The Academy of Medical Sciences' response to the House of Commons Science and Technology Select Committee consultation on National Health Screening

February 2014

Summary

- Most health screening provided in the UK through the NHS is based on available high quality evidence and regularly reviewed. There are, however, concerns regarding the evidence base of the Health Check programme.
- Screening programmes should be monitored to ensure that they are achieving their expected benefits. To enhance the evidence base, there should be improved data collection of uptake rates and person-specific outcomes from screening.
- Screening programmes expend commendable effort communicating the risks and benefits of screening to patients. However, more needs to be done to determine the effectiveness of this information and crucially, whether it assists in patients making informed choices.
- The UK is unique in the high quality and population-wide health screening offered, but new mechanisms to speed up the implementation of screening innovations would be beneficial to patients.

Introduction

1. The Academy of Medical Sciences promotes advances in medical science and campaigns to ensure that these are translated into healthcare benefits for society. Our elected Fellowship includes the UK's foremost experts drawn from a broad and diverse range of research areas.

2. We welcome the opportunity to respond to the House of Commons' Science and Technology Select Committee inquiry on National Health Screening. It is important that national screening programmes are introduced based on accepted principles and practice. The original guidance that still holds today is the World Health Organisation's Wilson and Jungner 1968 principles[1]. In the UK, the National Screening Committee (NSC) also has detailed programme appraisal criteria[2]. Our response to each of the questions posed in this inquiry (please see below) has been informed by the expertise of our Fellows. We would be pleased to provide further evidence if required.

What evidence are the national health screening programmes based on, and how regularly is the evidence base reviewed?

3. It is important that there is a national body with strong scientific and public health expertise which assesses the evidence of screening programme on a continuing basis. Otherwise there is a risk of programmes being introduced on an ad-hoc and piecemeal basis with limited evidence or ability to evaluate outcomes.

[1] Wilson JMG, Jungner G. (1968) Principles and practice of screening for disease. *WHO Chronicle* Geneva: World Health Organization. **22**(11):473. Public Health Papers, #34

[2] National Screening Committee programme appraisal criteria http://screening.nhs.uk/criteria

4. The role of the UK NSC is in making recommendations and evaluating programmes including their risks, costs and benefits. It is thought that the Committee generally has a sound process for decision making including determination of what not to screen for and identification of evidence gaps.

5. Regular reviews are commissioned by the NSC and there have been recent reviews of breast[3] and cervical cancer[4] screening. In light of the introduction of flexible sigmoidoscopy to the bowel cancer screening programme, a further review for this programme would be timely.

6. Adjustments are made to programmes (for example, changing screening age) based on evidence indicating more effective and cost effective ways of screening. Funding has been made available for pilot studies to prepare for national roll-out. An example is the introduction of human papillomavirus (HPV) testing to replace or supplement cytology screening. Evidence showed that this would achieve benefits in terms of streamlining cervical screening and greater sensitivity. It required significant changes to an already effective screening programme but following successful large-scale pilots there was a national roll-out of HPV testing.

7. Despite this, we consider that there are variations in the evidence base between the different screening programmes. The three national cancer screening programmes (breast, cervical and bowel cancer) are based on available high quality evidence, as are programmes for diabetic retinopathy and aortic aneurysm.

8. In contrast, there are concerns regarding the evidence base for the new Health Check programme[5]. We consider that there is a lack of necessary data to develop such an evidence base and to evaluate the programme. Coverage of the target group is extremely low and may duplicate some of the existing work of GPs. It may be more cost effective and efficient to offer preventative treatment to everyone over a certain age (for instance 50-55 years).

Could the evidence base and sources of scientific advice to Government on health screening be improved? If so, how?

9. The evidence base for UK screening programmes is generally thought to be sound as discussed above. However, we consider that the following improvements could be made.

Monitoring of screening programmes

10. Monitoring of screening programmes could be improved to ensure that the benefits that are predicted from them are actually achieved. Ongoing case-control audits will enable any departure from the delivery of anticipated clinical benefits to be identified and followed up. For example, the ability to test a cervical smear for HPV in women who subsequently develop cancer (and matched controls) would facilitate evaluation of the impact that HPV

[3] The UK National Screening Committee policy on Breast Cancer screening in women over 50. (October 2012) *http://www.screening.nhs.uk/policydb_download.php?doc=282*
[4] The UK NSC policy on Cervical Cancer screening in women. (November 2012) *http://www.screening.nhs.uk/policydb_download.php?doc=219*
[5] MacAuley D (2012) The value of conducting periodic health checks *BMJ*. **345**:e7775

testing would have on cancer rates. Such case control audits could be adopted in all three cancer screening programmes.

Data collection

11. Basic data on person-specific outcomes of screening are currently not collected but is valuable information. For example, how likely is a woman to develop breast cancer after having previously had a false-positive mammogram? Data on screening methods yet to be adopted but under consideration are also difficult to obtain, such as data on rates and outcomes in prostate specific antigen (PSA) testing. Collecting these types of data would greatly increase the evidence base for the screening programme. Additional data on screening uptake and research on reasons for non-participation, combined with investigation into acceptable ways to increase uptake, access and delivery of screening, is also important.

Cohort studies

12. There needs to be wider recognition of the value of data from well characterised large cohorts from screening programmes. Whilst the utility of randomised controlled trials in evidence generation is acknowledged, a small underpowered trial may be less informative than a large and well-conducted non-randomised study. The cervical screening programme, for instance, is based on results from observational studies with strong design and size. The NSC has a set of criteria which it requires for a given screening intervention but the research to produce evidence for or against the criteria could be designed in a variety of ways.

