Agenda Item 46

Screening report for the Health Overview and Scrutiny Committee 16th November 2011

1. PURPOSE OF THIS PAPER

The purpose of this paper is to provide the Health Overview and Scrutiny Committee with background information on national screening policy and programmes, to provide an update on the East Sussex Brighton and Hove breast cancer screening programme, and to highlight some of the other local screening programmes.

2. BACKGROUND TO SCREENING AND SCREENING PROGRAMMES

2.1 Definition of screening

The National Screening Committee defines screening as:

> *"A process of identifying apparently healthy people who may be at increased risk of a disease or condition. Once identified they can then be offered information, further tests and appropriate treatment to reduce their risk, and/or any complications arising from the disease or condition."*

2.3 The UK national screening committee (UK NSC)

The UK National Screening Committee (UK NSC), founded in 1996, is funded by the Department of Health to:

- advise Ministers and the NHS in the four UK countries about all aspects of screening;
- assess the evidence for programmes against a set of internationally recognised criteria - covering the condition, the test, the treatment options and the effectiveness and acceptability - to ensure screening does more harm than good at a reasonable cost;
- set up practical mechanisms to oversee the introduction of new programmes in the English NHS;
- monitor the effectiveness and quality of screening programmes;
- regularly review policy on screening for different conditions in the light of new research evidence becoming available;
- make recommendations for screening across all clinical areas, including cancer.

Implementation of cancer programmes is the responsibility of the NHS Cancer Screening Programmes and of non-cancer screening programmes the UK National Screening Committee.

2.4 Limitations of screening

In any screening programme, there are false positive results (people without the target condition identified as having it) and false negative results (people with the target condition identified as not having it); no screening programme is 100% accurate. The UK National Screening Committee

(NSC) is increasingly presenting screening as risk reduction to emphasise this point.

2.5 Screening policies

The UK NSC has over one hundred screening policies. A policy review takes between 6 and 24 months, depending on the amount of new evidence to review and the number of stakeholders involved. There are two outcomes of a review: the UK NSC will recommend that screening for a condition should be offered or based on the current available evidence, it should not be.

2.6 Criteria for appraising a screening programme

The UK NSC has developed 22 criteria to assess whether screening should be considered for a certain condition (see Appendix 1). Ideally all of those that are relevant to the condition should be met before a screening programme is initiated.

2.7 National Screening programmes (Appendix 2)

The following national screening programmes are available in England:

Antenatal and newborn

- Fetal anomaly – 1st and 2nd trimester Down's syndrome
- Fetal anomaly – 2nd trimester anomaly scan
- Infectious diseases in pregnancy
- Antenatal sickle cell and thalassaemia
- Newborn and infant physical examination
- Newborn bloodspot
- Newborn hearing screening

Young person and adult

- Cancer – breast
- Cancer – cervical
- Cancer – bowel
- Abdominal Aortic Aneurysm
- Diabetic retinopathy

Other related/national screening programmes (not discussed in this paper)

The following programmes have been introduced although they do not meet the criteria for national screening programmes.

- Chlamydia
- NHS Health checks

2.8 Quality assurance

Quality assurance and performance management are an integral part of all national screening programmes. NHS Cancer Screening Programmes oversee the three cancer screening programmes and the UK National Screening Committee the non-cancer programmes. Quality assurance includes supporting regional centres, provision of guidance on good practice, setting and monitoring standards and targets, and organising quality assurance visits.

3. CANCER SCREENING PROGRAMMES

3.1 Breast cancer

3.1.1 Background

The national breast cancer screening programme currently offers women aged 50-70 years screening every three years. The local programme for East Sussex, Brighton and Hove is provided by Brighton and Sussex University Hospitals' Trust and is commissioned by NHS Brighton and Hove (now part of NHS Sussex).

In 2006/7 as a result of the combination of staffing issues, poor facilities and administrative issues the screening round length of the local programme and some of the associated quality indicators began to slip. In 2008 the breast screening unit moved to new premises at "The Park Centre" which has new digital technology. Staff at the unit have worked extremely hard to return their programme to the high standards it was accustomed to delivering. The unit has also been successful in recruiting staff to vacant posts.

Current performance

The most recent official breast screening performance statistics are for the year 2009/10 and are summarised below.

