Recommendation

Members are asked to note the attached Public Health Screening Programmes Annual Report to March 2007.

Introduction

This annual report presents information about the following screening programmes offered to residents across NHS Greater Glasgow and Clyde:

- Cervical Screening
- Breast Screening
- Communicable Diseases in Pregnancy
- Down’s Syndrome and Neural Tube Defects
- Newborn Bloodspot
- Universal Newborn Hearing
- Diabetic Retinopathy screening
- Pre-School Vision Screening

In addition, plans for the implementation of bowel screening are highlighted.

Screening is a public health service offered to specific population groups to detect potential health conditions before symptoms appear. Screening has the potential to save lives and improve quality of life through early diagnosis of serious conditions.

Each year, approximately 250,000 NHS Greater Glasgow and Clyde residents are eligible for screening (see Table 1).
Table 1 Approximate Eligible Target Population

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Following the dissolution of NHS Argyll and Clyde and the formation of NHS Greater Glasgow and Clyde, one challenge for Public Health Screening Unit is the different modalities and service provision across NHS Greater Glasgow and Clyde.

This annual report highlights both similarities and differences in the delivery of the screening programmes and constitutes a benchmark in the path for integration and harmonisation across NHS Greater Glasgow and Clyde.

1 Cervical Screening

- Cervical cancer is caused by oncogenic types of human papilloma virus (HPV), mainly types 16 and 18, and the infection is generally transmitted sexually.

- Women aged 20 to 60 who live in Greater Glasgow and Clyde areas are invited to have a smear test taken every three years.

- There are approximately 360,000 women aged 20 to 60 resident in NHSGGC in the target population. Following the exclusion of those with no cervix, approximately 340,000 women are eligible to be invited to participate in the programme over three years. Each year approximately 113,000 women are sent an invitation to attend.
• The uptake rate has been dropping: between 1999 - 2000 and 2006 - 2007 the 5.5 years cervical screening uptake rate fell from 87% to 81.1% in Argyll and Clyde, from 82.5 to 79.5 in Greater Glasgow and from 86.7 to 82.6 Scotland wide. ISD data continues to be reported based on the old NHS Board boundaries as CHI continues to code patients according to those.

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• In 2006 we reviewed the notes of women who developed invasive cervical cancer, diagnosed in 2005 and 2006. Fifty patients were diagnosed with invasive cervical cancer in 2005 and 49 women were diagnosed with invasive cervical cancer in 2005. The largest number of cervical cancers occurs in women aged between 30 and 59 years.

• 33 of 50 invasive cervical cancers in 2005 and 16 of 49 in 2006 were detected at screening with the rest of the women presenting to the service with symptoms.

• Only 25 women out of the 50 with invasive cervical cancer in 2005 and 22 women of 49 with invasive cervical cancer in 2006 had a complete smear history. Over the two years audited 17 women out of the 99 that developed cancer had never had a smear; that represents approximately 1 in 5.2 women.

• There were 16 deaths from cervical cancer over the two years audited; 32 women were under follow up at colposcopy service and 44 were under follow up in the oncology service.

• There is a downward trend in the standardised rate per 100,000 population for both cervical cancer registrations and deaths. Due to the small numbers of cervical cancers and deaths from cervical cancer it is expected to see variations around a trend.

• In January 2007 the National Colposcopy Clinical Information Audit System (NCCIAS) was installed in all the Colposcopy clinics. The system allows Colposcopy staff to retrieve and audit colposcopy data.

• During 2006-2007 we planned for the implementation of the Scottish Cervical Call Recall System (SCCRS) that went live in May 2007 across Scotland. The advantage of the new system is that women have a complete e-health record detailing their whole smear history. In addition the system has inbuilt failsafe mechanisms to ensure that women are not lost to follow up when referred to colposcopy.

• As part of the initiatives aimed to improve uptake, we submitted comparative practice based uptake figures to all practices and to the Community Health (Care) Partnerships. In addition we submitted evidence to the Scottish Executive Health Department (now known as Scottish Government Health Directorates) to request changes to the GMS contract to remove “defaulter” as an exclusion category.
In addition plans are under way to develop an awareness campaign aimed specifically at the age and social groups with lowest uptake; to promote the cervical screening programme by the Sandyford Initiative; and to take smears at the termination of pregnancy clinics. An equity audit is planned for 2007-08.

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2 Breast Screening

This report presents data for the breast screening round 2003-2006 in NHS Greater Glasgow and Clyde.

For the purpose of this report the two Health Boards - NHS Argyll and Clyde and NHS Greater Glasgow – are reported side by side as national datasets are not yet merged.

The number of women eligible for breast screening across the area of NHS Greater Glasgow and Clyde increased from approximately 104,000 in 2003 when women aged 50 to 64 were eligible for screening to approximately 143,000 at the end of the round when women aged 50 to 70 were invited for screening.

132,133 women were invited to participate in breast screening over the 2003 -2006 screening round.

The uptake rate in NHS Greater Glasgow increased from 61.9% in the 1991 -1994 round to 71.8% in the 2003 - 2006 round. During the same period the uptake rate increased in NHS Argyll and Clyde from 68.8% to 73.2%. The uptake rates are similar across age bands, with a very small drop among women aged 65 to 70.

There has been an increase in the standardised rate of breast cancer from 95.9 per 100,000 population in 1994 to 124.1 per 100,000 population in 2004 for the area of NHS Argyll and Clyde; from 112.1 per 100,000 population in 1994 to 118.2 per 100,000 population in 2004 for the area of NHS Greater Glasgow. This is mirrored by a similar trend for the whole of Scotland where the rates increased from 104.4 in 1994 to 120 in 2004.

The standardised death rates from breast cancer have dropped from 40.3 per 100,000 population in 1994 to 32.9 per 100,000 population in 2006 for the area of NHS Argyll and Clyde; from 41.0 per 100,000 population in 1994 to 30.9 per 100,000 population in 2006 for the area of NHS Greater Glasgow and from 38.1 per 100,000 population in 1994 to 28.5 per 100,000 population in 2006 for Scotland.

3 Planning For Bowel Screening Programme

Colorectal (Bowel) Cancer is the third most common cancer in Scotland. Every year over 3,400 people are diagnosed with the disease. In NHS Greater Glasgow and Clyde each year there are approximately 750-830 new cases registered and approximately 350 to 400 deaths.
The Scottish Bowel Screening Programme was launched in 2007 and will be fully implemented across Scotland by the end of 2009. NHS Greater Glasgow and Clyde plan to implement the programme in April 2009.

