Screening in Scotland

NSC Programmes Director's Report

Summer 2002 – Spring 2003

Dr J A M Gray, CBE, DSc, MD, FRCP, FFPHM
Programmes Director
UK National Screening Committee
Institute of Health Sciences
Old Road
Headington
Oxford OX3 7LF

Tel: 01865 226833
Email: muir.gray@ihs.ox.ac.uk
Website http://www.nelh.nhs.uk/screening

SCREENING IN SCOTLAND

PROGRAMME DIRECTOR'S REPORT – 2002/2003

When the UK National Screening Committee started its work only six conditions had clear screening policies, namely screening for breast and cervical cancer in women, and newborn screening for phenylketonuria, hypothyroidism, neuroblastoma, and congenital dislocation of the hip. Only two of these programmes, the cancer screening programmes, had explicit standards and quality assurance schemes. The mission of the UK National Screening Committee has been to clarify and advise on policies and, where a policy decision has been made, to set up quality assurance systems – to advise on standards, prevent errors, and support continuous quality improvement.

1. Policy advice

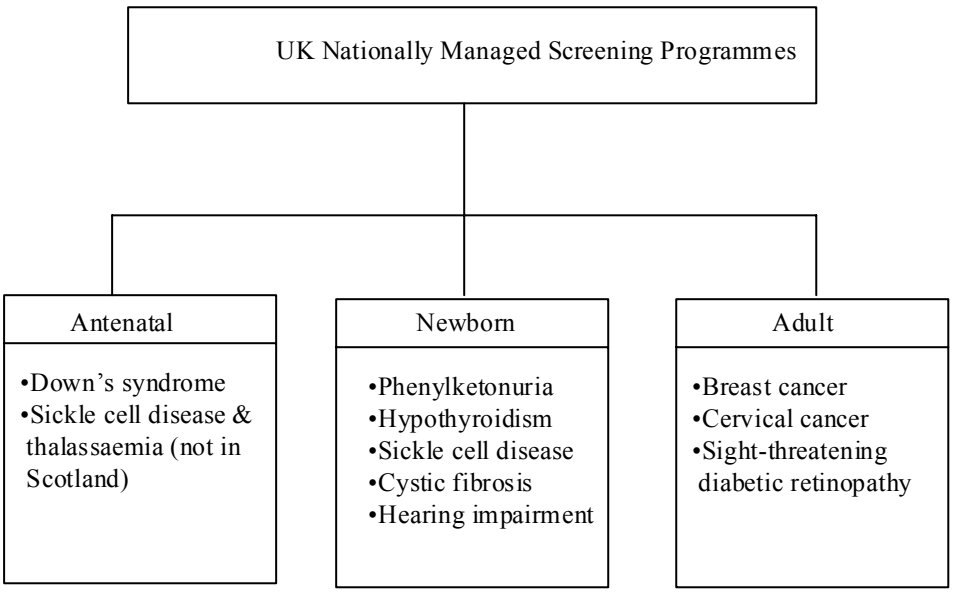
Our National Health - A plan for action, a plan for change published in December 2001 outlined the Scottish Executive's commitment to expanding and improving screening programmes throughout Scotland. In line with the plan the delivery of national screening programmes in Scotland is managed at a number of levels. The Scottish Executive is responsible for developing and agreeing screening policy, taking into account recommendations and advice from the UK National Screening Committee.

Guidance on policy is, however, only one of the responsibilities of the UK National Screening Committee; the other is the creation and development of national screening programmes.

2. Nationally managed screening programmes

Screening is a programme not a test. Appendix 1 lists all of the conditions for which screening has been proposed and for which the NSC has developed a policy. For 50 of the 88 conditions the policy is that screening should not be offered. Of the remaining 38, fifteen of the conditions are now covered by either screening programmes or projects which are co-ordinated and led nationally with management and delivery organised locally. The remaining 23 conditions do not as yet have clear national standards, and local management and public health combine to maximise benefit and minimise harm. The aim of the NSC is to develop national standards and national initiatives which need to be taken so that these standards can be achieved.

The resources invested in national screening programmes as a result of the NHS Plan have resulted in the programme structure set out in Figure 1 which sets out the nationally managed programmes and projects.



Nationally managed projects have also been set up on:

- Screening for Medium Chain Acyl Dehydrogenase Deficiency (MCAD)
- Screening for colorectal cancer
- The use of HPV testing and liquid-based cytology in screening for cervical cancer
- Diabetes, Stroke and Heart Disease Prevention Project
- Prostate cancer risk management

Figure 1

The national screening programmes now embrace a wide range of different conditions and about one-fifth of the population, about one million people, will be screened one way or another every year. The wide diversity in the range of conditions covered by screening, however, does not reflect a wide diversity in programme organisation and management, and there are a number of features common to all national programmes.

2.1 Common values

All national programmes have certain common values, set out in Table 2.

Table 2: Values common to all nationally managed screening programmes

- People should be offered the opportunity to enter a screening programme, and given the necessary information and support to make an informed choice based on their values.
- Professionals involved in screening programmes need development and support.
- Screening programmes aim to maximise benefit, minimise harm, and make the best use of the resources invested.
- Screening programmes need to work in partnership with related clinical services to provide a seamless experience for people needing treatment.
- Explicit and valid evaluation is essential both to fulfil a responsibility for accountability and provide a baseline for quality improvement.
- Programmes are committed to continuous improvement in performance and standards.
- Research can contribute to quality improvement and should be encouraged.

2.2 Common structure

Every national screening programme has a common structure, set out in Figure 2.