Area	Coverage for women aged 53-70 years (women screened within the last 3 years)
Brighton and Hove	71.2%
East Sussex Downs and Weald	62.9%
Hastings and Rother	75.9%
England	76.9%

The unofficial performance for coverage in 11/12 for Brighton and Hove is 71.2%. The minimum standard is 70%. All eligible women in Brighton and Hove have been offered screening within the previous three years. The unit is now also meeting the national standards for the time from screening to results, screening to assessment, and technical recalls and repeats (The percentage of women offered and attending an appointment within 3 weeks did fall in August 2011. This is attributed to the holiday season).

It has taken longer for the unit to recover the 36 month round length than expected. This is for two main reasons:

- Firstly the need to return to a programme of rotating site visits across East Sussex which can be maintained for the future. For example, to try to minimise the impact of the delays in previous years, women from some areas had been invited to different locations for screening compared with previous rounds and this has had a "knock-on" effect to the next round.
- Secondly the need to take into account the age expansion programme.

Since February 2011 the unit has consistently invited over 95% of women within 38 months of their previous screen and in August and September 85% were invited within 36 months. The unit expects to achieve the target of 90% of women across East Sussex being invited within 36 months of their previous screen by the end of October 2011.

Of the women from Brighton Marina area who were invited to attend the Park Centre between February and September 2011, 98% were invited within 36 months.

The table below shows, by the four Brighton and Hove planning areas used by the service, when women were last invited for screening and when they are due to be called for the next round.

Area	Due	Due end	Possible Start Date	Possible End Date	Last invited
Brighton Hollingbury	01/12/2011	14/05/2012	**20/09/2011**	**17/06/2012**	**02/12/08 – 14/05/09 Currently being invited**
Hove & Portslade (BN1)	14/01/2013	03/12/2013	**17/06/2012**	**16/07/2013**	**15/01/10 – 02/12/10**
Brighton Central	29/11/2013	01/02/2014	**16/07/2013**	**14/11/2013**	**30/11/10 – 02/02/11**
Brighton Marina	01/02/2014	19/09/2014	**14/11/2013**	**16/06/2014**	**02/02/11 – 20/09/11**

3.1.2 Age expansion and high risk women.

Nationally the programme is being expanded so that women will now be invited from age 47 to 49 and 71 to 73 years. This is being introduced over six years as a randomised project to establish the benefits and harm of being screened for the two new age groups. To be able to begin the round length, units had to be assessed by the national breast screening programme head office as having the capacity to cope with the introduction without adversely affecting the screening of women aged 50-70 years. The East Sussex, Brighton and Hove programme was granted approval to begin the expansion from April 2011.

From January 2012 the national breast screening programme will have responsibility for the surveillance of high-risk women, such as those with a strong family history of breast cancer associated with a breast cancer gene.

3.1.3 Improving uptake by locality

Since moving to The Park Centre the unit has invited local women to attend The Centre for their mammograms. This has helped the unit to recover the round length. However, for some women the extra distance required to

travel to the Centre may have discouraged them from attending for their mammogram. Further analysis of the data is being undertaken to investigate this. To try and mitigate this, the unit is working with the local cancer health promotion team to promote the service and is running additional clinics for those who fail to keep their first appointment.

The programme routinely distributes promotional materials to the GP practices of women it is currently inviting. This is being supplemented by a mail drop in areas where the uptake has been low. This includes information about cervical screening as well.

Promoting the breast screening programme is included in the ongoing work of the local cancer health promotion team. The team promotes the programme either directly to eligible women through educational sessions and attending community events or through key workers and key members of the local community. The local health trainers also support the programme.

3.2 Cervical cancer

3.2.1 Background

The national cervical cancer screening programme offers regular screening to women aged 25 to 64 years of age. Women are invited to attend their GP surgery every three years until age 49 and then every five years. Locally women can also attend the sexual health service at Morley Street. Most local cervical screens are undertaken by practice nurses.

To be routinely invited for their screen women must be on the GP registration system. If a woman does not attend for her screen after two written invitations her GP is advised so that the practice can directly contact her. Women with a result requiring further investigation are referred for colposcopy at BSUHT.

GPs receive payment both for providing the service, and for the coverage they achieve amongst their registered population through the Quality and Outcomes Framework (QOF). Through the QOF practices are able to "exception report" women (exclude them from their figures) who have not attended after being invited three times for their cervical screen. This is not permitted for the national programme. Hence the coverage reported through the QOF is higher than that reported for the national programme.