The programme will invite all men and women between the ages of 50 – 74 years registered with a General Practice. It is estimated that 307,000 NHS Greater Glasgow and Clyde residents would be eligible to be invited to participate in the Bowel Screening programme every 2 years.

A testing kit will be sent to individuals’ homes to provide three stool samples. The test will be completed at home and returned to the National Bowel Screening Centre in Dundee for analysis.

Based on data from the bowel screening pilot and assuming a 50% uptake rate of the faecal occult blood test (FOBT) in males and 52% uptake rate in females, it is estimated that each year 1628 NHS GGC residents will have a positive screening result, 1391 will proceed to have a colonoscopy and 137 will be diagnosed with invasive bowel cancer.

The business case submitted to the Performance Review Group on 19 September 2006 has secured the resources necessary for planning, implementation and delivery of the bowel screening programme.

It is highly desirable that a bowel screening IM&T module will be developed to monitor the performance of the programme and track patients through the process of diagnosis and treatment for colorectal cancer.

The system will have to be integrated with Patient Administration Systems, endoscopy, theatres, laboratory, pathology and radiology and will have multidisciplinary team (MDT) conference management facility. The system will have to be capable of producing reports, alerts and letters with results; reports on progress against quality assurance standards and NHS Quality Improvement Scotland standards.

4 Communicable Diseases in Pregnancy

To comply with the NHS Quality Improvement Scotland standards (Clinical Standards 2005, Pregnancy and Newborn Screening), protocols covering each of the 4 communicable diseases routinely tested for in pregnancy – HIV, rubella, hepatitis B virus and syphilis - have been developed and implemented throughout Greater Glasgow and Clyde. These protocols are major steps towards a consistent approach to co-ordinating this screening programme throughout the Board area.

All women are offered screening for the four communicable diseases, and receive an information leaflet about the screening tests prior to attendance at their first booking visit.

15,327 pregnant women had a first booking visit at a Greater Glasgow and Clyde hospital during 2006/07. This includes all first booking visits at hospital, at a clinic outside of hospital, including community outreach and at GP surgeries or at home.

Laboratory data indicates that the uptake of screening for communicable diseases in pregnancy is high, greater than 95% for all four tests.

The number of women detected in pregnancy as having HIV, hepatitis B virus or syphilis is small (7, 39, 12 respectively). However as the majority of these women were not previously
known to be infected, the detection of these women and the implications for their health and the health of their babies are immense and illustrates the success of the screening programme. All infected women and their babies were offered appropriate treatment and care.

5  **Down’s syndrome and Neural Tube Defects**

- In NHS Greater Glasgow and Clyde screening for Down’s syndrome and neural tube defects (NTDs) is offered to all pregnant women at their booking visit.

- In the year 2006/2007 there were a total of 15,327 women booking at antenatal clinics across NHS Greater Glasgow and Clyde. It is estimated that 15% of these booked in the second or third trimester (late bookers).

- Currently, there are three screening pathways in NHS Greater Glasgow and Clyde: first trimester combined testing for Down’s syndrome with second trimester blood testing (offered to women at the Queen Mother’s Maternity Hospital – around 22% of women); first trimester combined testing for Down’s syndrome with 18-20 week foetal anomaly ultrasonography (offered in the Clyde area of NHS Greater Glasgow and Clyde - around 22% of women) and second trimester blood testing (offered in all other areas of NHS Greater Glasgow and Clyde - around 55% of women).

- The overall uptake of Down’s syndrome and NTD laboratory screening in NHS Greater Glasgow and Clyde is 66.23%.

- The proportion of women that have a “high risk” screening result and are offered further investigation following screening testing are: 4.9% for the first trimester combined Down’s syndrome testing; 6.2% for second trimester blood testing for Down’s syndrome and 2.6% for NTD second trimester blood testing.

- The proportion of women who decide to take a diagnostic test following a “high risk” screening result are: 70% for women screened in the first trimester and 60% for women screened in the second trimester.

- The proportion of all cases which were detected by laboratory screening during pregnancy is: 88% for the first trimester combined Down’s syndrome test; 66% for second trimester blood testing and 85% for NTD second trimester blood testing.

- The National Screening Committee Good Practice Guidelines currently recommend that a detection rate of 90% with a false positive rate of less than 2% be achieved by 2010.

- The priority for the programme is to achieve an equitable and integrated programme for Down’s syndrome and neural tube defects throughout NHS Greater Glasgow and Clyde. The proposed model of care is to offer the first trimester combined testing for Down’s syndrome and the 18-20 week foetal anomaly ultrasonography. Late bookers will have access to second trimester quadruple serum testing for NTDs and foetal anomaly scanning.

6  **Newborn Bloodspot Screening**

- The newborn bloodspot screening programme offers tests to detect certain congenital metabolic abnormalities which can cause problems in growth and development and for which there is effective management or treatment. The conditions screened for are phenylketonuria (PKU), congenital hypothyroidism (CHT) and cystic fibrosis (CF)
Screening is offered to all newborn babies resident in Greater Glasgow and Clyde.

Newborn Screening for phenylketonuria (PKU) and congenital hypothyroidism (CHT) has been in progress since 1965 and 1979 respectively. Newborn screening for cystic fibrosis (CF) was added in Scotland in February 2003.

A heel prick sample of blood is taken by the community midwife on the baby’s fifth day of life and posted to the National Newborn Screening Laboratory in Yorkhill where it is analysed for markers of the three conditions.

Excellent communication and co-ordination between the hospital and community midwifery service, the National Newborn Screening Laboratory at Yorkhill, the screening department at Gartnavel and the paediatric service is required to be able to meet the NHS QIS pregnancy and newborn screening clinical standards of 95% of cases of CHT and PKU to have started treatment by 14 days age and of CF within 35 days age.

Normally 95% of samples arriving at the National Laboratory are reported within two working days as required by the clinical standards. However in 2006 for Scotland this fell to 91% due to equipment problems and staff shortage. National Services Division appointed two new members of staff in early 2007 and the equipment problems have been resolved.

The number of babies of NHS Greater Glasgow and Clyde residents screened in 2006 - 2007 was 13,458, 96% of the total eligible population of 14015.

From 1 April 2006 to 31 March 2007 one case of PKU, 7 cases of CHT and 13 cases of CF were detected. All received appropriate management within the timescale set.