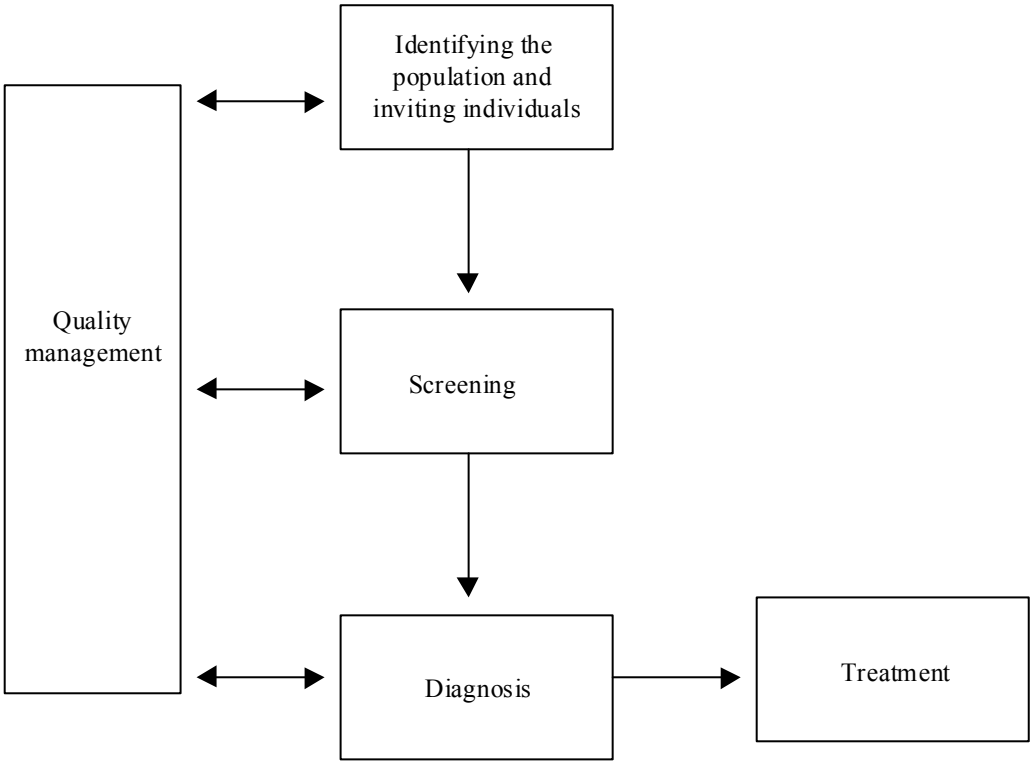


Figure 2

Nationally managed screening programmes are not directly responsible for treatment services but because they are identifying healthy people, some of whom will eventually be referred through to treatment services, there is a responsibility to do everything possible to ensure that treatment services are of high quality. In some screening programmes, for example screening for high blood pressure, there is not a diagnostic phase (Figure 3).

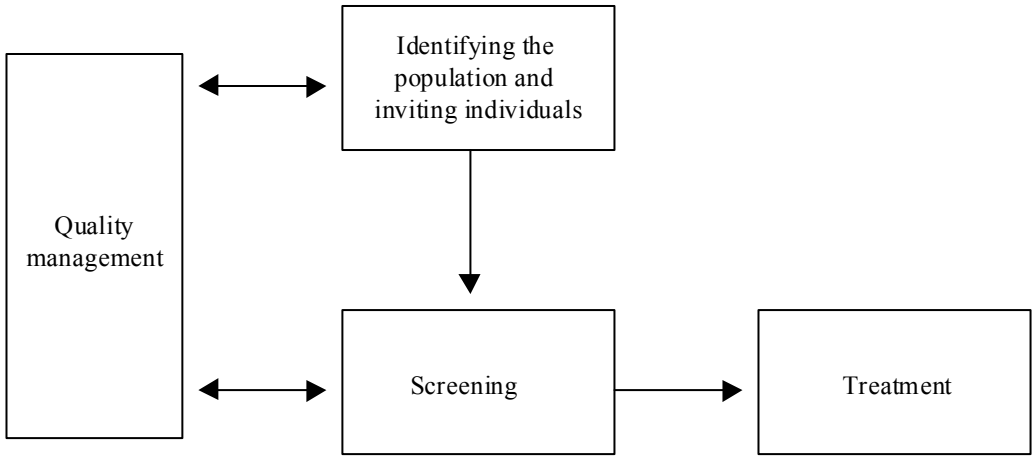


Figure 3

These stages can be identified in every screening programme and the management of the programme is primarily responsible for co-ordination, evaluation and quality improvement. The principles on which the quality improvement work is based were described in our previous report but, in brief, quality assurance has four objectives:

- to reduce the risk of error;
- to manage errors competently and sensitively when they do arise;
- to support continuous improvement in performance;
- to set and re-set standards.

2.3 Common features

Each national programme has a number of common features, set in Table 3.

Table 3: Features common to all nationally managed screening programmes
National screening programmes: • cover a defined population; • have a simple set of objectives; • develop valid and reliable criteria to measure performance and produce an annual report; • relate performance to explicit quality standards; • organise quality assurance systems to help professionals and organisations prevent errors and improve performance; • communicate clearly and efficiently with all interested individuals and organisations; • co-ordinate the management of these activities, clarifying the responsibilities of all individuals and organisations involved.

The programmes that meet these criteria are the screening programmes for:

- Down's syndrome (antenatal screening for trisomy 21);
- phenylketonuria (newborn);
- hypothyroidism (newborn);
- sickle cell disease (antenatal and newborn);
- thalassaemia (antenatal);
- hearing impairment (newborn);
- breast cancer;
- cervical cancer;
- sight-threatening retinopathy.

The National Screening Committee during the year 2002/3 also:

- supervised the pilot screening programme for colorectal cancer;
- supervised, in partnership with the Cervical Screening Advisory committee, the pilot of the use of human papilloma virus for triage in screening;
- initiated a major action research pilot, organised by the Institute of Child Health in London, on screening for medium chain acyl CoA dehydrogenase deficiency (MCADD) and other rare inborn errors of metabolism;
- prepared plans for the introduction of screening for cystic fibrosis in the newborn through the National Bloodspot Centre at Great Ormond Street Hospital;

- launched a pilot programme to screen for the risks of diabetes, heart disease and stroke and their complications in nine inner city populations (Bradford, Bristol, Coventry, Haringey, Leicester, Liverpool, Luton, Portsmouth and Sunderland).

3. Commissioning, co-ordination and monitoring

The NHS Scotland Screening Programmes, which is part of the National Services Division Common Services Agency, is responsible, in conjunction with NHS Boards, for taking forward appropriate national screening developments as well as the co-ordination and monitoring of the programmes.