In recent years in line with national policy the local programme has successfully introduced a new technique for screening (liquid based cytology) and has met the target for 98% of women to receive their results within two weeks. The latter is a great improvement from recent years when women were often waiting over three months for their result.

From 2012 HPV (Human Papillomavirus) testing will also be introduced to the programme. This will eventually reduce the number of referrals of women with screening results requiring further investigation. The HPV

vaccination programme which was introduced in 2008/9, and which is now routinely offered to all year eight schoolgirls, will also help protect against cervical cancer and reduce the need for further investigation. In 2010/11 85% of local year 8 girls completed their three HPV vaccinations.

3.2.2 Current performance

The most recent official coverage information for 2009/10 is shown in the table below:

Area	Coverage for women aged 25-49 years (women screened within the last three and a half years)	Coverage for women aged 50-64 years (women screened within the last five years)	Coverage for all women aged 25-64 years (women screened within the last five years)
Brighton and Hove	71.9%	74.6%	75.9%
East Sussex Downs and Weald	76.0%	77.8%	79.5%
Hastings and Rother	76.0%	77.3%	79.5%
England	74.0%	78.9%	78.9%

The most recent unpublished data from June 2011 shows the coverage for Brighton and Hove women aged 25-64 years to be 76.4%.

The QOF based coverage data for 2010/11 was 83.1% with 11,546 women being exception reported.

The current programme schedule was introduced in 2004, since when women have received their first invitation at 25 years rather than 20 years of age. The national and local coverage for women aged 25-64 years has fallen from 81.2% and 81.7% respectively since 2003. The most significant fall has been in younger women. The total eligible local population of women aged 25-64 years is approximately 78,000 of whom 26,000 are aged 25 to 34 years of age.

3.2.3 Improving local uptake.

As with most screening programmes the coverage for cervical screening tends to be lower amongst women from more socially disadvantaged groups, such as those living in the more socio-economically deprived parts of the city, women from Black and Minority Ethnic Communities and women with disabilities. In addition the uptake amongst women under 35 years and over 50 years has fallen nationally and locally in recent years.

The cancer health promotion team has worked with key professionals and different partner agencies to promote the programme to various local groups such as the Universities, Bangladeshi women's group, children's centres and travellers.

The PCT makes an annual visit to practices to discuss their overall performance using a "balanced scorecard" of performance relating to

various services. Cervical screening is included in this. Individual poor clinical performance is followed up by the PCT's quality team. The cancer health promotion team has also worked with the ten local practices with the lowest coverage to improve uptake of cervical screening. This has included phoning women who have not attended for their screen. Training for reception staff about screening programmes has also been provided.

Historically the information relating to whether lesbians should be offered cervical screening has not always been consistent. Recent research has made it clear that lesbian women are at risk of cervical cancer and that all women should be offered screening. The cancer health promotion team has run an information campaign aimed at the local lesbian population.

Every opportunity is taken to promote cervical screening through local media. These are often linked to national news items such as the tragic death of Jade Goody and a recent storyline on the Eastenders television programme. These national news items tend to result in a temporary increase in the number women having their cervical screen.

3.3 Bowel cancer

3.3.1 Background

The national bowel cancer screening programme invites men and women aged 60 to 69 to be screened every two years; they are sent a home screening kit and an envelope for test return. People over 70 years of age can request a screening kit via a helpline number. The test looks for Faecal Occult Blood (FOB) ['occult blood' means hidden blood] in stool samples. The FOB test does not diagnose bowel cancer, but the results will identify those who need an examination of the bowel (a colonoscopy).

Results are usually received from the laboratory within two weeks of sending the sample. There are three types of results: normal (no FOB detected); unclear (requires repeat FOB test); abnormal (FOB found) and hence colonoscopy required. About twenty in every thousand who have the test will have an abnormal result.

Of those requiring colonoscopy; about 5 in 10 will have a normal result (they do not have cancer or polyps); about 4 in 10 will be found to have a polyp, which if removed may prevent cancer developing; and about 1in 10 will be found to have cancer.

3.3.2 Performance

In 2010/11 the average uptake of bowel cancer screening in Brighton and Hove was 53%, compared to 58% across Sussex. However, up-take increased considerably from November 2010 and reached 70.5% in March 2011.

As with breast and cervical cancer screening, the cancer health promotion team have worked across the city to increase up-take with a particular focus on the more deprived areas.