An integrated bloodspot screening programme has been developed across Greater Glasgow and Clyde adhering to the principles of the NHS QIS standards. Steps are being taken to ensure all the standards are met.

7 Universal Newborn Hearing Screening

The aim of the Universal Newborn Hearing Screening (UNHS) programme is the early detection of permanent congenital hearing impairment greater than 40 decibels in the better ear. One to two babies in 1000 are born with a profound hearing loss in one or both ears.

The screening programme covers all babies born to Greater Glasgow and Clyde residents and any babies moving into the area who are aged less than 6 months.

The majority of babies are screened in the maternity units in the Greater Glasgow area and in the community in the Clyde area.

The hospital based hearing screen is carried out at around 1-2 days of age by dedicated hearing screeners who are based in the maternity units using Automated Auditory Brainstem Response (AABR). The initial community based hearing screen is carried out at 6-21 days by health visitors in the baby’s home using Otoacoustic Emissions (OAE).

From 1 April 2006 to 31 March 2007 in Clyde 98.49% (3733 babies) completed the screening programme and in Greater Glasgow 95% (9562) completed the programme. There were 115 referrals to audiology.
Diagnostic testing was carried out on 25 babies in Clyde and 53 babies in Greater Glasgow. All who required it received appropriate and timely ongoing management.

In Clyde 2 babies with profound bilateral loss were identified and in Greater Glasgow 11. The median age of diagnosis was less than 3 months for all babies identified.

The hearing screening programme has a national IT system – eSP (escreener plus) which is a web based database into which all screening results and demographic data are entered. The Child Health Surveillance Programme system is used as a failsafe for checking on any missed babies.

The integrated UNHS programme continues to provide different methods of initial screening due to previous decisions in separate health board areas. Monitoring and evaluation of the programme confirms that the expected number of deaf children are being identified at a far earlier age than was possible before newborn screening was introduced. Lowering the age of identification to less than 3 months has allowed intervention to take place before the critical age of 6 months.

8 Diabetic Retinopathy Screening

Diabetic Retinopathy is a complication of diabetes affecting blood vessels of the retina and is the biggest single cause of blindness and visual impairment amongst working age people in Scotland.

All people with diabetes aged 12 and over are eligible for the diabetic retinopathy screening using digital photography.

The diabetes retinopathy screening using the digital photography service started screening in August 2006 in Argyll and Clyde. The service in Greater Glasgow started screening in 2002 but to cope with screening all diabetics resident in Greater Glasgow, the service capacity was expanded in 2006 and 2007.

The screening programme takes place in a variety of settings across Greater Glasgow and Clyde (including the Argyll and Bute area). There are three mobile screening units and six fixed site locations.

There are approximately 35,000 people with diabetes in Greater Glasgow and 15,600 in Argyll and Clyde.

The estimated uptake rate for the programme is 47.18% for Argyll and Clyde area and 37.97% for Glasgow area.

Nearly a quarter of appointments offered for screening (22% and 23%) are missed.

This new service experienced some teething problems in 2006/07 mainly around the introduction of the new screening software and also the slower than expected expansion of the Greater Glasgow service to full operating capacity. It is anticipated that all eligible patients in Greater Glasgow and Clyde, and Argyll and Bute, will be offered retinal screening in 2007/08.

Work is planned for 2008 to integrate the information management systems and it will be possible to provide combined reports on the NHS Greater Glasgow and Clyde Diabetic Retinopathy Screening programme.
9 Pre-School Vision Screening

- This is the first report of the pre-school vision screening programme.
- Approximately 15,000 children, residents in NHS Greater Glasgow and Clyde, aged between 4 – 5 years old in 2006/2007, were identified using the CHI system.
- 10,573 children were on nursery lists across NHS Greater Glasgow and Clyde. The proportion of children attached to a nursery across geographical areas varied and was dependent on the nurseries returning the children lists to the screening department.
- 3,189 (22.9%) of the eligible children were not on nursery lists submitted to the screening department. The lowest nursery returns were seen in the East where only 32.24% of children were on returned nursery lists. Following the change in the administrative process a higher return rate has already been achieved in 2007-08.
- Only 62 (0.45%) parents refused consent for their children to be screened.
- 10,890 children have been screened out of 15,194 eligible children in 2006 - 2007. This gives an uptake rate of 68.43%. The uptake rate varied across the geographical location from 32.79% in East Glasgow to 84.94% in Renfrewshire.
- The children who could not be screened in the programme at the end of the school year were referred to community optometry for screening. This represents 5% (721) of the total eligible population (15914). Of the 721 not screened, 91% (660) of children were from East Glasgow.
- 9,864 children have been screened in a nursery setting; that represents 91% of all screened children and 62% of all eligible children. 1,026 children were screened in hospital that represents 6% of eligible children.
- 7,411 (62.5%) children screened had a normal result following screening and 2,496 (21%) children have been referred for further assessments.
- The challenges and priorities for pre-school vision screening programme are: the development of a more mature IT system; the integration of the services across the whole of NHS Greater Glasgow and Clyde; the recruitment of staff to allow screening as agreed and improving the submission of the list of children attending individual nurseries.

Conclusion

Approximately 250,000 NHS Greater Glasgow and Clyde residents are offered screening each year. While some programmes like cervical screening and breast screening are well established and have been running since the end of the 1980s, a number of new screening programmes like diabetic retinopathy screening and pre school vision screening have recently been introduced or expanded to cover the whole NHS Board area and have been faced with issues specific to the implementation of complex health care interventions. The uptake rates vary across programmes; the cervical screening uptake has seen a drop in uptake, while the breast screening uptake has been going up. The highest uptake rates are seen in newborn bloodspot screening, communicable diseases in pregnancy and universal newborn hearing screening.

A concerted effort is required across all screening programmes to ensure a high uptake within the confines of informed consent, while ensuring that the impact on inequalities in health is monitored and addressed.
Public Health Screening Programmes

Annual Report

TO 31 MARCH 2007
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Screening is a public health service offered to specific population groups to detect potential health conditions before symptoms appear. Screening has the potential to save lives and improve quality of life through early diagnosis of serious conditions.

In NHS Greater Glasgow and Clyde, the co-ordination of all screening programmes is the responsibility of the Public Health Screening Unit led by a Consultant in Public Health Medicine. Multidisciplinary Steering Groups for the programmes have been set up to monitor performance, uptake and quality assurance. Figure 1 illustrates the reporting and accountability lines.