In addition NHSScotland Screening Programmes is also responsible for the commissioning of the breast screening programme, the colorectal cancer screening pilot, and laboratory aspects of newborn screening programmes. NHS Boards are responsible for commissioning the other national screening programmes for their populations and for ensuring that the programmes meet the required standards and objectives. NHS Board co-ordinators are designated for each screening programme by individual Boards to take responsibility for ensuring the effective delivery of screening programmes.

4. Screening Developments in Scotland in 2002/03

Cancer screening programmes

- Breast screening - extension of routine age of invitation to women aged 65-70 began in spring 2003 with a phased implementation across Scotland over one three year round of screening.
- Cervical screening - introduction of a national system for cervical screening call/recall began in late spring 2003 and will be fully introduced by around 2006. Introduction of liquid based cytology into the cervical screening programme began in early 2003 and will be fully implemented by spring 2004.
- Second round of the Scottish colorectal cancer screening pilot commenced in late 2002.

Pregnancy and newborn screening programmes

- Newborn screening for cystic fibrosis began in February 2003.
- Newborn hearing screening pathfinder sites established in Lothian and Tayside. Screening programme to be rolled out across Scotland by April 2005.
- Haemoglobinopathy screening - assessment work underway. No decision has been taken in relation to a screening programme.

As well as the above specific initiatives there have been a number of generic developments aimed at supporting the introduction of new screening programmes and the improvement and standardisation of the range of pregnancy and newborn screening programmes in Scotland.

- Pregnancy and Newborn Screening Conference for NHS Board Screening Co-ordinators, Child Health Commissioners and other relevant staff, held on 20 March 2003.
- Initial patient information leaflets have been developed;
- A contract has been agreed and product training on the Laboratory Information Management System (LIMS) for all users has been carried out. A phased implementation will now commence in the pregnancy screening laboratories in Glasgow, Tayside, Grampian and Edinburgh, and a single implementation in the newborn screening laboratory in Glasgow.
- The hearing screening pathfinder sites both use the same hearing screening IT system as is used in England (adapted for NHSScotland). Implementation has commenced in Tayside and will then roll out to Lothian. This is not a nationally commissioned system but it is recommended that all NHS Boards use this system.
- Detailed specification for each screening programme and protocols for health care professional staff have been developed;
- Three training roadshow events were held, aimed at providing information for health visitors and midwives involved in pregnancy and newborn screening.

Diabetic retinopathy

- Since the announcement in *Our National Health* that there would be a national strategy for diabetic retinopathy screening, work has been progressing to deliver this commitment.
- All patients with diabetes aged 12 and over in Scotland will be offered diabetic retinopathy screening using digital photography within an organised NHS Board programme that meets the recommendations of the Health Technology Board Scotland report and the Diabetic Retinopathy Screening Implementation Group. The Scottish programme will use a three stage process for mydriasis: (1) digital retinal photography without mydriasis; (2) digital retinal photography with mydriasis; (3) use of biomicroscopy in the event of technical failure with mydriatic digital photography. A comprehensive programme is to be fully operational throughout Scotland by March 2006.

5. Improving the quality of screening programmes

The development of QA standards is the responsibility of NHS Quality Improvement Scotland, taking into account advice from the National Screening Committee and in consultation with NHS organisations. During 2002/03 NHS Quality Improvement Scotland has developed the QA standards for the breast and cervical screening programmes and has begun to assess performance throughout Scotland against these standards. Their findings will be published in due course. In addition the development of QA standards for pregnancy and newborn screening programmes is underway.

In addition to the measures being taken in relation to the individual national screening programmes, cross-cutting work has taken place on a number of issues.

5.1 Professional development

Each national screening programme has to develop training specifically for the professionals involved in a particular type of screening. There is, however, much common ground and it is important for those professionals involved in more than one programme, for example general practitioners or midwives, to understand the general principles of screening and how the different programmes relate to one another.

The work being done to develop the knowledge and skills of public health professionals will be developed to provide generic screening education resources that could be used for any professional group, and should be used by all.

5.2 Development of information systems

Screening is a programme, not a test, and screening programmes need high quality information systems to measure their impact and their quality.

Screening programmes focus on performance measurements as their main indicator of quality but it is also very important to measure outcome, particularly when screening is for an uncommon disease. It is essential to be able to identify all the individuals affected by a condition for which screening has been organised because it may be that the population that is most at risk is that which is not receiving screening. No matter how good the quality of the screening programme, its impact on the population will be significantly reduced if it is not covering the proportion of the population at greatest risk. For this reason registers play an essential part in programme management and monitoring. Understandable concern about confidentiality has led to changes in data management which have made registers more difficult to organise and sustain.

This has been recognised for cancer registers but not yet for other disease registers, and the National Screening Committee has expressed the need for population registers to be developed and maintained, and for those offered screening to be given information describing why this is important.

5.3 Public involvement

The involvement of members of the public, both individually and collectively, in the development and management programmes is of great importance, particularly where population concerns are high. The need to respond to the challenges posed by the Race Relations (Amendment) Act of 2000 led to a review of screening programmes and the necessary action will be taken in 2003/2004. Every programme needs to take into account the needs of different groups and the possibility of prejudice.

The National electronic Library for Screening (www.nelh.nhs.uk/screening) has grown in scope as each nationally managed screening programme has put resources up on the web, and members of the public have access to the same information as healthcare or public health professionals.

5.4 Informed choice

At an individual level, work has continued on the meaning of the term "informed choice", on its measurement, and on the development of resources both for individuals being offered screening and for those professionals who help them come to a decision about whether or not to accept the invitation to be screened.

The issue of informed choice has become of greater significance, not only because of the need to give all people involved in healthcare better information but also because of the technological developments which mean that it is increasingly easy to screen for genetic disorders or to detect mutations that might result in disease. The National Screening Committee worked with the Human Genetics Commission to develop a set of principles to be used in population screening for genetic disorders. These were discussed at an NSC workshop in July 2002 and the report was received and approved by the National Screening Committee.

