⁰ Q57

would opt to go through screening [...] even though there is no effective treatment available. That is about planning. There are some families who have had two boys with Duchenne because the first boy was diagnosed only at four or five, and they have had a second son. In those situations it is about planning your home and the arrangements you need to cope with it, because somebody is going to become a wheelchair user, so there is that sense.¹⁵¹

53. Enabling informed choice is not a new approach. As early as 2000, the UK NSC stated that it had:

a responsibility to ensure that people who accept an invitation do so on the basis of informed choice, and appreciate that in accepting an invitation or participating in a programme to reduce their risk of a disease there is a risk of an adverse outcome.¹⁵²

Item 20 of the UK NSC criteria for appraising the viability, effectiveness and appropriateness of a screening programme also states that “evidence-based information, explaining the consequences of testing, investigation and treatment, should be made available to potential participants to assist them in making an informed choice”.¹⁵³ We were not, however, provided with a clear definition of “informed choice” or what it means to be “informed”. When asked how the Government defined informed choice, and how it measured if someone was informed enough to make a choice about screening, the Minister responded that it was “a challenge”.¹⁵⁴ Without a clear definition, or metrics, it will be difficult to know if people are making informed choices. The Academy of Medical Sciences noted that the UK NSC “does not provide information on [...] rates of informed choice for those offered the programmes they manage and there does not seem to be a systematic review of the topic available in the scientific literature”.¹⁵⁵

54. 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.

¹⁵¹ Q86 [Robert Meadowcroft]

¹⁵² UK National Screening Committee, *Second report of the UK National Screening Committee*, p 1

¹⁵³ UK National Screening Committee, [‘Programme appraisal criteria’](#), accessed 15 August 2014

¹⁵⁴ Q249 [the Minister]

¹⁵⁵ NHS0018 [Academy of Medical Sciences] para 15

Designing and producing information

55. Communications about screening for breast cancer have recently been overhauled. Jessica Kirby, Cancer Research UK, identified the revised leaflet on breast cancer screening as “probably the first example within the national screening programme of a piece of information material that is explicitly on informed choice”.¹⁵⁶ Several witnesses told us that they had been members of the “expert panel” that was involved in producing those “new resources” on breast cancer screening.¹⁵⁷ Capturing the full range of benefits and harms, and presenting them in a concise, accessible fashion was identified by witnesses as a one of the key challenges facing the panel. Professor Jane Wardle, Academy of Medical Sciences, described “a constant trade-off between giving people so much material that they would be overwhelmed by it and including all the caveats and information you wanted”.¹⁵⁸ Professor David Walker, Chair, UK NSC, agreed, adding:

The message that we got back was, “This doesn’t work. We need simpler messages.” We put together a leaflet with simpler messages, and the scientists then said, “Yes, but that’s not quite accurate. You’re not being fair. You are not informing people properly, because you haven’t told them all the nuances around that particular message”.¹⁵⁹

Explaining over-diagnosis was identified by Professor Wardle as particularly demanding. Recounting her experience of focus group work, she stated that the public “find it extraordinarily difficult to understand both how there could be a cancer that might not have done you harm, and how it could possibly be that, if there is such a thing, we do not already know”.¹⁶⁰

56. Noting that the leaflet development process “involved a citizens jury of women, [...] a public consultation with over 1,000 people and 50 professional groups”, Professor Walker was of the view that continually “involving all of our stakeholders, particularly [...] the people who are going to be using the services” was essential in order to make the leaflet “as good as we can”.¹⁶¹ Witnesses concurred that public and patient involvement in the production of all screening information materials was vital. Speaking in the context of newborn screening, Robert Meadowcroft, Muscular Dystrophy Campaign, suggested that patient groups “would have credibility in adding to information and making sure the language was accessible”.¹⁶²

57. Citing “early anecdotal” feedback, Cancer Research UK reported that the new information materials on breast cancer were “helping women appreciate the existence of

¹⁵⁶ Q35 [Jessica Kirby]

¹⁵⁷ NHS0036 [Breakthrough Breast Cancer and Breast Cancer Campaign] para 4.2; see also Q67; Q35 [Professor Wardle, Jessica Kirby]; King’s Health Partners - Informed Choice about Cancer Screening, [‘Information about NHS Cancer Screening Programmes Consultation Report’](#), December 2012

¹⁵⁸ Q35 [Professor Wardle]

¹⁵⁹ Q249 [Professor Walker]

¹⁶⁰ Q35 [Professor Wardle]

¹⁶¹ Q249 [Professor Walker]

¹⁶² Q63 [Robert Meadowcroft]; see also Q69 [Steve Hannigan]

benefits and risks” but raised concerns that there were “no public plans for the update or review of the [...] materials over time”.¹⁶³ Others disagreed that the new leaflet represented an improvement. Dr Margaret McCartney stated that the leaflet “still does not fully explain the hazards of false positive diagnosis, i.e. mastectomy and radiotherapy being given unnecessarily”¹⁶⁴ while Professor Susan Bewley, King’s College, London, commented that the “risks [of breast cancer screening] are not being communicated fairly”.¹⁶⁵

58. Our attention was also drawn to inconsistencies in the content and production of information materials, both within and across programmes. Sense About Science noted that NHS patient information on breast cancer screening for “those over the age of 70 [...] does not mention risks, false positives/negatives or overdiagnosis”.¹⁶⁶ Cancer Research UK suggested that “the overall positioning of NHS communications about screening [appeared] somewhat disjointed and inconsistent”, since the principles guiding the production of the breast cancer screening leaflet for the 50-70 age group had “not been applied to the information about all screening programmes, in all UK nations”.¹⁶⁷

59. Submissions to the inquiry also highlighted that the information needs of screening programme participants varied. The Academy of Medical Sciences noted that “some patients want simple messages, while others seek more comprehensive information” and questioned whether “routinely provided information” was “adequately meeting the needs of the less advantaged”.¹⁶⁸ Delivering “meaningful information [...] to groups with low levels of health literacy” was cited by Public Health Wales as posing a particular challenge, while the Royal National Institute of Blind People (RNIB) stated that “health information is not usually provided to blind and partially sighted people in a format that they can access”.¹⁶⁹ To cater for different information requirements, Cancer Research UK suggested providing information “at a number of levels of detail”, such as “a brief overview with options to move on to more in-depth explanations”.¹⁷⁰