Figure 1
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• The programme will invite all men and women between the ages of 50 – 74 years registered with a General Practice. It is estimated that 307,000 NHS Greater Glasgow and Clyde residents would be eligible to be invited to participate in the Bowel Screening programme every 2 years.

• A testing kit will be sent to individuals’ homes to provide three stool samples. The test will be completed at home and returned to the National Bowel Screening Centre in Dundee for analysis.

• Based on data from the bowel screening pilot and assuming a 50% uptake rate of the faecal occult blood test (FOBT) in males and 52% uptake rate in females, it is estimated that each year 1628 NHS GGC residents will have a positive screening result, 1391 will proceed to have a colonoscopy and 137 will be diagnosed with invasive bowel cancer.

• The business case submitted to the Performance Review Group on 19 September 2006 has secured the resources necessary for planning, implementation and delivery of the bowel screening programme.

• It is highly desirable that a bowel screening IM&T module will be developed to monitor the performance of the programme and track patients through the process of diagnosis and treatment for colorectal cancer.

• The system will have to be integrated with Patient Administration Systems, endoscopy, theatres, laboratory, pathology and radiology and will have multidisciplinary team (MDT) conference management facility. The system will have to be capable of producing reports, alerts and letters with results; reports on progress against quality assurance standards and NHS Quality Improvement Scotland standards.

CHAPTER 4: COMMUNICABLE DISEASES IN PREGNANCY

• To comply with the NHS Quality Improvement Scotland standards (Clinical Standards 2005, Pregnancy and Newborn Screening), protocols covering each of the 4 communicable diseases routinely tested for in pregnancy – HIV, rubella, hepatitis B virus and syphilis - have been developed and implemented throughout Greater Glasgow and Clyde. These protocols are major steps towards a consistent approach to co-ordinating this screening programme throughout the Board area.

• All women are offered screening for the four communicable diseases, and receive an information leaflet about the screening tests prior to attendance at their first booking visit.

• 15,327 pregnant women had a first booking visit at a Greater Glasgow and Clyde hospital during 2006/07. This includes all first booking visits at hospital, at a clinic outside of hospital, including community outreach and at GP surgeries or at home.
• Laboratory data indicates that the uptake of screening for communicable diseases in pregnancy is high, greater than 95% for all four tests.

• The number of women detected in pregnancy as having HIV, hepatitis B virus or syphilis is small (7, 39, 12 respectively). However as the majority of these women were not previously known to be infected, the detection of these women and the implications for their health and the health of their babies are immense and illustrates the success of the screening programme. All infected women and their babies were offered appropriate treatment and care.

CHAPTER 5: DOWN’S SYNDROME AND NEURAL TUBE DEFECTS

• In NHS Greater Glasgow and Clyde screening for Down’s syndrome and neural tube defects (NTDs) is offered to all pregnant women at their booking visit.

• In the year 2006/2007 there were a total of 15,327 women booking at antenatal clinics across NHS Greater Glasgow and Clyde. It is estimated that 15% of these booked in the second or third trimester (late bookers).

• Currently, there are three screening pathways in NHS Greater Glasgow and Clyde: first trimester combined testing for Down’s syndrome with second trimester blood testing (offered to women at the Queen Mother’s Maternity Hospital – around 22% of women); first trimester combined testing for Down’s syndrome with 18-20 week foetal anomaly ultrasonography (offered in the Clyde area of NHS Greater Glasgow and Clyde - around 22% of women) and second trimester blood testing (offered in all other areas of NHS Greater Glasgow and Clyde - around 55% of women).

• The overall uptake of Down’s syndrome and NTD screening in NHS Greater Glasgow and Clyde is 66.23%.

• The proportion of women that have a “high risk” screening result and are offered further investigation following screening testing are: 4.9% for the first trimester combined Down’s syndrome test; 6.2% for second trimester blood testing for Down’s syndrome and 2.6% for NTD second trimester blood testing.

• The proportion of women who decide to take a diagnostic test following a “high risk” screening result are: 70% for women screened in the first trimester and 60% for women screened in the second trimester.

• The proportion of all cases which were detected by laboratory screening during pregnancy is: 88% for the first trimester combined Down’s syndrome testing; 66% for second trimester blood testing and 85% for NTD second trimester blood testing.
• The National Screening Committee Good Practice Guidelines currently recommend that a detection rate of 90% with a false positive rate of less than 2% be achieved by 2010.

• The priority for the programme is to achieve an equitable and integrated programme for Down’s syndrome and neural tube defects throughout NHS Greater Glasgow and Clyde. The proposed model of care is to offer the first trimester combined testing for Down’s syndrome and the 18-20 week foetal anomaly ultrasonography. Late bookers will have access to second trimester quadruple serum testing for NTDs and foetal anomaly scanning.

CHAPTER 6: NEWBORN BLOODSPOT SCREENING

• The newborn bloodspot screening programme offers tests to detect certain congenital metabolic abnormalities which can cause problems in growth and development and for which there is effective management or treatment. The conditions screened for are phenylketonuria (PKU), congenital hypothyroidism (CHT) and cystic fibrosis (CF)

• Screening is offered to all newborn babies resident in Greater Glasgow and Clyde.

• Newborn Screening for phenylketonuria (PKU) and congenital hypothyroidism (CHT) has been in progress since 1965 and 1979 respectively. Newborn screening for cystic fibrosis (CF) was added in Scotland in February 2003.

• A heel prick sample of blood is taken by the community midwife on the baby’s fifth day of life and posted to the National Newborn Screening Laboratory in Yorkhill where it is analysed for markers of the three conditions

• Excellent communication and co-ordination between the hospital and community midwifery service, the National Newborn Screening Laboratory at Yorkhill, the screening department at Gartnavel and the paediatric service is required to be able to meet the NHS QIS pregnancy and newborn screening clinical standards of 95% of cases of CHT and PKU to have started treatment by 14 days age and of CF within 35 days age.

• Normally 95% of samples arriving at the National Laboratory are reported within two working days as required by the clinical standards. However in 2006 for Scotland this fell to 91% due to equipment problems and staff shortage. National Services Division appointed two new members of staff in early 2007 and the equipment problems have been resolved.

• The number of babies of NHS Greater Glasgow and Clyde residents screened in 2006 - 2007 was 13,458, 96% of the total eligible population of 14015.