Four principles emerged:

1. each programme should have clear aims with the outcome of screening being defined in terms that can be understood by the person being offered screening;
2. before screening starts all the consequences of screening should be identified and the course of action for each outcome agreed;
3. ethical issues need to be identified and resolved before screening starts and need to be monitored if screening is offered;
4. there needs to be careful planning for implementation.

The full report of the workshop is available in the National electronic Library for Screening.

The mission is to ensure that all those who are offered screening make a decision either to accept or not to accept the invitation based on best current knowledge as it relates to their own situation, and values remains one of the highest priorities of the National Screening Committee.

6. Population screening and individual risk management

As the work of the teams supervised by the National Screening Committee moves from policy-making to implementation, the emphasis on screening also changes. While remaining strong to the public health principles of screening with the emphasis on doing more good than harm for defined populations, screening programmes also need to respond more sensitively to the individual's need to make decisions about risk that are not only informed by

best current knowledge but also takes into account that individual's values and attitudes towards risk.

Screening programmes either reduce the risk of disease or the risk of the complications of disease, and risk is simultaneously a statistical probability and a part of life. The challenge will be to maintain public health principles, monitoring programmes with respect to the population served while delivering each programme as a personal service uniquely tailored to that individual's values.

Appendix 1

UK NATIONAL SCREENING COMMITTEE

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

Ideally all the following criteria should be met before screening for a condition is initiated:

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).

17. There should be a plan for managing and monitoring the screening programme and an agreed set of quality assurance standards

18. Adequate staffing and facilities for testing, diagnosis, treatment and programme management should be available prior to the commencement of the screening programme

19 All other options for managing the condition should have been considered (e.g. improving treatment, providing other services), to ensure that no more cost effective intervention could be introduced or current interventions increased within the resources available.

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.

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Appendix 2
UK NATIONAL SCREENING COMMITTEE'S POLICY POSITIONS and estimated timeframe for future consideration
March 2003

The table below is a synopsis of the current NSC position on a wide range of conditions. For full details see the web site http://www.nelh.nhs.uk/screening/vbls.html

(NB: NSC = National Screening Committee. HTA – Health Technology Assessment)

DISEASE	CURRENT NSC POLICY	ESTIMATED TIMEFRAME FOR NSC CONSIDERATION
Anaemia	All pregnant women should be tested for anaemia.	To be reviewed by March 2004
Bacteruria in pregnancy	This should not be offered routinely; it may be offered as part of a peer reviewed and ethically approved research project.	To be reviewed in 2005
Chlamydia	Chlamydia screening should not be offered to women with a continuing pregnancy except in the context of a research project approved by an ethics committee.	To be reviewed in 2006
Cystic fibrosis	The HTA report on antenatal screening for cystic fibrosis recommended antenatal screening. The Antenatal Sub-Group of the NSC is currently considering national implementation of antenatal screening based on the experience of the Antenatal Screening Programme which has run in Edinburgh and the Lothians for a number of years.	ANSG recommendation to come to NSC in March 2003
Cytomegalovirus	The NSC endorsed the recommendation of its Antenatal Sub-Group that screening for cytomegalovirus should not be introduced. The recommendation of the Sub-Group was based on a review of the literature.	To be reviewed by March 2004
Diabetes	The Antenatal Sub-Group of the NSC is reviewing the evidence on screening for diabetes in pregnancy following publication of the HTA systematic review and economic evaluation (2002; Vol 6: no 11).	To be reviewed in 2003
Down's syndrome	The government announced on 30 April 2001 a Down's syndrome screening programme. This is part of new initiatives to modernise neonatal and antenatal screening. The UK National Screening Committee (NSC) has recommended that all pregnant women, irrespective of age, should be offered second trimester serum screening. The test used should comprise at least a double test but it would be desirable for laboratories to move to triple or quadruple tests when possible. For these tests the cut-off level for an increased risk should usually be around 1 in 250 at term. Using ultrasound dating this would be expected to yield a detection rate of about 60% for a 5% false positive rate, or better. Screening in both the first and second trimesters will continue to be	Ongoing re implementation

	kept under review and amended guidance will be issued as appropriate. The rapidly changing circumstances are likely to require a systematic review in the near future. A network of regional co-ordinators has been to set up across the country to ensure proper management and co-ordination of local programmes. A meeting was held on Dec 2nd, 2002 and a report prepared for the NSC. The SURUSS report has been published and the Antenatal Subgroup will consider these two reports at their meeting in April 2003 with the NSC receiving their recommendations in June 2003.	
Foetal anomalies	A recent HTA systematic review of second trimester ultrasound screening found some advantage to a scan before 24 weeks. Guidance about markers used in Down's Syndrome Screening will be included in the report on Down's Syndrome Screening that the Antenatal Subgroup will make to the NSC in June 2003.	To be reviewed in 2004
Fetomaternal alloimmune thrombocytopenia	This should not be offered routinely; it may be offered as part of a peer reviewed and ethically approved research project.	To be reviewed by March 2004
Fragile X	On the basis of two HTA reports, a decision was made that Fragile X screening should not be introduced. It may be offered as part of a peer reviewed and ethically approved project.	To be reviewed by March 2004
Haemoglobinopathies, thalassaemia and sickle cell disease	Two HTA reports have been published. There is as yet no agreed detailed policy on antenatal screening for these disorders and the first priority of the NSC is to reach agreement on a screening policy. Following the development of a policy, implementation will be managed in a discrete project under the supervision of the Antenatal Screening Programme. Screening for both sickle cell disease and thalassaemia will be offered antenatally. A pilot antenatal screening programme will be launched in Leeds/Bradford in 2003/4. Screening for sickle cell disease by testing the blood spot taken from newborn babies will be introduced. In Scotland screening assessment work is underway. It is expected that decisions about haemoglobinopathy screening will be taken later in 2003.	Policy re antenatal screening to be decided in 2003 based on the experience of the Leeds/Bradford pilot.
Haemolytic disease of the newborn	Screening for rhesus incompatibility should be offered as part of antenatal screening.	To be reviewed by March 2004
Hepatitis B	Screening for hepatitis B should be offered to all pregnant women in order to identify infants who should be offered immunisation.	To be reviewed in 2006
Hepatitis C	Antenatal screening for Hepatitis C should not be offered routinely. It may be offered as part of a peer reviewed and ethically approved research project. The Antenatal subgroup of the NSC reviewed the literature in 2002.	To be reviewed in 2006
Herpes	Antenatal screening for genital herpes should not be offered routinely. It may be offered as part of a peer reviewed and ethically approved research project.	To be reviewed in 2005
High blood pressure	The significance of high blood pressure screening, as distinct from screening for pre-eclampsia, will be considered by the Antenatal Sub-Group of the NSC.	To be reviewed by March 2004
HIV	Screening for HIV should be offered to all pregnant women to reduce the rate of mother to child transmission.	To be reviewed in 2005