60. Dr Anne Mackie, Director of Programmes, UK NSC, told us that “almost all of the leaflets” were “being updated in one way or another”, though it was not clear if the updates were following the same process used to revise the breast cancer screening leaflet.¹⁷¹ When asked if a set of best practice guidelines was being developed to direct the production of consistent materials across all screening programmes, Professor David Walker, Chair, UK NSC, replied that “it is done in each individual programme. We do not necessarily do that at a national level over all the programmes”.¹⁷² The Minister added that she did “not see”

¹⁶³ NHS0035 [Cancer Research UK] para 5.3 & 5.4

¹⁶⁴ NHS0004 [Dr Margaret McCartney] para 13

¹⁶⁵ NHS008 [Professor Bewley] para 21

¹⁶⁶ NHS00016 [Sense About Science] para 2.3

¹⁶⁷ NHS0035 [Cancer Research UK] para 5.4. However, Cancer Research UK did state that information materials on cervical cancer screening were updated through a similar process.

¹⁶⁸ NHS0018 [Academy of Medical Sciences] paras 19 & 16

¹⁶⁹ NHS0048 [Public Health Wales]; NHS0028 [Royal National Institute of Blind People] para 2.1

¹⁷⁰ NHS0035 [Cancer Research UK] para 5.7

¹⁷¹ Q231

¹⁷² Q259

what independent oversight across all the programmes “would bring” but stated that she was “open-minded about looking at it”.¹⁷³

61. 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.

62. 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.

63. 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.

Expressing the outcomes of screening: screening statistics

64. The statistics used to express the outcomes of screening to the public were a source of confusion and disagreement among witnesses. Concerns focused on the uncertainty surrounding the numbers needed to treat (NNT) to save a life from screening and the risk of “over-diagnosis”. Evidence relating to these concerns was put to us primarily in the context of screening for breast cancer. Professor Michael Baum, Advocates for Honesty and Transparency in Breast Screening, told us that the most recent leaflet on breast cancer screening claimed that “screening saves about 1 life from breast cancer for every 200 women who are screened. This adds up to 1,300 lives saved”.¹⁷⁴ Professor Baum stated that this figure was “based on mathematical models that are simply not true”.¹⁷⁵ Dr John Middleton, UK Faculty of Public Health, noted that he had seen “only 84” as the NNT to save one life “in an American journal”.¹⁷⁶ HealthWatch cited different figures from the “Cochrane Library website”¹⁷⁷ while Breakthrough Breast Cancer highlighted the Independent UK Panel on Breast Cancer Screening (“the Panel”) and its 2012 review of the *Benefits and Harms of Breast Cancer Screening* which, it stated, “was established to evaluate

¹⁷³ Q261

¹⁷⁴ Q56

¹⁷⁵ Q56

¹⁷⁶ Q123

¹⁷⁷ NHS0037 [HealthWatch] para 9

the available evidence” and provide “an up-to-date estimate of the likely benefits and risks associated with routine screening”.¹⁷⁸

65. According to the Panel, variation between estimates arises from “the age of women screened and the durations of screening and follow-up”.¹⁷⁹ The Panel also noted that differing views of the evidence had arisen, in part, “from disagreements over the validity and applicability of the available randomised controlled trials of breast screening, and from questions about the usefulness and interpretation of observational data on breast cancer incidence and mortality”.¹⁸⁰ The Panel assessed that 1 breast cancer death is “averted for every 235 women invited to screening for 20 years” and that, in the UK, “inviting women aged 50-70 every three years, prevents about 1300 breast cancer deaths a year”.¹⁸¹

66. Concerns about the risk of “over-diagnosis”, namely “the diagnosis of [...] cancers by the screening programme which wouldn’t have been detected otherwise, but which would have grown so slowly they would never caused problems during a woman’s life”,¹⁸² were also highlighted to us.¹⁸³ Professor Baum stated that “the estimate is that for every one breast cancer death avoided either three or, as the upper limit, nine women are over-diagnosed and over-treated”.¹⁸⁴ The Panel reported that there were diverging views “on how to estimate the amount of overdiagnosis” resulting in “estimates of the frequency of overdiagnosis [varying] widely, from approximately 0% to 50%”.¹⁸⁵ Prefacing its calculation with the statement that “there are no data to answer this question directly”, the Panel provisionally estimated that the “frequency of overdiagnosis was of the order of 11% from a population perspective, and about 19% from the perspective of a woman invited to screening”.¹⁸⁶

67. When asked how the UK NSC handled uncertainty in the breast cancer screening figures, Dr Anne Mackie, Director of Programmes, UK NSC, replied that “we do our very best to try and get an answer”.¹⁸⁷ She went on to note that the UK NSC “cannot do a randomised control trial and say, ‘Let’s leave these women and see what happens, and let’s treat these’” and therefore it has “to make assumptions [...] about how many women we

¹⁷⁸ NHS0036 [Breakthrough Breast Cancer and Breast Cancer Campaign] para 2.2

¹⁷⁹ The Independent UK Panel on Breast Cancer Screening, ‘[The Benefits and Harms of Breast Cancer Screening: An Independent Review](#)’, (October 2012), para 1.3

¹⁸⁰ The Independent UK Panel on Breast Cancer Screening, ‘[The Benefits and Harms of Breast Cancer Screening: An Independent Review](#)’, (October 2012), para 2.3

¹⁸¹ The Independent UK Panel on Breast Cancer Screening, ‘[The Benefits and Harms of Breast Cancer Screening: An Independent Review](#)’, (October 2012), para 1.6

¹⁸² NHS0035 [Cancer Research UK] para 3.4

¹⁸³ For example: NHS008 [Professor Bewley]; NHS0035 [Cancer Research UK]; NHS0037 [HealthWatch]; NHS0046 [PROMISE 2016]

¹⁸⁴ Q59

¹⁸⁵ The Independent UK Panel on Breast Cancer Screening, ‘[The Benefits and Harms of Breast Cancer Screening: An Independent Review](#)’, (October 2012), para 4.3

¹⁸⁶ The Independent UK Panel on Breast Cancer Screening, ‘[The Benefits and Harms of Breast Cancer Screening: An Independent Review](#)’, (October 2012), para 1.4.