Advisory committees

13. In addition to having individuals with the appropriate expertise, the review process adopted by the Advisory Committee can help to ensure that screening programmes are based on sound evidence. A number of years ago, the Advisory Committee on Cervical Screening advised that the screening age should be increased from 20 to 25 following emergence of strong evidence that screening women under the age of 25 is not effective. This was met with public and some professional opposition, eventually leading to a government request for a review. The Advisory Committee conducted the review with lay input from charity and interested families and again advised that the screening age be retained at 25. The minutes were posted on the internet. This indicates that when there is a transparent approach with strong science, appropriate evidence-based decision making can occur even when there is public disapproval.

How effectively are the potential risks and benefits of health screening communicated to and understood by the public?

Lack of evidence

14. Much effort is expended in all screening programmes in an attempt to communicate the potential risks and possible benefits of screening to those offered the tests. Public information about cancer screening, for instance, is developed by a team independent of the screening programmes and is thorough in its description of both positive and negative aspects. It is thought that the level of understanding among those offered screening tests is better than in the past. For example, many women receiving an abnormal cervical smear

test results believed that, erroneously, that this meant they had cancer, a belief what was corrected with the provision of simple information[6].

15. Despite these efforts there is, however, a lack of evidence of whether this information has been effective. The NSC does not provide information on levels of knowledge or 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.

16. Informed decision making by all those offered a screening test is central to the screening process, so results from the following studies are of concern. One showed that although written information is generally effective at increasing knowledge, it is less effective at achieving informed choices[7]. Another study, as part of a trial offering GP- and midwife-led screening of two serious blood conditions, sickle cell and thalassemia[8], showed that only 35% of women were deemed to have knowledge sufficient to make an informed choice[9]. This study also showed that levels of education, age and fluency in English language all affected the level of knowledge about the screening test, raising further concerns about whether routinely provided information is adequately meeting the needs of the less advantaged. Such findings are replicated in other screening programmes[10].

Difficulty of communicating risks and benefits

17. The difficulty of communicating the complex concepts behind screening is acknowledged: for instance, how to convey the information that you may need to screen 150 women ten times each to prevent one woman dying from cervical cancer and that screening will take less than two days (cumulatively) but that the one woman saved will live for some 15,000 extra days. There is variation in the level of comprehension amongst the public but in general there is a poor understanding of the trade-off between the detection rate (sensitivity) of a test and the corresponding false-positive rate (when the test gives a positive result when no disease is present).

18. There is also confusion over whether the health benefit should be expressed as the relative risk reduction (the proportional difference in mortality rates from a disease between screened and unscreened patients) or absolute risk reduction (the simple mathematical difference in mortality rates from a disease between screened and unscreened patients) and when to use each estimate. It would be helpful to develop a new and simpler way of expressing the health benefits of screening, with academic input.

19. Another factor to consider is that some patients want simple messages, while others seek more comprehensive information. More comprehensive information risks disenfranchising the less advantaged or disengaging busy people, whilst simple information may leave

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[6] Wilkinson C, Jones JM, McBride J. (1990) Anxiety caused by abnormal result of cervical smear test: a controlled trial. *BMJ.* **300**: 440–440

[7] Fox R. (2006) Informed choice in screening programmes: Do leaflets help? A critical literature review *J Publi health.* 29: 309-317.

[8] Dormandy E, Gulliford M, Bryan S, Roberts TE, Calnan M, Atkin K, *et al.* (2010) Effectiveness of earlier antenatal screening for sickle cell disease and thalassaemia in primary care: cluster randomised trial. *BMJ.* **341**:c5132

[9] Brown K, Dormandy E, Reid E, Gulliford M, Marteau TM. (2011) Impact on informed choice of offering antenatal sickle cell and thalassaemia screening in primary care: a randomized trial. *J Med Screen*. **18**:65-75.

[10] Smith SK, Simplson JM, Trevena LJ, McCaffery KJ (2014) Factors associated with informed decisions and participation in bowel cancer screening among adults with lower education and literacy. Medical Decision Making.

other patients dissatisfied. Recently the cancer screening information has been overhauled and this provides a useful opportunity to conduct research to develop the evidence base in this area.

Programme specific concerns

20. We would like to highlight our concern over the information on risks and benefits of screening accompanying the Health Checks. There do not seem to be sufficient details provided, which may be due in part to the weak evidence for the benefit of these checks as discussed above. It is not clear, however, that where evidence does exist whether this is being communicated to patients, for example the side-effects of statins.

How does health screening provided in the UK through the NHS compare with that offered by other countries?

21. We consider that screening in the UK is generally based on available high quality evidence, is cost-effective and regularly reviewed. There is uniform coverage and patients are not 'lost' from a screening programme if they fail to attend one round of screening. The system operates at a population level, which few countries achieve, making the UK unique.

22. However, there is sometimes delay in putting proven interventions into practice. These include HPV testing as the first-line cervical screening test and immunochemical testing – as a more specific and more acceptable test – in the bowel screening programme. Whilst recognising the need to assess evidence and for pilot studies prior to introducing innovations, we would welcome the development of mechanisms to more rapidly introduce changes in screening once they have been proven to be beneficial.

23. Another factor to note is that it is difficult to change screening procedures to tailor for specific groups. We acknowledge that this may be a result of the centralised nature of screening in the UK but this also makes obtaining evidence about people's non-attendance more difficult.

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