HTLV1	This should not be offered to pregnant women except in the context of a research project approved by an ethics committee. The evidence on screening has been reviewed recently by the Antenatal Subgroup and the NSC meeting in March 2003 endorsed this decision that antenatal screening for HTLV1 should not be offered routinely.	To be reviewed in 2006
Neural tube defect	Screening for spina bifida should be offered to all pregnant women.	To be reviewed by March 2004
Pre-eclampsia	Blood pressure is taken regularly but this has been shown to be ineffectual in screening for pre-eclampsia. A systematic review has been commissioned by the HTA.	To be reviewed in 2005 following HTA review report.
Rubella immunity	In December 2002 the NSC accepted the Antenatal Subgroup's recommendation that screening for rubella immunity should continue on the basis of a review of the evidence.	To be reviewed by March 2004
Streptococcus B	This should not be offered to pregnant women except in the context of a research project approved by an ethics committee. The evidence on screening will be reviewed by the NSC following the HTA evaluation of rapid testing for women in early labour.	To be reviewed by March 2004 following BPSU surveillance results.
Syphilis	Universal screening for syphilis has been reviewed because it had been suggested that there was no longer a need for this screening, and the NSC concluded that such screening should continue on the basis of a report produced by the Public Health Laboratory Service.	To be reviewed in 2006
Tay Sachs disease	Screening for Tay Sachs disease is supported by the NSC.	To be reviewed by March 2004
Thrombophilia	At a workshop in Oxford in December 2000, the evidence for screening for heritable thrombophilia was reviewed. It was agreed at the workshop that there was no evidence to support the universal screening of women of childbearing age to identify those deemed to be at increased risk of venous thrombosis during pregnancy;	To be reviewed in 2005
Toxoplasmosis	Screening for toxoplasmosis should not be offered routinely. It may be offered as part of a peer reviewed and ethically approved research project. The Antenatal Subgroup of the NSC reviewed the literature in 2001.	To be reviewed by March 2004
CHILD : NEWBORN BLOODSPOT		
Biotinidase deficiency	The Child Health Sub-Group of the NSC reported to the NSC in December 1999 that "at the present time it did not recommend that this programme should be included with other newborn biochemical screening", having reviewed two HTA reports on screening for inborn errors of metabolism. The NSC accepted this recommendation, aware of the review of the evidence that the sub-group had undertaken.	To be reviewed by March 2004/5
Congenital adrenal hyperplasia	The Child Health Sub-Group of the NSC reported to the NSC in December 1999 that "at the present time it did not recommend that this programme should be included with other newborn biochemical screening", having reviewed two HTA reports on screening for inborn errors of metabolism (A). The NSC accepted this recommendation, aware of the review of the evidence that the sub-group had undertaken	To be reviewed by March 2004

Congenital hypothyroidism	Screening for congenital hypothyroidism is part of the screening programme for all newborn babies. The UK Newborn Screening Programme Centre has been set up to monitor this and screening for other inborn errors of metabolism.	Update in 2003 on Bloodspot Programme
Cystic fibrosis	Following a decision to introduce Cystic Fibrosis screening, an Implementation Group has been set up to provide advice on screening protocol. The newborn CF screening programme began in Scotland in February 2003.	Update early 2003
Duchenne muscular dystrophy	The Child Health Sub-Group of the NSC reported to the NSC in December 1999 that "at the present time it did not recommend that this programme should be included with other newborn biochemical screening", having reviewed two HTA reports on screening for inborn errors of metabolism. The NSC accepted this recommendation, aware of the review of the evidence that the sub-group had undertaken. The sub-group was informed about the programme for screening that was taking place in Wales but came to the conclusion that this programme should still be regarded as experimental.	To be reviewed by March 2004
Sickle cell disease	Within the national programme of screening haemoglobinopathy and sickle cell disease, priority is being given to neonatal screening. The Antenatal Sub-Group will be considering screening for sickle cell disease during 2002/3. Their considerations are based on two HTA reports on these diseases. Neonatal screening for sickle cell is being introduced into high prevalence areas in 2003 with other areas to follow. In Scotland screening assessment work is underway. It is expected that decisions about sickle cell screening will be taken later in2003.	Update in 2003 on Bloodspot Programme
Inborn errors of metabolism (IEM)	The HTA programme reviewed screening for inborn errors of metabolism stimulated by the development of tandem mass spectrometry. The inborn errors of greatest significance are discussed in separate parts of the National electronic Library for Screening, namely biotidinase deficiency, congenital hypothyroidism, phenylketonuria and medium chain acyl CoA dehydrogenase deficiency. Developments are taking place in both biochemistry and genetics which mean that this topic will be kept under close review by the NSC, working in partnership with NICE, the HTA programme, and the Genetics Commissioning Advisory Group.	For review 2003
Medium chain acyl CoA dehydrogenase deficiency (MCADD)	This should not be offered routinely; it maybe offered as part of a peer reviewed and ethically approved research project. An evaluative study will be commissioned this year to examine the effectiveness of MCADD screening using Tandem Mass Spectometry (TMS) and inform future policy.	For review 2003
PKU	Screening for PKU is part of the screening programme for all newborn babies. UK Newborn Screening Programme Centre has been set up to monitor this and screening for other inborn errors of metabolism.	Update 2003 in Bloodspot Programme
NEWBORN BABIES OTHER		
Biliary atresia	This should not be offered routinely; it may be offered as part of a peer reviewed and ethically approved research project.	To be reviewed by March 2004
Congenital heart disease	Screening for congenital heart disease is part of the routine physical examination of newborn babies. It is the subject of an HTA systematic review that is currently in progress. The Child Health Sub-Group	Update 2004