¹⁸⁷ Q208

are helping and harming”.¹⁸⁸ Dr Mackie added that it was necessary “to be open” with the public and say “our best estimate is 1,300 lives that we save’ [...] but we have to be honest and say that it might be a bit more or a bit less”.¹⁸⁹ After hearing witnesses’ concerns about the uncertainty relating to the numbers needed to treat and the risk of over-diagnosis, the Committee put it to Professor David Walker, Chair, UK NSC, that the statistics should be reviewed by the UK Statistics Authority. Professor Walker stated that he “would have no objection” to this but added that he did “not think it [was] a necessary step”.¹⁹⁰

68. Pointing to the “poor” level of “statistical comprehension of the majority of the UK population”,¹⁹¹ other witnesses suggested using different “techniques to aid understanding” in information materials including “minimising the amount of numerical information” and relying more on “clear graphical or visual representations” (also referred to as “infographic methods”¹⁹²) and “natural frequencies rather than percentages or fractions”.¹⁹³

69. 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.

Training health professionals

70. Health professionals were highlighted at the beginning of Chapter 4 as an important route via which members of the public may access information on the benefits and harms of screening. The opportunity for individuals to discuss screening with their General Practitioner (GP) appeared to vary according to the programme in question. Dr Margaret McCartney, a GP from Glasgow, stated that she did “not get a chance”¹⁹⁴ to discuss with her eligible patients whether they wished to participate in the breast cancer screening programme because the invitation to attend come from a “centralised organisation”¹⁹⁵ and not the patient’s GP. Other witnesses suggested that GPs were not taking the opportunity

¹⁸⁸ Q208

¹⁸⁹ Q208

¹⁹⁰ Q278

¹⁹¹ NHS0035 [Cancer Research UK] para 5.7; Q106; NHS0018 [Academy of Medical Sciences] para 17 & 18

¹⁹² Q54

¹⁹³ NHS0035 [Cancer Research UK] para 5.7

¹⁹⁴ Q102

¹⁹⁵ Q97

to instigate discussions. Citing results from a 2014 survey of 500 GPs, the Prostate Cancer Advisory Group reported that while men over the age of 50 are entitled to a PSA (Prostate-specific antigen) test free of charge on the NHS, provided they have first had a discussion about the pros and cons with their GP, “fewer than 1 in 10 GPs proactively initiate a discussion about prostate health”.¹⁹⁶

71. Other submissions stated that “screening is often poorly understood by [...] clinicians”¹⁹⁷ and that health professionals more broadly can “struggle with the terminology and concepts”.¹⁹⁸ The Royal College of Midwives pointed to the “rapidity” of developments in the field and noted that it could be “difficult for midwives to [...] remain informed and up to date with the evidence”.¹⁹⁹ We also heard evidence that the routine nature of screening for many health professionals, combined with the rarity of some of the diseases screened for (particularly in newborns), may negatively influence the way that information is delivered. Robert Meadowcroft, Muscular Dystrophy Campaign, highlighted the cases of families in Wales who had taken part in newborn screening for Duchenne muscular dystrophy and who had been advised by health professionals, “Oh, don’t worry; it [the test] always comes back negative”.²⁰⁰ He noted that while the information they were being given was “well intentioned”, it was “not helpful” and potentially increased “the sense of devastation” when a test came back positive.²⁰¹

72. However, Professor David Walker, Chair, UK NSC, stated that “an extensive educational programme” was in place that targeted “everybody, from the clinicians who are delivering the programmes, the patients and the public who are going to receive them, and also the commissioners of services”. He added: “we have everything from leaflets and videos to e-learning modules—and even university-accredited courses—for these people”.²⁰²

73. 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.

¹⁹⁶ NHS0022 [Prostate Cancer Advisory Group]

¹⁹⁷ NHS0025 [Warwick Medical School] para 21

¹⁹⁸ NHS0035 [Cancer Research UK] para 5.1

¹⁹⁹ NHS0047 [Royal College of Midwives]

²⁰⁰ Q54 [Robert Meadowcroft]. Screening for Duchenne muscular dystrophy was implemented in Wales in 1990 and was withdrawn in late 2011. The programme was never recommended by the UK NSC.

²⁰¹ Q54 [Robert Meadowcroft]

²⁰² Q262

Private health screening

74. While focusing predominately on NHS screening programmes, we received some evidence during this inquiry—chiefly from Dr Margaret McCartney—relating to programmes offered by private screening providers. Dr McCartney drew attention to what she saw as the low quality of information provided to individuals paying for private screening. Citing a study undertaken for the consumer rights group *Which?*, Dr McCartney reported that “one out of six or seven companies was prepared to say that their screening tests could do harm when we asked them that specifically on the telephone”.²⁰³ She also indicated that private screening companies were making claims in advertising material—such as “we’ve saved thousands of lives”—which, she told us, they had “no evidence” for since they had “not followed up on people in the long term”.²⁰⁴

75. Síle Lane, Sense About Science, and Dr McCartney, noted that the screening offered by private companies was “not being run and overseen by the National Screening Committee” and that it was indiscriminate; it was “inviting everyone to come along” rather than “inviting specific people in a specific population to come along for a specific test”.²⁰⁵ Dr Anne Mackie, Director of Programmes, UK NSC, confirmed that the UK NSC “does not have oversight” of screening information delivered in private settings and noted that there had been “quite a lot of discussions” about whether this information was “sufficiently balanced”.²⁰⁶ It was not clear, however, who does have oversight of the information materials produced by private screening companies. Dr McCartney told us that she had:

been to the Advertising Standards Authority who have done what they can [...] I have been to Trading Standards, who said the companies are doing what they have said they will do, so there is nothing they can do about it. I have been to the General Medical Council, because I believe that the doctors who run these clinics have been complicit in allowing misinformation and poor advertising to perpetuate. The GMC have not acted.²⁰⁷