• From 1 April 2006 to 31 March 2007 one case of PKU, 7 cases of CHT and 13 cases of CF were detected. All received appropriate management within the timescale set.
• An integrated bloodspot screening programme has been developed across Greater Glasgow and Clyde adhering to the principles of the NHS QIS standards. Steps are being taken to ensure all the standards are met.

CHAPTER 7: UNIVERSAL NEWBORN HEARING SCREENING

• The aim of the Universal Newborn Hearing Screening (UNHS) programme is the early detection of permanent congenital hearing impairment greater than 40 decibels in the better ear. One to two babies in 1000 are born with a profound hearing loss in one or both ears.

• The screening programme covers all babies born to Greater Glasgow and Clyde residents and any babies moving into the area who are aged less than 6 months.

• The majority of babies are screened in the maternity units in the Greater Glasgow area and in the community in the Clyde area.

• The hospital based hearing screen is carried out at around 1-2 days of age by dedicated hearing screeners who are based in the maternity units using Automated Auditory Brainstem Response (AABR). The initial community based hearing screen is carried out at 6-21 days by health visitors in the baby's home using Otoacoustic Emissions (OAE).

• From 1 April 2006 to 31 March 2007 in Clyde 98.49% (3733 babies) completed the screening programme and in Greater Glasgow 95% (9562) completed the programme. There were 115 referrals to audiology.

• Diagnostic testing was carried out on 25 babies in Clyde and 53 babies in Greater Glasgow. All who required it received appropriate and timely ongoing management.

• In Clyde 2 babies with profound bilateral loss were identified and in Greater Glasgow 11. The median age of diagnosis was less than 3 months for all babies identified.

• The hearing screening programme has a national IT system – eSP (escreener plus) which is a web based database into which all screening results and demographic data are entered. The Child Health Surveillance Programme system is used as a failsafe for checking on any missed babies.

• The integrated UNHS programme continues to provide different methods of initial screening due to previous decisions in separate health board areas. Monitoring and evaluation of the programme confirms that the expected number of deaf children are being identified at a far earlier age than was possible before newborn screening was introduced. Lowering the age of identification to less than 3 months has allowed intervention to take place before the critical age of 6 months.
CHAPTER 8: DIABETIC RETINOPATHY SCREENING

- Diabetic Retinopathy is a complication of diabetes affecting blood vessels of the retina and is the biggest single cause of blindness and visual impairment amongst working age people in Scotland.

- All people with diabetes aged 12 and over are eligible for the diabetic retinopathy screening using digital photography.

- The diabetes retinopathy screening using the digital photography service started screening in August 2006 in Argyll and Clyde. The service in Greater Glasgow started screening in 2002 but to cope with screening all diabetics resident in Greater Glasgow, the service capacity was expanded in 2006 and 2007.

- The screening programme takes place in a variety of settings across Greater Glasgow and Clyde (including the Argyll and Bute area). There are three mobile screening units and six fixed site locations.

- There are approximately 35,000 people with diabetes in Greater Glasgow and 15,600 in Argyll and Clyde.

- The estimated uptake rate for the programme is 47.18% for Argyll and Clyde area and 37.97% for Glasgow area.

- Nearly a quarter of appointments offered for screening (22% and 23%) are missed.

- This new service experienced some teething problems in 2006/07 mainly around the introduction of the new screening software and also the slower than expected expansion of the Greater Glasgow service to full operating capacity. It is anticipated that all eligible patients in Greater Glasgow and Clyde, and Argyll and Bute, will be offered retinal screening in 2007/08.

- Work is planned for 2008 to integrate the information management systems and it will be possible to provide combined reports on the NHS Greater Glasgow and Clyde Diabetic Retinopathy Screening programme.

CHAPTER 9: PRE-SCHOOL VISION SCREENING

- This is the first report of the pre-school vision screening programme.

- Approximately 15,000 children, residents in NHS Greater Glasgow and Clyde, aged between 4 – 5 years old in 2006/2007, were identified using the CHI system.
• 10,573 children were on nursery lists across NHS Greater Glasgow and Clyde. The proportion of children attached to a nursery across geographical areas varied and was dependent on the nurseries returning the children lists to the screening department.

• 3,189 (22.9%) of the eligible children were not on nursery lists submitted to the screening department. The lowest nursery returns were seen in the East where only 32.24% of children were on returned nursery lists. Following the change in the administrative process a higher return rate has already been achieved in 2007-08.

• Only 62 (0.45%) parents refused consent for their children to be screened.

• 10,890 children have been screened out of 15,194 eligible children in 2006 - 2007. This gives an uptake rate of 68.43%. The uptake rate varied across the geographical location from 32.79% in East Glasgow to 84.94% in Renfrewshire.

• The children who could not be screened in the programme at the end of the school year were referred to community optometry for screening. This represents 5% (721) of the total eligible population (15914). Of the 721 not screened, 91% (660) of children were from East Glasgow.

• 9,864 children have been screened in a nursery setting; that represents 91% of all screened children and 62% of all eligible children. 1,026 children were screened in hospital that represents 6% of eligible children.

• 7,411 (62.5%) children screened had a normal result following screening and 2,496 (21%) children have been referred for further assessments.

• The challenges and priorities for pre-school vision screening programme are: the development of a more mature IT system; the integration of the services across the whole of NHS Greater Glasgow and Clyde; the recruitment of staff to allow screening as agreed and improving the submission of the list of children attending individual nurseries.
CANCER SCREENING PROGRAMMES
CHAPTER 1: CERVICAL SCREENING

Background

Systematic cervical screening began in 1989 as part of the National Scottish Cervical Screening Programme (SCSP). Over the last 18 years women aged 20 to 60 resident in NHS Greater Glasgow and Clyde area have been invited to have a cervical smear at least every 5 years.

Cervical cancer is caused by oncogenic types of human papilloma virus (HPV), mainly types 16 and 18, and the infection is generally transmitted sexually. HPV can evolve during a period of 10 to 20 years through precancerous lesions to invasive cancer and death.

Aim of screening programme

The aim of the Scottish Cervical Screening Programme (SCSP) is to reduce the number of women who develop invasive cancer and the number of women who die from it by detecting precancerous changes. By taking a cytological smear from the cervix, followed where necessary by a diagnostic test, it is possible to identify changes in individual cells which may mean that the woman is at risk of developing invasive cancer at a later date. Prompt treatment can result in permanent removal of affected areas of the cervix and prevent the development of cancer.