	of the NSC is concerned about the standard of examination and is aware that at least one other group is considering ways in which it could be improved.	
Congenital cataract	Screening for congenital cataract, other media opacities and anatomical abnormalities is part of the physical examination of newborn babies. As a result of a working party, no recommendations have been made.	Update 2003 under newborn physical examination
Congenital malformations	Detection of congenital malformations is part of the routine physical examination of all newborn babies. Examination for many malformations could not strictly speaking be considered a screening activity. The Child Health Sub-Group of the NSC is concerned about the variability in the quality of this screening examination and is aware that at least one other group is considering steps that could be taken to improve quality. As part of the newborn physical examination a training programme is being developed.	Update 2003 under newborn physical examination
Cryptorchidism	Detection of delayed descent of the testicle forms part of the routine physical examination of all newborn boys. It is under review.	Update 2003 under newborn physical examination
Hearing	The Child Health Sub-Group of the NSC appraised the HTA report on neonatal hearing screening and recommended that the distraction test should be replaced by universal neonatal hearing screening. As part of the NHS Plan for England, additional resources were identified to allow the introduction of the new screening programme. Ministers in England agreed to a pilot project at 20 health authorities to pilot the technology and develop the resources that will be needed for national roll-out, including advising on he best method of rolling out a national UNHS programme. The programme is now in Phase 2 of the roll out. The Institute of Hearing Research in Nottingham has been commissioned to project manage the pilot and there will be an independent evaluation of the pilot phase of the programme. In Scotland newborn hearing screening pathfinder sites have been established in Lothian and Tayside. In addition there is a 3 year screening pilot underway in Highland and Western Isles. Screening programme to be rolled out across Scotland by April 2005.	Ongoing Pilot review
Neuroblastoma	Screening for neuroblastoma should not be offered.	To be reviewed by March 2004
CHILD **Other**		
Autism	The Child Health Sub-Group of the NSC reviewed the evidence on screening for autism and decided that the introduction of screening could not be recommended to the NSC.	To be reviewed by March 2004
Cryptorchidism (delayed descent of the testicle)	Screening for delayed descent of the testicle currently forms part of the physical examination of the newborn baby. The desirability of subsequent examinations is to be reviewed.	Update 2004 under newborn physical examination
Dental disease	The Child Health Sub-Group of the NSC reported to the NSC in December 1999 on screening for dental disease. They identified screening for dental disease as a priority for review and made a number of recommendations, set out on a linked web site.	Review 2003
Developmental and behavioural problems	The Child Health Sub-Group of the NSC reported to the NSC in December 1999 that "screening for these complex developmental conditions does not meet the NSC criteria". The Child Health Sub-	To be reviewed by March 2004

	Group emphasised that this does not mean that these are unimportant problems but that other approaches had to be used to prevent and mitigate these problems and their effects.	
Developmental dislocation of the hip	Screening for CDH/DDH is part of the physical examination of newborn babies. The NSC recommends that every child should have a clinical examination based on the Ortolani Barlow manoeuvre within the first week of life and again at six weeks. Children who have a positive clinical examination should have an ultrasound examination of the hips. Further research is needed to determine whether children with significant risk factors, such as a positive family history or breech presentation at birth, but in whom there are no abnormal clinical findings, would benefit from ultrasound examination. The changes and training required will be co-ordinated through a national implementation project managed by the Child Health Screening Programme following a workshop in May 2002.	Update 2003 under newborn physical examination
Growth	The Child Health Sub-Group of the NSC reported to the NSC in December 1999. They recommended a number of actions including "children should have their height and weight measured at around the time of school entry and the 0.4 cut-off for height should be used to initiate referral".	Review 2003
Hearing	Although most cases of hearing impairment should be identified before school entry, there will be some cases that are missed and the Child Health Sub-Group of the NSC made recommendations that screening for hearing loss in school age children should continue while further research was being undertaken.	Review 2003
Hypertension	Screening for hypertension should not be offered to children.	To be reviewed by March 2004
Hypertrophic cardiomyopathy	The NSC commissioned a review of the evidence about the benefits of screening in 2000. The NSC endorsed the recommendation of its Child Health Sub-Committee that there should not be a national screening programme until further evidence is available.	To be reviewed by March 2004
Hyperlipidaemia	The NSC received the Health Technology Assessment report on screening for hyperlipidaemia which reviewed the evidence about screening all people aged 16 years to identify those who could be further investigated to diagnose familial hypercholesterolaemia. The NSC decided to support the other method proposed in the HTA report, namely cascade screening of the relatives of patients with confirmed familial hypercholesterolaemia.	To be reviewed by March 2004
Iron deficiency anaemia	The evidence about the benefits of screening for iron deficiency anaemia was appraised by the Child Health Sub-Group and in its report to the NSC in December 1999 the Sub-Group recommended that the emphasis should be on primary prevention by good nutritional advice but did not recommend screening for this disease.	To be reviewed by March 2004
Lead poisoning	The NSC does not recommend screening for lead poisoning.	To be reviewed by March 2004
Obesity	The NSC received the report of a consensus conference held at Coventry on 29 July 2000 and agreed that there is not enough evidence, at this time, to recommend screening for obesity. The Child Health subgroup emphasised that this does not mean this is an unimportant problem but that other approaches had to be used to prevent and mitigate this problem and its effects.	To be reviewed by March 2004
Scoliosis	The NSC reviewed the evidence on screening for scoliosis and decided that the introduction of	To be reviewed by March 2004