76. In response to the points made by Dr McCartney, we wrote to private screening companies to offer them a right of reply. The European Scanning Centre concurred with Dr McCartney’s concerns about claims made “by certain companies that they have saved lives as a result of the screening procedures”, adding that it was “not something that [their] organisation has ever endorsed or used”.²⁰⁸ Life Line Screening stated that it had “reviewed the messaging” in its “promotional literature” and that, in “consultation with the ASA [Advertising Standards Authority]” it had “recently amended a mention in our literature which stated that we ‘helped save thousands of lives’”.²⁰⁹ Life Line Screening was clear that

²⁰³ Q140

²⁰⁴ Q142

²⁰⁵ Q132 [Síle Lane]; Q124

²⁰⁶ Q232

²⁰⁷ Q138

²⁰⁸ NHS0051 [European Scanning Centre]

²⁰⁹ NHS0052 [Life Line Screening]

private screening was a “matter of personal choice” while the European Scanning Centre suggested that it could be “positive both to the individual and to the NHS purse”.²¹⁰

77. The Minister told us that the advertising materials used by private screening providers had not been drawn to her attention “as a major problem” though she recognised it was a point of “ongoing concern”.²¹¹ When asked if it would be difficult to require advertising materials to go through a process of independent validation, Professor David Walker, Chair, UK NSC, stated that he did not know, but noted that “the same proposal” was being discussed in the context of e-cigarettes; a point echoed by the Minister.²¹²

78. 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.

Innovations in screening

79. Medicine is a constantly evolving field and screening is no exception. We received evidence from a number of academics currently undertaking research to enhance the targeting of screening through improved “risk stratification”. The approach rests on the premise that “a population is not totally homogeneous”²¹³ and that individuals have detectable characteristics associated with an increased chance of experiencing unwanted outcomes.²¹⁴ At present, screening programmes recommended by the UK NSC stratify (or target) based on two “detectable characteristics”: age and gender. The PHG Foundation, Cambridge Cancer Centre and PROMISE 2016²¹⁵ indicated that risk stratification for cancer screening could be enhanced by broadening the detectable characteristics to include genomic information.²¹⁶ According to the Cambridge Cancer Centre, “genomic technologies”, such as “sequencing”, can provide a better understanding of “inherited genetic variants that are associated with susceptibility to cancer” and that modify individual risk.²¹⁷ Dr Hilary Burton, PHG Foundation, suggested that by using information about “the most deleterious variants” to target a breast screening programme “the benefit-

²¹⁰ NHS0052 [Life Line Screening]; NHS0051 [European Scanning Centre]

²¹¹ Q266 [the Minister]

²¹² Q269 [Professor Walker, the Minister]

²¹³ Q154

²¹⁴ See, for example, Charles C. Miller, Michael J. Reardon, Hazim J. Safi, *Risk Stratification: A Practical Guide for Clinicians* (Cambridge, 2001)

²¹⁵ Predicting Risk of Ovarian Malignancies, Improved Screening and Early detection (PROMISE)

²¹⁶ NHS0023 [Cambridge Cancer Centre]; NHS0034 [PHG Foundation]; NHS0046 [PROMISE 2016]

²¹⁷ NHS0023 [Cambridge Cancer Centre] para 7

harm ratio” can be optimised “because you can screen fewer women and detect a similar number of cases”.²¹⁸ Also referring to the specific example of breast cancer screening, Professor Baum told the Committee that the programme could be improved by “undertaking a risk assessment” rather than “screening everybody” in the 50-70 age group.²¹⁹ He added that this would “exclude the very high-risk from screening, because what they need is genetic counselling”.²²⁰

80. The need to consider the non-genetic components of risk—including lifestyle and environmental factors—was also raised by witnesses, particularly in relation to prostate, breast and ovarian cancers. Professor Ian Jacobs, PROMISE 2016, suggested that the “nirvana” he was looking to achieve rested on combining “genetic predisposition, [...] demographic and social differences and epidemiological differences, into an algorithm” that accurately defined a women’s risk of ovarian cancer.²²¹ Owen Sharp, Prostate Cancer UK, stated that, “masses of information” was not necessarily needed in the context of prostate cancer to “develop different risk trajectories” for men.²²² Instead, he suggested that putting “pieces of information together”, including family history and ethnicity, alongside an assessment of lifestyle, could be used to establish a risk profile alongside screening.²²³ Looking further into the future, Professor Ian Cree, Early Cancer Detection Consortium, highlighted the consortium’s preliminary work examining whether it was possible “to deliver a series of tests done on one blood sample that allow you to look for multiple cancers”.²²⁴ According to Professor Cree, the benefits of such an approach include the ability “to look for rare cancers” that are too uncommon to sustain an individual screening programme, as well as decreasing the risk of over-diagnosis and false positives through having “a single test that has a high sensitivity”.²²⁵

81. In its report *Stratified Screening for Cancer*, the PHG Foundation anticipated that a risk-stratified screening programme would be more complex to set up and administer than the screening programmes currently offered.²²⁶ To avoid delays, Breakthrough Breast Cancer stated it was “important” to think ahead about the “implementation of increased risk stratification, so that as effective tools become available they can be adopted rapidly”.²²⁷ Considering “how emerging trends and developments might potentially affect current policy and practice” is, according to the Government, an integral part of “horizon scanning” and is “already being done in government departments”.²²⁸ Our inquiry into

²¹⁸ Q154

²¹⁹ Q62

²²⁰ Q62

²²¹ Q156 [Professor Jacobs]

²²² Q160 [Owen Sharp]

²²³ Q160 [Owen Sharp]

²²⁴ Q161

²²⁵ Q162. The sensitivity of a clinical test refers to its ability to correctly identify those patients with the disease.