3.3.3 Age expansion

The age range for screening has now been extended to include men and women up to their 75th birthday. Nationally, screening centres are rolling out the extension following their first two-year screening round (subject to meeting criteria and subsequent approval by the national office). By October 2011, 32 of the 58 screening centres had started inviting the extended population. However, there is a delay in introducing the age extension in Brighton and Hove due to the endoscopy waiting list times in East and West Sussex. Plans have been formulated to address this issue and the intention is that the age expansion will be introduced in 2012.

4. NON-CANCER SCREENING PROGRAMMES

4.1 Diabetic retinopathy

Diabetic retinopathy screening is offered annually to people aged 12 or over with diabetes. The aim of the screening programme is to reduce the risk of sight loss amongst people with diabetes by the prompt identification and effective treatment, if necessary, of sight threatening diabetic retinopathy, at the appropriate stage during the disease process. Systematic screening involves digital photography of the retina followed by a two or three stage image grading process to identify the changes of sight-threatening diabetic retinopathy in the retina.

4.2 Abdominal Aortic Aneurysm (AAA) screening for men

The National Screening Committee has introduced a national screening programme for Abdominal Aortic Aneurysms (AAA) in men in their 65th year. Brighton and Hove is part of a successful bid to introduce AAA screening across Sussex from 2012. The programme is already established in West Sussex. The evidence does not support the introduction of screening for women.

Death from a ruptured AAA is more than twice as common in men as in women. About one-third of AAAs will rupture if untreated, with those above 5.5cm in diameter most likely to rupture. Half of those patients with a ruptured AAA will die before they reach hospital and for those who survive to undergo emergency repair the operative mortality is around 40%. Most AAAs are asymptomatic, but they can present with symptoms such as pain, or may be detected incidentally. When repaired electively there is a risk of peri-operative mortality, which can be up to 6%. The current local peri-operative performance is below 1%.

For Brighton and Hove the screening programme will invite between 1300 and 1400 men aged 65 for an ultrasound scan at a small number of sites across the city. Most men will have a normal scan and will then be discharged from the programme and not screened again. When an aneurysm is detected, depending on its size, the patient will either be kept under surveillance within the programme or referred to secondary services for possible elective surgical repair.

After approximately 10 years, the numbers needing elective surgery will plateau and the number needing emergency repair of ruptured AAA will start to decrease as those who would have needed emergency surgery will already have had their aneurysm repaired electively.

5. ANTENATAL AND NEONATAL SCREENING PROGRAMMES

5.1 Fetal Anomaly Screening Programme (FASP)

Around 700,000 women get pregnant in the UK every year. Over 95% of these pregnancies result in the birth of a healthy baby. However, in a few cases, there are problems affecting the baby's development. Fetal anomaly screening is a way of assessing whether the unborn baby (fetus) could develop or has developed an abnormality or other condition during pregnancy.

Within this programme all women should be offered:

- A screening test for Down's syndrome that meets agreed national standards;
- An ultrasound scan between 18 – 20 weeks 6 days to check for physical abnormalities in their unborn baby;
- Information to help them decide if they want screening or not.

Combined screening for Downs syndrome was introduced locally in October 2009. Prior to this time women had to be referred by their GP to Kings College Hospital, London; only around 50% took up this opportunity.

5.2 Infectious diseases in pregnancy (IDPS)

The infectious diseases in pregnancy screening programme offers screening to all pregnant women for four conditions: Hepatitis B, HIV, Rubella susceptibility and Syphilis. The tests are performed at one of the first antenatal visits and are usually all done from one blood sample. Results are provided at the next clinic visit.

The new IDPS Programme Standards and Laboratory Handbook, published in September 2010, set out the UK National Screening Committee's expectations around the delivery and quality of the IDPS programme locally. These standards were introduced from April 2011 and are to be fully embedded in practice by April 2012

5.3 Antenatal sickle cell and thalassaemia

Sickle Cell disorders are a group of inheritable genetic conditions in which there is an abnormality of the haemoglobin. Haemoglobin carries oxygen to the various organs of the body and is contained in the red blood cells. In the sickle cell disorders some of the red blood cells assume a sickle shape following the release of oxygen. This abnormal shape causes the cells to clump together making their passage through smaller blood vessels difficult, which may lead to blockage of these small blood vessels and an associated inflammatory reaction.