Target population

Women aged 20 to 60 who live in Greater Glasgow and Clyde areas are invited to have a smear test taken every three years.

Screening test

A smear test is whereby cells are collected from the surface of the cervix, or ‘neck of womb’ and is sent to a specialist laboratory. The cells are then examined under a microscope to see if any of them appear abnormal.

Liquid based cytology (LBC) is a new way of preparing cervical samples for examination in the laboratory. The sample is collected in a similar way to the conventional smear, using a special device which brushes cells from the neck of the womb. Rather than smearing the sample onto a microscope slide as happens with the conventional smear, the head of the brush, where the cells are lodged, is broken off into a small glass vial containing preservative fluid, or rinsed directly into the preservative fluid.
The sample is sent to the laboratory where it is spun and treated to remove obscuring material, for example mucus or pus, and a random sample of the remaining cells is taken. A thin layer of the cells is deposited onto a slide. The slide is examined in the usual way under a microscope by a cytologist.

**Screening pathway**

**Figure 1.1** illustrates the pathway for cervical screening programme. Following the invitation being issued, a woman will attend for a test. Women can also have opportunistic smears at the time of attending medical care for another reason. Depending on the result of the test she will be recalled to attend, if eligible, in 3 years (normal result), 6 months (for a borderline result); will have a repeat smear (if result not satisfactory); or will be referred to colposcopy for diagnostic tests and treatment. Treatment of invasive cervical cancers follows agreed cancer treatment pathways.

The responsibility for making the referral to the Colposcopy/Gynaecology service lies with the originator of the referral smear.

**Figure 1.1 cervical screening pathway**

[Diagram showing the screening pathway]

Screened by Liquid Based Cytology (LBC) → Results normal → Invite 3 years later

Results unsatisfactory → Repeat smear

Results borderline → 6 month recall

Results abnormal → Colposcopy for: Assessment treatment and follow up (See Appendix 1.1)

Results normal → Colposcopy for: Assessment treatment and follow up (See Appendix 1.1)

Treatment if cancer:
- Surgery
- Radiotherapy
- Chemotherapy
- Palliative
Delivery of screening programme 2006/07

Table 1 identifies the numbers of women in the target and eligible populations for the cervical screening programme. There are approximately 360,000 women aged 20 to 60 resident in NHS Greater Glasgow and Clyde in the target population. Following the exclusion of those with no cervix, approximately 340,000 women are eligible to be invited to participate in the programme over three years. Each year approximately 113,000 women are sent an invitation to attend.

The new GMS Contract introduced in 2004 includes cervical screening in the additional services domain and awards practices for providing the service under the Quality and Outcomes Framework. The cervical screening indicator 1 (80% of patients aged 21 to 60 whose notes record that a cervical smear has been performed in the last 5 years) reflects the previous GMS Contract target payment system for cervical screening and is designed to encourage and provide an incentive to continue to achieve high levels of uptake in cervical screening. The indicator excludes women who have had hysterectomy involving the complete removal of the cervix.

In addition practices are allowed to exclude “patients who have been recorded as refusing to attend review who have been invited on at least 3 occasions during the proceeding 12 months” under the exception reporting. Table 1.1 identifies the number of women that were considered to be eligible for cervical screening after the application of the exclusions allowed by the GMS contract.

Table 1.1 NHS Greater Glasgow and Clyde Cervical screening populations

<table>
<thead>
<tr>
<th>Year</th>
<th>Target Population women aged 20 to 60 years</th>
<th>Eligible Population1</th>
<th>Target GMS payments3</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001</td>
<td>360,361</td>
<td>338,068</td>
<td></td>
</tr>
<tr>
<td>2002</td>
<td>360,170</td>
<td>337,919</td>
<td></td>
</tr>
<tr>
<td>2003</td>
<td>360,069</td>
<td>338,184</td>
<td></td>
</tr>
<tr>
<td>2004</td>
<td>360,644</td>
<td>339,460</td>
<td>292,652</td>
</tr>
<tr>
<td>2005</td>
<td>358,617</td>
<td>338,291</td>
<td>273,106</td>
</tr>
<tr>
<td>2006</td>
<td>364,919</td>
<td>345,408</td>
<td>272,447</td>
</tr>
<tr>
<td>2007</td>
<td>359,436</td>
<td>340,446</td>
<td>272,104</td>
</tr>
</tbody>
</table>

Source: CHI via Cervical Cytology System

1. Women aged 20 to 60 years except medically exempt women, as defined in 3 and 4
2. No cervix excludes those women with the exclusion category “no cervix”
3. Target payments excludes those women with the exclusion categories as defined in the GP contract, implemented in 2004
Table 1.2 shows the ISD published 5.5 year cervical screening uptake rates as calculated for the NHS QIS standards and the Performance Assessment Framework target for the two areas that form Greater Glasgow and Clyde. Argyll and Bute (now NHS Highland) uptake rate figures are included in the Argyll and Clyde rates. ISD data continues to be reported based on the old NHS Board boundaries as CHI continues to code patients according to those.

The uptake rate has been dropping in both areas and Scotland. Between 1999-2000 and 2006-2007 the 5.5 years cervical screening uptake rate fell from 87% to 81.1% in Argyll and Clyde, from 82.5 to 79.5 in Greater Glasgow and from 86.7 to 82.6 Scotland wide.

Table 1.2 Uptake for Cervical Screening 1st January 1995 to 31st March 2007
Percentage uptake of females aged 20-60 who had a record of a previous smear taken within last 5.5 years

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Argyll &amp; Clyde</td>
<td>87.0</td>
<td>85.8</td>
<td>85.2</td>
<td>84.3</td>
<td>83.3</td>
<td>82.2</td>
<td>81.1</td>
</tr>
<tr>
<td>Greater Glasgow</td>
<td>82.5</td>
<td>82.3</td>
<td>82.2</td>
<td>82.1</td>
<td>81.7</td>
<td>80.9</td>
<td>79.5</td>
</tr>
<tr>
<td>Scotland 2</td>
<td>86.7</td>
<td>86.5</td>
<td>86.0</td>
<td>85.5</td>
<td>84.6</td>
<td>83.8</td>
<td>82.6</td>
</tr>
</tbody>
</table>

Source: ISD(D)4
1. Based on adjusted Community Health Index (CHI) population denominator (20-59 years, excluding medically ineligible women).
2. Excludes Lothian NHS Board (data unavailable/calculated on a different basis).
3. Figures are derived from GP self-reporting claim forms submitted to Primary Care Finance in support of claims for target payments.
4. Cervical screening year runs from 1st April to 31st March.