²²⁶ PHG Foundation, *‘Stratified screening for cancer: Recommendations and analysis from COGS’*, January 2014, p 20

²²⁷ NHS0036 [Breakthrough Breast Cancer and Breast Cancer Campaign] para 3.2.4

²²⁸ Cabinet Office/Government Office for Science, “Horizon scanning programme: a new approach for policy making”, 12 July 2013

Government horizon scanning found it to be a “potentially valuable activity” that could “enhance both short- and long-term decision-making” but we also identified “inconsistencies of practice and performance” across government departments.²²⁹

82. During this inquiry, we heard that the UK NSC’s consideration of emerging trends, and their possible impact on policy and practice, varied across screening programmes. Both Children Living with Inherited Metabolic Diseases (Climb) and the Save Babies Through Screening Foundation identified an apparent lack of forward planning by the UK NSC in the context of newborn screening, with Climb stating that it had “found little evidence” that the UK NSC was “planning for the future”.²³⁰ The Prostate Cancer Advisory Group also questioned what processes were “in place to adapt the [current delivery] model” when new risk information became available.²³¹ Professor Jacobs, PROMISE 2016, was more positive and reported that his team “already have a dialogue” with the UK NSC in advance of trial data being published on ovarian cancer screening.²³² Dr Anne Mackie, Director of Programmes, UK NSC, stated that the Committee was “pretty well” equipped to adapt to changing technologies, as well as genomic information, and pointed to the example of “non-invasive prenatal diagnosis for Down’s [Syndrome]”.²³³

83. 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.

²²⁹ Science and Technology Committee, Ninth Report of Session 2013–14, [Government horizon scanning](#), HC 703, para 10 & para 25

²³⁰ NHS0013 [Climb]; NHS0006 [Save Babies Through Screening Foundation UK] paras 14 to 16

²³¹ NHS0022 [Prostate Cancer Advisory Group]

²³² Q168 [Professor Jacobs]

²³³ Q222 & Q224

5 Screening policy and advice

84. During our inquiry we heard that the UK National Screening Committee’s (UK NSC) independence from Government was highly valued and gave added legitimacy to its advice. Dr Sian Taylor-Phillips, Warwick Medical School, told us that health screening advice to government “needs to be as independent as it can be”²³⁴ while Dr Margaret McCartney, a GP from Glasgow, stated that the UK NSC being “as independent as possible” could “only be to the population’s advantage”.²³⁵ For Professor Susan Bewley, King’s College, London, the UK NSC’s independence was something that had “to be fiercely protected”.²³⁶ However, some witnesses questioned if recent changes to the structure of the NHS in England had negatively impinged upon the UK NSC’s independence.²³⁷

The governance of the UK National Screening Committee

85. Building on the work of our predecessor Committees, we have taken a close interest in ensuring that the institutional design of scientific advisory bodies facilitates the production of high-quality, evidence-based advice to government.²³⁸ In particular, we have considered the growth of the network of Scientific Advisory Committees (SACs); an advisory structure highlighted by our predecessor Committee as holding the potential “to strengthen the UK’s ability to make policy decisions that are based on the best available evidence” and establish the UK Government as “an international exemplar” in scientific advisory systems.²³⁹

86. The Government Office for Science (GO-Science) describes the purpose of SACs as helping government departments to:

access, interpret and understand the full range of relevant scientific information, and to make judgements about its relevance, potential and application [...] They review, and sometimes commission, scientific research, and offer independent expert judgement, including highlighting where facts are missing and where uncertainty or disagreement exists [...] Depending upon their remit, a committee may have to frame their advice to take account of social and ethical issues and public and stakeholder concerns.²⁴⁰

The current functions of the UK NSC appear broadly consistent with those of an SAC. According to its most recent policy review and annual report, the UK NSC provides

²³⁴ Q3

²³⁵ Q112 [Dr McCartney]

²³⁶ NHS008 [Professor Bewley] para 20

²³⁷ NHS0036 [Breakthrough Breast Cancer and Breast Cancer Campaign] para 3.4.2; NHS0049 [UK Faculty of Public Health] para 1.2.7

²³⁸ Oral evidence taken before the Science and Technology Committee on [2 April 2014](#), HC 1185, (2013-2014); Science and Technology Committee, Second Report of the Session 2014–15, [After the storm? UK blood safety and the risk of variant Creutzfeldt-Jakob Disease](#), HC 327

²³⁹ Science and Technology Committee, Third Report of Session 2009–10, [The Government’s review of the principles applying to the treatment of independent scientific advice provided to government](#), HC 158-I, para 2

²⁴⁰ Government Office for Science, [Code of Practice for Scientific Advisory Committees](#), (November 2011), para 6

“authoritative evidence-based”²⁴¹ and “independent advice” to “ministers and health services across the four UK countries on screening policy for all conditions”.²⁴² Dr Anne Mackie, Director of Programmes, UK NSC, explained that the purpose of her team was to “bring together the best international evidence and expert opinion, following consultation and a synthesis of the peer review literature, to the committee”.²⁴³ Public Health England (PHE) noted that this “active review process” was “based on the latest science”,²⁴⁴ with the UK NSC then considering “the review and its recommendations, any stakeholder submissions and the view of UK NSC Director of Programmes”²⁴⁵ in order to make “a recommendation to the four UK Governments”.²⁴⁶

87. Despite the similarities between the functions of an SAC and those of the UK NSC, the formal status of the UK NSC appeared ill-defined. Dr Mackie told us that the UK NSC was “a standing ministerial advisory committee in terms of governance”²⁴⁷ and that it was “not classed as a scientific advisory committee or a public body”.²⁴⁸ The Minister confirmed that, for “historical reasons”, the UK NSC was “not at the moment” an SAC but considered it a “reasonable question to ask”, noting that part of the current Independent Review of the UK National Screening Committee would be examining this point.²⁴⁹

88. SACs fall within the scope of both GO-Science’s 2011 *Code of Practice for Scientific Advisory Committees* (“the Code”) and its 2010 *Principles of scientific advice to government* (“the Principles”).²⁵⁰ The Principles set out the high-level “rules of engagement” between government and those providing independent scientific advice and point to the need for “clear roles and responsibilities”, “transparency and openness”, and “independence”.²⁵¹ The Code goes further and provides detailed guidance on the establishment, management and conduct of SACs, as well as its relationship with the sponsor department.