	screening should not be recommended.	
Speech and language delay	Based on an HTA report, the NSC decided that screening for speech and language delay should not be offered.	To be reviewed by March 2004
Vision defects	The Child Health Sub-Group of the NSC reported to the NSC in December 1999 recommending a number of changes to the screening programme for visual problems. As part of the implementation of the National Plan, the Child Health Sub-Group will be supervising a programme of work to improve the quality and reduce the variability of screening for vision defects following a workshop in May 2002. The NSC agreed with the recommendation in Health for All Children 4th Edition that screening for vision defects in 7 yr old children be abandoned.	Review 2003
ADULT		
Abdominal aortic aneurysm	The Medical Research Council has funded a major RCT of screening. The trial reported in 2002. A feasibility study is currently being carried out.	To be reviewed by March 2004
Alcohol problems	There is no evidence to support the systematic screening of either the whole population or sub-sets of the population for alcohol problems. If there is a clinical suspicion of excessive intake of alcohol, for example in patients with liver disease, then it may be appropriate to enquire about alcohol history, but this is part of good clinical practice and is not screening.	To be reviewed by April 2006
Alzheimer's disease	The NSC considered this topic in March 2003 and concluded that screening for Alzheimer's Disease should not be recommended	
Bladder cancer	Screening for bladder cancer should not be offered routinely to the whole population; it may be offered via the Health & Safety Executive who organise a screening programme for people at high risk of bladder cancer because of occupational exposure, or as part of a peer reviewed and ethically approved research project. The NSC reviewed the evidence on the effectiveness of dipstick testing for microscopic haematuria and decided that it should no longer take place.	To be reviewed by April 2004
Breast cancer	Women aged over 50 on population registers are invited for mammography every three *years through the Breast Cancer Screening Programme*. Full information about the NHS Breast Screening Programme is contained on the programme web site. In Scotland the extension of the age range of invitation to 70 years will begin in Spring 2003 on a phased basis.	To be reviewed by April 2005
Cervical cancer	All women aged 20-64 (20-60 in Scotland) on population registers are invited for screening by the NHS Cervical Screening Programme. Full information about the NHS Cervical Screening Programme is contained on the programme website. In Scotland the introduction of liquid based cytology into the screening programme began in early 2003 and will be fully implemented by spring 2004.	To be reviewed by April 2005
Chlamydia infection	Following the publication of a report by the Department of Health Advisory Group, a pilot screening programme was funded in Portsmouth and the Wirral. The evaluation report of the pilot was made to the NSC in June 2001. The report was also made available to the group in the Department of Health in London developing the Sexual Health Strategy and the strategy was published in the autumn of 2001. This led to a programme being rolled out at ten sites. In Scotland a Sexual Health Strategy is currently being	To be reviewed in Dec 2003

	developed. One of the issues which the Report will address is action aimed at reducing the incidence of sexually transmitted infections.	
Colorectal cancer	A pilot screening programme for colorectal cancer was started in 2000. Results are expected in 2003. The NSC organised a workshop on the use of family history or genetic markers to identify a high risk group and made recommendations to the National Screening Committee at its meeting on 13th June 2001, based on a report of the workshop, and the policy on genetic screening for colorectal cancer was agreed: there is no evidence to support the introduction of a screening programme designed to identify people at high risk of hereditary colorectal cancer.	To be reviewed before April 2004
Coronary heart disease	The National Service Framework in England recommends that priority be given to the identification of people with coronary heart disease so that they can be given systematic follow-up and offered advice and treatment to reduce the risk of recurrent infarction. For people who are not in this high risk group, the priority is to promote lifestyle change, including a wide range of social measures, in addition to health education, and screening is not recommended for people at low risk of coronary heart disease or stroke. The NSC is integrating these recommendations with those of the National Service Framework for Diabetes to create the Diabetic , Heart Disease and Stroke Prevention Project. The project is being piloted in nine inner city Primary Care Trusts where the need is greatest.	To be reviewed by April 2004
Deafness	Screening for hearing loss is one aspect of screening in old age which is being evaluated in a major randomised control trial funded by the MRC.	To be reviewed by April 2004
Depression	Routine screening of the population or sub-sets of the population for depression is not recommended by the NSC. The Antenatal subgroup will be reviewing the evidence about screening for depression and other psychotic problems in pregnancy in 2003. The Child Health Sub Group reviewed the evidence for screening for postnatal depression in 2002 and the recommendation was that until more research is conducted into its potential for routine use in screening for postnatal depression, the National Screening Committee recommends that the EPDS should not be used as a screening tool. It may, however, serve as a check list as part of a mood assessment for postnatal mothers, when it should only be used alongside professional judgement and a clinical interview. The professional administering it should have training in its appropriate use and should not use it as a pass/fail screening tool. Practitioners using it should also be mindful that, although it has been translated into many different languages, it can pose cultural difficulties for the interpretation, particularly when used with non English speaking mothers and those from non-western cultures.	To be reviewed by April 2004.
Diabetes	General population screening should not be offered except as part of a peer reviewed and ethically approved project. Whole population screening has been assessed against the NSC criteria and does not meet a number of the criteria. The National Screening Committee has integrated the screening for diabetes with screening of those at	To be reviewed by April 2003