In order to test if the cervical screening uptake has been affected by the implementation of the changes in the GMS contract we calculated the 5 year uptake rates by applying the “no cervix” exclusion and then the GMS exclusion categories. Table 1.3 shows the numbers and percentages of women screened by the programme in the last 5 years.

The 5-year uptake rate for the Greater Glasgow area when only the no cervix exclusion has been applied, has been 77.1% in 2007 and this has seen a drop from 81.5% in 2001. When exception categories allowed under the GMS contract were included, the calculated 5 year uptake rate has been 89.4% in 2007.

On average across Greater Glasgow and Clyde 25.42% of women aged 20 to 60 have been excluded under one of the categories: 17.54% of women have been excluded as they defaulted following invitations to participate in screening and 5.64% of women have been excluded as they have no cervix.
The data in **Table 1.3** demonstrates and **Figure 1.2** illustrates the difference in uptake rates calculated for the purpose of NHS QIS Standards and Performance assessment framework and GMS target payment. The uptake rates for the purpose of the target payments are approximately 12% higher than the QIS standard uptake rate; the downward trend in the cervical screening uptake has seen a sharper drop following the implementation of the new GMS contract while the uptake for the purpose of GMS contract has initially seen a marked increase followed by a slow decline.

### Table 1.3 Cervical screening uptake

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Women Screened</th>
<th>5 year Percentage uptake</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>no cervix</td>
<td>GMS target payments</td>
</tr>
<tr>
<td>2001</td>
<td>275,361</td>
<td></td>
</tr>
<tr>
<td>2002</td>
<td>276,239</td>
<td></td>
</tr>
<tr>
<td>2003</td>
<td>276,666</td>
<td></td>
</tr>
<tr>
<td>2004</td>
<td>271,419</td>
<td>260,863</td>
</tr>
<tr>
<td>2005</td>
<td>268,860</td>
<td>251,457</td>
</tr>
<tr>
<td>2006</td>
<td>267,931</td>
<td>246,570</td>
</tr>
<tr>
<td>2007</td>
<td>262,604</td>
<td>243,388</td>
</tr>
</tbody>
</table>

Source: CHI via Cervical Cytology System

1. Women aged 20 to 60 years with an adequate smear within the last 5 years, except medically exempt women, as defined in 3 and 4
2. NHS Greater Glasgow and Clyde aims to identify, invite and encourage women to have a cervical smear at least once every 5 years.
3. No cervix excludes those women with the exclusion category "no cervix"
4. Target payments excludes those women with the exclusion categories as defined in the GP contract, implemented in 2004

### Figure 1.2

**NHSGG&C Cervical Screening programme percentage uptakes**

Source: CHI via Cervical Cytology System
Table 1.4 shows the uptake rates of cervical screening by Community Health (Care) Partnership (CH(C)P) for the no cervix category as calculated for NHS QIS standards and the Performance Assessment Framework.

Table 1.4  Cervical screening uptake rates by CH(C)P

<table>
<thead>
<tr>
<th>CHP/CHCP</th>
<th>2006/7</th>
<th>2005/6</th>
<th>2004/5</th>
<th>2003/4</th>
<th>2002/3</th>
<th>2001/2</th>
</tr>
</thead>
<tbody>
<tr>
<td>East Glasgow</td>
<td>75.0%</td>
<td>78.7%</td>
<td>78.1%</td>
<td>80.3%</td>
<td>80.4%</td>
<td>80.1%</td>
</tr>
<tr>
<td>North Glasgow</td>
<td>73.2%</td>
<td>77.0%</td>
<td>76.7%</td>
<td>79.0%</td>
<td>78.6%</td>
<td>78.6%</td>
</tr>
<tr>
<td>South East Glasgow</td>
<td>77.1%</td>
<td>79.6%</td>
<td>80.3%</td>
<td>81.0%</td>
<td>81.1%</td>
<td>80.5%</td>
</tr>
<tr>
<td>South West Glasgow</td>
<td>76.4%</td>
<td>79.2%</td>
<td>80.4%</td>
<td>82.5%</td>
<td>82.7%</td>
<td>82.3%</td>
</tr>
<tr>
<td>West Glasgow</td>
<td>73.1%</td>
<td>74.8%</td>
<td>75.8%</td>
<td>77.8%</td>
<td>76.7%</td>
<td>76.8%</td>
</tr>
<tr>
<td>East Dunbartonshire</td>
<td>83.3%</td>
<td>84.8%</td>
<td>85.2%</td>
<td>85.4%</td>
<td>85.6%</td>
<td>85.0%</td>
</tr>
<tr>
<td>East Renfrewshire</td>
<td>81.6%</td>
<td>83.8%</td>
<td>84.6%</td>
<td>85.7%</td>
<td>85.8%</td>
<td>85.0%</td>
</tr>
<tr>
<td>West Dunbartonshire</td>
<td>78.9%</td>
<td>80.4%</td>
<td>80.6%</td>
<td>73.1%</td>
<td>83.3%</td>
<td>82.7%</td>
</tr>
<tr>
<td>Inverclyde</td>
<td>77.2%</td>
<td>78.9%</td>
<td>79.7%</td>
<td>81.7%</td>
<td>82.2%</td>
<td>82.1%</td>
</tr>
<tr>
<td>Renfrewshire</td>
<td>77.8%</td>
<td>80.0%</td>
<td>80.6%</td>
<td>83.5%</td>
<td>83.8%</td>
<td>83.8%</td>
</tr>
<tr>
<td>NHSGG&amp;C</td>
<td>77.1%</td>
<td>79.5%</td>
<td>80.0%</td>
<td>81.8%</td>
<td>81.7%</td>
<td>81.5%</td>
</tr>
</tbody>
</table>

Source: Cervical Cytology System

1. CHP/CHCP divided by GP practice

Table 1.5 shows that the uptake of cervical screening varies across different age groups with the lowest uptake among the 20 to 24 year olds. Calculations were made taking into account only the women eligible for screening.