89. Dr Mackie was, at first, unsure which code of practice the UK NSC adhered to, stating that she would “need to talk to the Department to understand which code of practice we work within”.²⁵² She subsequently told us that the UK NSC was “not required to comply with the code of practice for scientific advisory committees” but that there was a set of

²⁴¹ UK National Screening Committee, [Policy Review. Screening in the UK 2011-2012](#), p 5

²⁴² UK National Screening Committee, NHS Screening Programmes, [Annual Report. Screening in England 2011-2012](#), p 8

²⁴³ Q191

²⁴⁴ NHS0040 [Public Health England] Appendix 3 para 17

²⁴⁵ UK National Screening Committee, [Policy Review Process](#), accessed 10 July 2014

²⁴⁶ Q191

²⁴⁷ Q192

²⁴⁸ Q213

²⁴⁹ Q239

²⁵⁰ Government Office for Science, [Code of Practice for Scientific Advisory Committees](#), (November 2011); Government Office for Science, [Principles of scientific advice to government](#), 2010

²⁵¹ Government Office for Science, [Principles of scientific advice to government](#), 2010

²⁵² Q195

“procedural rules” agreed “between the four countries”.²⁵³ However, she noted that a “code of practice” was “being developed that draws on CoPSAC [Code of Practice for Scientific Advisory Committees]”.²⁵⁴

90. 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.

91. 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.*

The relationship between Public Health England and the UK National Screening Committee

92. In April 2013, the UK NSC became “part of” Public Health England (PHE), an executive agency of the Department of Health (DH).²⁵⁵ Prior to this date, the UK NSC's annual reports indicate that it was funded by, and reported directly to, the DH.²⁵⁶ While some witnesses were unconcerned by the UK NSC becoming part of PHE,²⁵⁷ others expressed uncertainty about the impact of this move on the UK NSC's independence. The UK Faculty of Public Health raised concerns that “the current home” of the UK NSC in PHE “could be seen by the public as putting its continuing independence in doubt”.²⁵⁸ The Faculty also highlighted that wider questions about PHE's own independence from the DH had been examined by the Health Select Committee in early 2014.²⁵⁹ Breakthrough Breast Cancer noted that the Advisory Committee on Breast Cancer Screening, which feeds into the UK NSC's deliberations, had also “fallen under the jurisdiction of [...] PHE”.²⁶⁰ While there was no suggestion that this had resulted in any “restriction on the ability of the group

²⁵³ Q213; Public Health England, *Agreement between the four countries in respect of the UK National Screening Committee*, November 2012 [the document is held in confidence but available upon request from Public Health England].

²⁵⁴ Q213

²⁵⁵ UK National Screening Committee, NHS Screening Programmes, [Annual Report. Screening in England 2011-2012](#), p 7

²⁵⁶ UK National Screening Committee, [Annual Report April 2007- March 2008](#), (August 2009), p 32

²⁵⁷ Qq4-5 [Jessica Kirby]

²⁵⁸ NHS0049 [UK Faculty of Public Health] para 1.2.7

²⁵⁹ NHS0049 [UK Faculty of Public Health] para 1.2.7; Health Committee, Eighth Report of Session 2013–14, [Public Health England](#), HC 840

²⁶⁰ NHS0036 [Breakthrough Breast Cancer and Breast Cancer Campaign] para 4.3.2

to give independent advice”, Breakthrough Breast Cancer stated that “consideration should be given to how this group can be held at arms-length from PHE to maintain its reputation as an independent source of advice”.²⁶¹

93. The *Code of Practice for Scientific Advisory Committees* states that they “should expect to operate free of influence from the sponsor department officials”.²⁶² We therefore asked the Minister if this meant the Deputy Chief Medical Officer for England should not also be Chair of the UK NSC. The Minister replied that “the CMO team is independent and gives Ministers independent-minded advice”.²⁶³ The Minister therefore did not see “one [role as] being independent and the other not”.²⁶⁴ Professor David Walker, Chair, UK NSC, concurred noting that the “CMO has a statutory independent role and is allowed to take an independent view, separate from the Department. Therefore, it can act independently”.²⁶⁵

94. Dr Anne Mackie, Director of Programmes, UK NSC, told us that while PHE “hosts” her and her team, “the members [of the Committee] are independent of Public Health England”.²⁶⁶ The Minister echoed this point, stating that she was “not aware” of any problem relating to the UK NSC’s independence, adding that the UK NSC was “not within PHE” but rather that PHE “provides the secretariat” for the UK NSC.²⁶⁷ However, different language is used in the *Immunisation and Screening National Delivery Framework & Local Operating Model* (“the Framework”), published jointly by PHE and NHS England in May 2013. The Framework states that the UK NSC, alongside the English National Screening Programmes and the NHS Cancer Screening Programmes, “sit within the Health and Wellbeing Directorate of PHE”.²⁶⁸ Evidence from PHE expanded further upon the relationship, acknowledging that PHE is:

responsible for the team that provides the expert public health advice needed to support the work of the UK National Screening Committee (UK NSC) through a rolling programme of evidence reviews working with key stakeholders and experts.²⁶⁹

95. 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

²⁶¹ NHS0036 [Breakthrough Breast Cancer and Breast Cancer Campaign] para 4.3.2

²⁶² Government Office for Science, [Code of Practice for Scientific Advisory Committees](#), (November 2011), para 31

²⁶³ Q240 [the Minister]

²⁶⁴ Q240 [the Minister]

²⁶⁵ Q240 [Professor Walker]

²⁶⁶ Q191

²⁶⁷ Q242

²⁶⁸ Public Health England and NHS England, [Immunisation & Screening National Delivery Framework & Local Operating Model](#), (May 2013), para 2.4.7

²⁶⁹ NHS0040 [Public Health England] para 2.1

Public Health England is promptly drawn up and placed in the public domain no later than December 2014.