ß Thalassaemia major is a life threatening, genetically inherited, progressive anaemia common in the Mediterranean, Asian, South East Asian and Middle Eastern countries.

The NHS Sickle Cell and Thalassaemia Screening Programme offers a linked programme of:

- Screening during pregnancy for all pregnant women in England
- Screening for sickle cell disease for all newborn babies in England

The NHS Sickle Cell and Thalassaemia Screening Programme is the first service in the world to aim to link antenatal and newborn screening.

The approach in high and low prevalence areas differs; Brighton and Hove is a low prevalence area. From April 2007, all units defined as low prevalence (a fetal prevalence of sickle cell lower than 1.5 per 10,000 pregnancies) were required to offer screening using the recommended family origin question, as well as a formal process of inspection of routine blood indices to screen for thalassaemia.

5.4 Newborn and Infant physical examination (NIPE)

The NHS Newborn and Infant Physical Examination Programme (NIPE) offers parents the opportunity of a head to toe physical examination for their baby to check for problems or abnormalities. The examination is carried out within 72 hours of birth and then again at 6 to 8 weeks of age, as some conditions can develop later. It includes: a general all over physical check, as well as specific examination of the baby's eyes, heart, hips, and testes, in boys. NIPE aims to maintain and improve the standards of care for babies and is part of the Government's Updated Child Health Promotion Programme. Brighton and Sussex University Hospital is one of a number of pilot sites who are piloting the 72 hour examination and the use of web-based software for monitoring and reporting results.

5.5 Newborn bloodspot (See Appendices 3 and 4)

Newborn blood spot screening identifies babies who may have rare but serious conditions. All babies in the UK are offered screening for: phenylketonuria (PKU), congenital hypothyroidism (CHT), sickle cell disease (SCD), cystic fibrosis (CF) and medium-chain acyl-CoA dehydrogenase deficiency (MCADD). For the small number of babies that have one of these conditions early treatment can improve their health and prevent severe disability or even death. It is one of the largest screening programmes in the UK and each year over 700,000 newborns are screened. Uptake of screening tests is high with more than 99% of the babies born each year being screened.

The bloodspot is taken via a heel prick conducted by the midwife between day 5 and day 8 after birth. It is collected on a card which is sent to a London laboratory for analysis.

If a baby is thought to have one of the conditions, he or she will need further tests to confirm the result. The purpose of screening is to identify babies more likely to have these conditions.

5.6 Newborn hearing screening programme

The early identification of hearing loss is known to be important for a child's development. One to two babies in every 1,000 are born with a hearing loss in one or both ears. Most of these babies are born into families with no history of hearing loss. The NHS Newborn Hearing Screening Programme's major aim is to identify all children born with moderate to profound permanent bilateral deafness within 4-5 weeks of birth, and to ensure the provision of safe, high quality age-appropriate assessments and support for deaf children and their families.

6. RECOMMENDATIONS

6.1 The Health Overview and Scrutiny Committee is asked to note the continued improvement and progress towards recovery of the 36 month screening round length by the East Sussex, Brighton and Hove breast screening programme.

6.2 The Health Overview and Scrutiny Committee is asked to note the background information about national screening programmes and the updates on local programmes.

Martina Pickin
Public Health Improvement Principal
Public Health Directorate
NHS Sussex (Brighton and Hove)

Peter Wilkinson
Consultant in Public Health

APPENDIX 1

Criteria for assessing screening programmes

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.