	highest risk of heart disease and stroke and has set up a pilot Diabetes, Heart Disease and Stroke Prevention Project in nine inner city populations.	
Sight threatening diabetic retinopathy	The NSC, working in partnership with the relevant professional organisations, reviewed the evidence about screening for *sight threatening* diabetic retinopathy and has made recommendations for action which have been enacted in Scotland, Wales and N Ireland. In England the Diabetes NSF set a target that by 2006, a minimum of 80% of people with diabetes are to be offered screening for the early detection (and treatment if needed) of diabetic retinopathy as part of a systematic programme that meets national standards, rising to 100% coverage of those at risk of retinopathy by end 2007. Diabetic retinopathy screening programme to be operational through Scotland by March 2006.	To be reviewed by April 2004
Domestic violence	The NSC commissioned a report from the Department of Primary Care at the Royal London and Bart's Medical School. The report was received at the NSC meeting in Cardiff in March 2001; on the basis of this report the NSC decided that screening for domestic violence should not be introduced. Further consideration of this topic is being done under the umbrella of the Children's National Service Framework.	To be reviewed by April 2004
Glaucoma	The NSC in co-ordination with the Welsh Assembly convened a workshop on screening for glaucoma in September 2001 and report has been issued. No action is being taken on this at present because of the scale of work needed to achieve the diabetic retinopathy targets.	To be reviewed by April 2004
Haemochromatosis	The NSC received a review of the evidence of screening for haemochromatosis set against its criteria. On the basis of this review it was decided that screening for haemochromatosis should not be recommended.	To be reviewed by April 2005
Hepatitis C	The routine testing of all intravenous drug users for Hepatitis C has been discussed but this is an issue relating to clinical practice and is not screening.	To be reviewed by April 2005
Lung cancer	The National Screening Committee considered data from an American study at its meeting in March 2003 and concluded that the findings reinforced the policy not to offer screening. A major trial is currently under way in New York and the topic will be reviewed when that trial reports because there are no plans for a UK trial of adequate power.	To be reviewed 2005
Oral cancer	A series of workshops was held by small expert groups and a report presented to the NSC in March 2003. Oral cancer is increasing in young adults but the natural history of the disease remains largely unknown. The experts recommended that 1) the epidemiology of the disease be investigated with long-term prospective studies, 2) opportunistic screening by all health professionals should be encouraged and 3) population awareness should be increased through other health education programmes.	To be reviewed in 2005
Osteoporosis	The NSC reviewed the evidence about the benefits of screening for osteoporosis and concluded that this should not be introduced at present. NICE is currently carrying out a review of osteoporosis screening.	To be reviewed by April 2004
Ovarian cancer	The MRC has funded an RCT of ovarian cancer screening. No screening should take place outside this trial. Some services are offering a screening service to people deemed to be at "high risk", but with no agreement about the criteria used to assess risk, no-one outside the context of the MRC trial	To be reviewed by April 2004

	should be offered screening because they are deemed to be at high risk unless the offer is made in the context of a peer reviewed and ethically approved trial.	
Postnatal depression	Until more research is conducted into its potential for routine use in screening for postnatal depression, the National Screening Committee recommends that the EPDS should not be used as a screening tool. It may, however, serve as a check list as part of a mood assessment for postnatal mothers, when it should only be used alongside professional judgement and a clinical interview. The professional administering it should have training in its appropriate use and should not use it as a pass/fail screening tool. Practitioners using it should also be mindful that, although it has been translated into many different languages, it can pose cultural difficulties for the interpretation, particularly when used with non English speaking mothers and those from non-western cultures.	To be reviewed by April 2004
Prostate cancer	Two systematic reviews of prostate cancer screening were published in 1997 by the R&D Programme of the Department of Health. On the basis of these reviews, the UK National Screening Committee recommended to the Ministers of the four Health Departments of the United Kingdom that prostate cancer screening should not be introduced and that men should not be invited for PSA testing in the way that women are invited for mammography. The main reason is that there was no good evidence of benefit from PSA testing when the evidence was set against the NSC criteria for screening programmes. The UK National Screening Committee recognises, however, that many men ask for PSA testing either because they believe that PSA testing would increase the chance that their cancer would be cured if found or simply to relieve their anxiety if the test result was negative. Therefore, a service to allow people to appraise the probable benefits and harms of the PSA test, called the Prostate Cancer Risk Management Programme, is being introduced. The key elements in this programme would be: • ensuring that people considering a PSA test are given all the information about the risks of the test, using methods for ensuring informed choice that have been tested in research settings and piloted in ordinary service settings • ensuring that prostate specific antigen testing to an explicit quality standard is available to everyone who agrees to have a test • ensuring the availability of a systematic and standardised follow-up pathway for people whose test is above the threshold. A Prostate Cancer Risk Management Programme Information Pack for Primary Care was launched on 24th Sept 2002 and more information can also be found in the Cancer Bacup booklet "Understanding the PSA test". The HTA has funded a trial of prostate cancers detected at an early stage..	To be reviewed by April 2004
Renal disease	Screening for glomerulonephritis *or renal failure* should not be offered to the whole population	To be reviewed in 2005

	routinely. It may be offered as part of a peer reviewed and ethically approved research project. This decision, taken in conjunction with the Committee's decision on testing for bladder cancer and diabetes that screening by urine dip stick testing is not recommended. Screening by dip stick testing for proteinuria should no longer take place.	
Stomach cancer	The MRC has not funded the proposed application for a randomised controlled trial to assess the efficacy of population screening for *helicobacter pylori* as a means of reducing the risk of gastric cancer. Screening for stomach cancer should not be undertaken.	To be reviewed by April 2005
Screening in old age	The MRC is currently conducting a randomised controlled trial of screening in old age and the NSC will review the evidence when this trial has been completed.	To be reviewed by April 2004
Stroke	The NSC is currently awaiting the publication of the second HTA report on stroke prevention by the detection and treatment of high blood pressure and a NICE review of the management of high blood pressure. The findings of these two studies will be incorporated in the Diabetes, Heart Disease and Stroke Prevention Project.	
Testicular cancer	A number of sources recommend testicular self-examination. The NSC does not classify interventions designed to promote earlier presentation to be screening and therefore does not give policy guidance *on such interventions.*.	To be reviewed by April 2004
Thrombophilia	At a workshop in Oxford in December 2000, the evidence for screening for heritable thrombophilia was reviewed. It was agreed at the workshop that there was: ♦ no evidence to support the universal screening of women of childbearing age to identify those deemed to be at increased risk of venous thrombosis during pregnancy; ♦ no evidence to support screening for heritable thrombophilia in asymptomatic women prior to prescription of oral contraception or hormone replacement therapy; a woman with a personal history of venous thrombosis should be advised to avoid oral contraception and hormone replacement therapy if acceptable alternatives are available and should be counselled regarding the level of risk faced; ♦ no evidence to support the identification and screening of the relatives of people diagnosed as having heritable thrombophilia.	To be reviewed by April 2004
Thyroid disease	No screening except in the context of peer-reviewed and ethically approved research. A research project funded by PPP Healthcare Trust stated in 2001, lead investigator Professor Jim Parle, University of Birmingham.	To be reviewed in April 2004