Conclusions and recommendations

National health screening in the UK

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)

Reviewing the evidence base

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)
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)
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)

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)
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)
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)
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)
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)
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)

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)

Communicating the risks and benefits of screening

Informed choice

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)

Producing public information on screening

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)
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)
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)

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)
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)

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)

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)

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)
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)
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)

Annex: Criteria for appraising the viability, effectiveness and appropriateness of a screening programme

UK National Screening Committee Criteria

The Condition

1. The condition should be an important health problem
2. The epidemiology and natural history of the condition, including development from latent to declared disease, should be adequately understood and there should be a detectable risk factor, disease marker, latent period or early symptomatic stage.
3. All the cost-effective primary prevention interventions should have been implemented as far as practicable.
4. If the carriers of a mutation are identified as a result of screening the natural history of people with this status should be understood, including the psychological implications.

The Test

5. There should be a simple, safe, precise and validated screening test.
6. The distribution of test values in the target population should be known and a suitable cut-off level defined and agreed.
7. The test should be acceptable to the population.
8. There should be an agreed policy on the further diagnostic investigation of individuals with a positive test result and on the choices available to those individuals.
9. If the test is for mutations the criteria used to select the subset of mutations to be covered by screening, if all possible mutations are not being tested, should be clearly set out.

The Treatment

10. There should be an effective treatment or intervention for patients identified through early detection, with evidence of early treatment leading to better outcomes than late treatment.
11. There should be agreed evidence based policies covering which individuals should be offered treatment and the appropriate treatment to be offered.

12. Clinical management of the condition and patient outcomes should be optimised in all health care providers prior to participation in a screening programme.

The Screening Programme

13. There should be evidence from high quality Randomised Controlled Trials that the screening programme is effective in reducing mortality or morbidity. Where screening is aimed solely at providing information to allow the person being screened to make an “informed choice” (eg. Down’s syndrome, cystic fibrosis carrier screening), there must be evidence from high quality trials that the test accurately measures risk. The information that is provided about the test and its outcome must be of value and readily understood by the individual being screened.
14. There should be evidence that the complete screening programme (test, diagnostic procedures, treatment/ intervention) is clinically, socially and ethically acceptable to health professionals and the public.
15. The benefit from the screening programme should outweigh the physical and psychological harm (caused by the test, diagnostic procedures and treatment).
16. The opportunity cost of the screening programme (including testing, diagnosis and treatment, administration, training and quality assurance) should be economically balanced in relation to expenditure on medical care as a whole (ie. value for money). Assessment against this criteria should have regard to evidence from cost benefit and/or cost effectiveness analyses and have regard to the effective use of available resource.
17. All other options for managing the condition should have been considered (eg. improving treatment, providing other services), to ensure that no more cost effective intervention could be introduced or current interventions increased within the resources available.
18. There should be a plan for managing and monitoring the screening programme and an agreed set of quality assurance standards.
19. Adequate staffing and facilities for testing, diagnosis, treatment and programme management should be available prior to the commencement of the screening programme.
20. Evidence-based information, explaining the consequences of testing, investigation and treatment, should be made available to potential participants to assist them in making an informed choice.
21. Public pressure for widening the eligibility criteria for reducing the screening interval, and for increasing the sensitivity of the testing process, should be anticipated. Decisions about these parameters should be scientifically justifiable to the public.

22. If screening is for a mutation the programme should be acceptable to people identified as carriers and to other family members.²⁷⁰

²⁷⁰ UK National Screening Committee, ['Criteria for appraising the viability, effectiveness and appropriateness of a screening programme'](#), accessed 10 September 2014

Formal Minutes

Monday 20 October 2014

Members present:

Andrew Miller, in the Chair

Jim Dowd
David Heath
Stephen Metcalfe
Stephen Mosley

Pamela Nash
Sarah Newton
Graham Stringer

Draft Report (*National Health Screening*), proposed by the Chair, brought up and read.

Ordered, That the draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 95 read and agreed to.

Annex and Summary agreed to.

Resolved, That the Report be the Third Report of the Committee to the House.

Ordered, That the Chair make the Report to the House.

Ordered, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

[Adjourned till Wednesday 22 October at 9.00 am

Witnesses

The following witnesses gave evidence. Transcripts can be viewed on the Committee's inquiry page at www.parliament.uk/science.

Wednesday 7 May 2014

Question number

Professor Jane Wardle, Professor of Clinical Psychology and Director of the Health Behaviour Research Centre at University College London, representing the Academy of Medical Sciences, **Jessica Kirby**, Senior Health Information Manager, Cancer Research UK, and **Dr Sian Taylor-Phillips**, Senior Research Fellow, Warwick Medical School, University of Warwick

[Q1-52](#)

Wednesday 11 June 2014

Robert Meadowcroft, Chief Executive, Muscular Dystrophy Campaign, **Professor Michael Baum**, Professor Emeritus of Surgery, University College London, representing Advocates for Honesty and Transparency in Breast Screening, and **Steve Hannigan**, Executive Director, Children Living with Inherited Metabolic Diseases (Climb)

[Q53-94](#)

Sile Lane, Director of Campaigns, Sense About Science, **Dr Margaret McCartney**, Glasgow GP, and **Dr John Middleton**, Vice President for Health Policy, UK Faculty of Public Health

[Q95-152](#)

Wednesday 25 June 2014

Owen Sharp, Chief Executive, Prostate Cancer UK, **Professor Ian Cree**, Yvonne Carter Professor of Pathology, Warwick Medical School, representing the Early Cancer Detection Consortium, **Dr Hilary Burton**, Director, PHG Foundation, and **Professor Ian Jacobs**, Director, PROMISE 2016

[Q153-189](#)

Dr Anne Mackie, Director of Programmes, UK National Screening Committee, **Dr Kevin Dunbar**, Director, National Chlamydia Screening Programme, **Jamie Waterall**, NHS Health Check National Lead, Public Health England, and **Dr Sharon Hillier**, Deputy Director of Screening Division, Public Health Wales

[Q190-236](#)

Wednesday 9 July 2014

Jane Ellison MP, Parliamentary Under-Secretary of State for Public Health, Department of Health, and **Professor David Walker**, Deputy Chief Medical Officer for England, Department of Health

[Q237-305](#)

Published written evidence

The following written evidence was received and can be viewed on the Committee's inquiry web page at www.parliament.uk/science. INQ numbers are generated by the evidence processing system and so may not be complete.