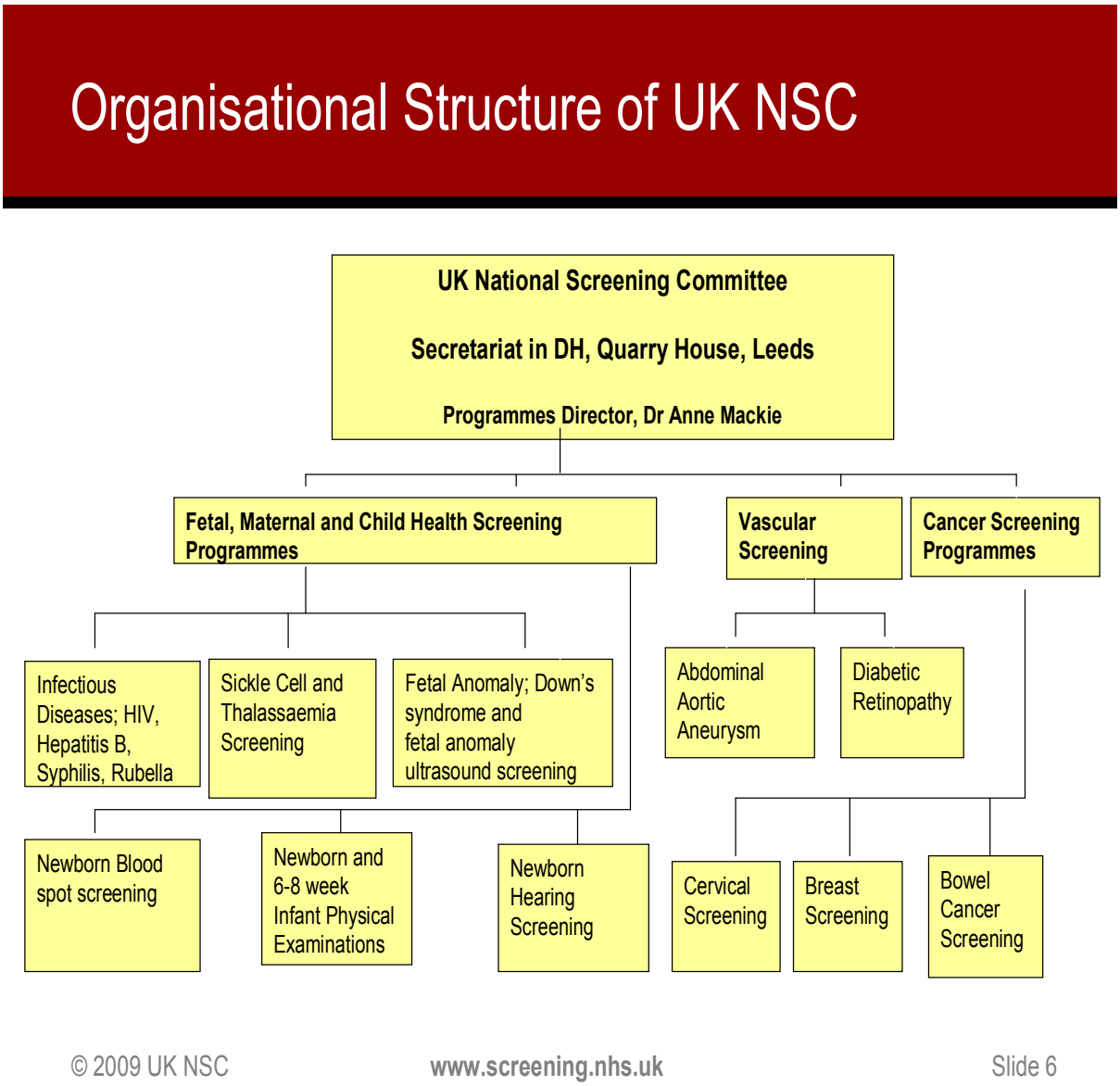
The Screening Programme

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 (i.e. value for money). Assessment against this criterion 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

APPENDIX 2:

Organisational structure of UK National Screening Committee



APPENDIX 3:

Conditions screened for by newborn bloodspot

About 1 in 10,000 babies born in the UK has phenylketonuria (PKU). Babies with this inherited condition are unable to process a substance in their food called phenylalanine. If untreated, they will develop serious, irreversible, mental disability.

About 1 in 4,000 babies born in the UK has congenital hypothyroidism (CHT). Babies with CHT do not have enough of the hormone thyroxine. Without this hormone, they do not grow properly and can develop serious, permanent, physical and mental disability.

About 1 in 1,900 babies born in the UK has a sickle cell diseases (SCD). These are inherited disorders that affect the red blood cells. If a baby has a sickle cell disease, their red blood cells can change to a sickle shape and become stuck in the small blood vessels. This can cause pain and damage to the baby's body, serious infection, or even death.

About 1 in 2,500 babies born in the UK has cystic fibrosis (CF). This inherited condition can affect the digestion and lungs. Babies with CF may not gain weight well, and have frequent chest infections.

About 1 in 10,000 babies born in the UK has MCADD. Babies with this inherited condition have problems breaking down fats to make energy for the body. This can lead to serious illness, or even death.

APPENDIX 4:

Newborn Bloodspot screening pathway