1	Miriam Pryke	NHS0001
2	Sue Warman	NHS0002
3	Elizabeth Dawson	NHS0003
4	Dr Margaret McCartney	NHS0004
5	Advocates for Honesty and Transparency in Breast Screening	NHS0005
6	Save Babies through Screening Foundation UK on behalf of the UK Patient Advocates for Newborn Screening Group	NHS0006
7	The Royal College of Radiologists	NHS0007
8	Professor Susan Bewley	NHS0008
9	Mrs Pamela Redding	NHS0010
10	Life Line Screening	NHS0011
11	Mitzi Blennerhassett	NHS0012
12	Children Living with Inherited Metabolic Diseases (Climb)	NHS0013
13	British Thoracic Society	NHS0014
14	UK ProtecT (prostate testing for cancer and treatment) and CAP (cluster randomised controlled trial of PSA testing) Study Groups	NHS0015
15	Sense About Science	NHS0016
16	British Association of Urological Surgeons	NHS0017
17	Academy of Medical Sciences	NHS0018
18	Cancer Epidemiology Unit, Nuffield Department of Population Health, University of Oxford	NHS0019
19	Tackle Prostate Cancer	NHS0020
20	Prostate Cancer UK	NHS0021
21	Prostate Cancer Advisory Group	NHS0022
22	Cambridge Cancer Centre	NHS0023
23	Institute of Physics and Engineering in Medicine	NHS0024
24	Department of Health Sciences, Warwick Medical School	NHS0025
25	Muscular Dystrophy Campaign	NHS0026
26	Group B Strep Support	NHS0027
27	Royal National Institute of Blind People	NHS0028
28	Institute of Biomedical Science	NHS0029
29	Early Cancer Detection Consortium	NHS0031
30	Ovarian Cancer Action	NHS0032
31	C R Bard	NHS0033
32	PHG Foundation	NHS0034
33	Cancer Research UK	NHS0035
34	Breakthrough Breast Cancer and Breast Cancer Campaign	NHS0036
35	HealthWatch	NHS0037
36	National Institute for Health Research (NIHR) Evaluation Trials and Studies Coordinating Centre (NETSCC)	NHS0038

37	Professor Kenneth Muir, Mr David Smith, Mr Sandy Tyndale-Biscoe, Dr Jonathan Rees and Dr Artitaya Lophatananon on behalf of the "Riskman" development group	NHS0039
38	Public Health England	NHS0040
39	British Association for Counselling and Psychotherapy	NHS0041
40	Charlotta H Pisinger	NHS0043
41	Royal College of Physicians	NHS0044
42	PROMISE 2016 (Predicting Risk of Ovarian Malignancies, Improved Screening and Early detection)	NHS0046
43	Royal College of Midwives	NHS0047
44	Public Health Wales	NHS0048
45	UK Faculty of Public Health	NHS0049
46	Academy of Medical Sciences (supplementary to NHS0018)	NHS0050
47	European Scanning Centre	NHS0051
48	Life Line Screening	NHS0052
49	Department of Health	NHS0053
50	BMI Healthcare	NHS0054

List of Reports from the Committee during the current Parliament

All publications from the Committee are available on the Committee's website at www.parliament.uk/science.

The reference number of the Government's response to each Report is printed in brackets after the HC printing number.

Session 2014–15

First Special Report	Communicating climate science: Government Response to the Committee's Eighth Report of Session 2013–14	HC 376
First Report	Ensuring access to working antimicrobials	HC 509 (Cm 8919)
Second Special Report	Government horizon scanning: Government Response to the Committee's Ninth Report of Session 2013–14	HC 592
Second Report	After the storm? UK blood safety and the risk of variant Creutzfeldt-Jakob Disease	HC 327 (Cm 8940)

Session 2013–14

First Special Report	Educating tomorrow's engineers: the impact of Government reforms on 14–19 education: Government Response to the Committee's Seventh Report of Session 2012–13	HC 102
First Report	Water quality: priority substances	HC 272-I (HC 648)
Second Special Report	Marine science: Government Response to the Committee's Ninth Report of Session 2012–13	HC 443
Third Special Report	Bridging the valley of death: improving the commercialisation of research: Government response to the Committee's Eighth Report of Session 2012–13	HC 559
Second Report	Forensic science	HC 610 (Cm 8750)
Fourth Special Report	Water quality: priority substances: Government response to the Committee's First Report of Session 2013–14	HC 648
Third Report	Clinical trials	HC 104 (Cm 8743)
Fifth Special Report	Clinical trials: Health Research Authority Response to the Committee's Third Report of Session 2013–14	HC 753
Fourth Report	Work of the European and UK Space Agencies	HC 253 (HC 1112)
Fifth Report	Pre-appointment hearing with the Government's preferred candidate for Chair of the Natural Environment Research Council (NERC)	HC 702
Sixth Special Report	Forensic science: Research Councils UK Response to the Committee's Second Report of Session 2013–14	HC 843
Seventh Special Report	Clinical trials: Medical Research Council Response to the Committee's Third Report of Session 2013–14	HC 874
Sixth Report	Women in scientific careers	HC 701 (HC 1268)
Seventh Report	Pre-appointment hearing with the Government's	HC 989

	preferred candidate for Chair of the Arts and Humanities Research Council (AHRC)	
Eighth Special Report	Work of the European and UK Space Agencies: Government Response to the Committee's Fourth Report of Session 2013–14	HC 1112
Eighth Report	Communicating climate science	HC 254 (HC 376, Session 2014–15)
Ninth Report	Government horizon scanning	HC 703
Ninth Special Report	Women in scientific careers: Government Response to the Committee's Sixth Report of Session 2013–14	HC 1268
Session 2012–13		
First Special Report	Science in the Met Office: Government Response to the Committee's Thirteenth Report of Session 2010–12	HC 162
First Report	Devil's bargain? Energy risks and the public	HC 428 (HC 677)
Second Report	Pre-appointment hearing with the Government's preferred candidate for Chair of the Medical Research Council	HC 510–I
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