Table 1.5  Uptake by Age Group across NHS Greater Glasgow and Clyde

<table>
<thead>
<tr>
<th>2006/07 Eligible women</th>
<th>3.5 year uptake</th>
<th>5.5 year uptake</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Total</td>
<td>Total</td>
</tr>
<tr>
<td>20-24</td>
<td>52786</td>
<td>28884</td>
</tr>
<tr>
<td>25-29</td>
<td>42760</td>
<td>26756</td>
</tr>
<tr>
<td>30-39</td>
<td>86325</td>
<td>63071</td>
</tr>
<tr>
<td>40-49</td>
<td>83376</td>
<td>63002</td>
</tr>
<tr>
<td>50-60</td>
<td>54748</td>
<td>39943</td>
</tr>
</tbody>
</table>

Source: Cervical Cytology System for period ending 31 March 2007

Calculations only apply to eligible women
Table 1.6 shows that the uptake across deprivation categories with the lowest uptake among the most deprived. Calculations were made taking into account only the women eligible for screening.

**Table 1.6 Uptake by deprivation category**

<table>
<thead>
<tr>
<th>DEPCAT</th>
<th>Eligible women</th>
<th>3.5 year uptake</th>
<th>5.5 year uptake</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
<td>Total</td>
<td>%</td>
</tr>
<tr>
<td>1</td>
<td>15026</td>
<td>12092</td>
<td>80.5%</td>
</tr>
<tr>
<td>2</td>
<td>36691</td>
<td>27603</td>
<td>75.2%</td>
</tr>
<tr>
<td>3</td>
<td>34992</td>
<td>25954</td>
<td>74.2%</td>
</tr>
<tr>
<td>4</td>
<td>54571</td>
<td>38457</td>
<td>70.5%</td>
</tr>
<tr>
<td>5</td>
<td>45694</td>
<td>31197</td>
<td>68.3%</td>
</tr>
<tr>
<td>6</td>
<td>58459</td>
<td>38393</td>
<td>65.7%</td>
</tr>
<tr>
<td>7</td>
<td>72757</td>
<td>46740</td>
<td>64.2%</td>
</tr>
<tr>
<td>N/K</td>
<td>1805</td>
<td>1220</td>
<td>67.6%</td>
</tr>
</tbody>
</table>

Source: Cervical Cytology System for period ending 31 March 2007
Calculations only apply to eligible women

**Cytopathology Laboratories Workload**

Table 1.7 shows the number of tests performed in Cytopathology laboratories in the NHS Greater Glasgow and Clyde area. An essential criterion of the NHSQIS standards requires the laboratories to process 15,000 screening programme smears annually and this has been achieved throughout the area. Approximately 103,000 smear tests are processed and reported in laboratories in NHS Glasgow and Clyde. These include repeat smears and smears taken at colposcopy and one woman can therefore have more than one smear test.

**Table 1.7 Number of smear tests performed in NHSGGC laboratories**

<table>
<thead>
<tr>
<th>Year</th>
<th>IRH</th>
<th>VOL</th>
<th>Total</th>
<th>SGH</th>
<th>GRI</th>
<th>STOB</th>
<th>VIC</th>
<th>Total</th>
<th>Scotland</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000/1</td>
<td>25,453</td>
<td>17,486</td>
<td>42,939</td>
<td>10,266</td>
<td>29,667</td>
<td>15,907</td>
<td>18,959</td>
<td>74,799</td>
<td>457,774</td>
</tr>
<tr>
<td>2001/2</td>
<td>27,378</td>
<td>14,973</td>
<td>42,351</td>
<td>23,326</td>
<td>49,162</td>
<td>190</td>
<td>7,101</td>
<td>79,779</td>
<td>471,722</td>
</tr>
<tr>
<td>2002/3</td>
<td>24,627</td>
<td>12,384</td>
<td>37,011</td>
<td>25,953</td>
<td>44,713</td>
<td>n/a</td>
<td>n/a</td>
<td>70,666</td>
<td>439,678</td>
</tr>
<tr>
<td>2003/4</td>
<td>23,607</td>
<td>12,052</td>
<td>35,659</td>
<td>25,824</td>
<td>44,422</td>
<td>n/a</td>
<td>n/a</td>
<td>70,246</td>
<td>429,522</td>
</tr>
<tr>
<td>2004/5</td>
<td>28,326</td>
<td>5,843</td>
<td>34,169</td>
<td>25,975</td>
<td>43,194</td>
<td>n/a</td>
<td>n/a</td>
<td>69,169</td>
<td>406,305</td>
</tr>
<tr>
<td>2005/6</td>
<td>36,166</td>
<td>n/a</td>
<td>36,166</td>
<td>23,160</td>
<td>44,035</td>
<td>n/a</td>
<td>n/a</td>
<td>67,195</td>
<td>410,241</td>
</tr>
<tr>
<td>2006/7</td>
<td>36,137</td>
<td>n/a</td>
<td>36,137</td>
<td>23,141</td>
<td>40,732</td>
<td>n/a</td>
<td>n/a</td>
<td>63,873</td>
<td>401,749</td>
</tr>
</tbody>
</table>

VOL - stopped reporting smears taken as at quarter ending 30th Sept 2004
STOB - stopped reporting smears taken as at quarter ending 30th June 2001
VIC - stopped reporting smears taken as at quarter ending 30th Sept 2001
Source Cervical Cytology System
Table 1.8 demonstrates the marked decrease in the percentage of unsatisfactory smears since the introduction of LBC testing in 2003 with only 2.5% of smears required to be repeated due to an unsatisfactory result.

Table 1.8  Percentage of unsatisfactory smears reported in NHSGGC laboratories

<table>
<thead>
<tr>
<th>Year</th>
<th>IRH</th>
<th>VOL</th>
<th>Total</th>
<th>SGH</th>
<th>GRI</th>
<th>STOB</th>
<th>VIC</th>
<th>Total</th>
<th>Scotland</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000/1</td>
<td>6.0%</td>
<td>7.6%</td>
<td>6.6%</td>
<td>9.1%</td>
<td>7.2%</td>
<td>7.6%</td>
<td>10.2%</td>
<td>8.3%</td>
<td>8.5%</td>
</tr>
<tr>
<td>2001/2</td>
<td>5.5%</td>
<td>6.3%</td>
<td>5.8%</td>
<td>7.3%</td>
<td>10.5%</td>
<td>4.2%</td>
<td>8.5%</td>
<td>9.4%</td>
<td>8.8%</td>
</tr>
<tr>
<td>2002/3</td>
<td>5.9%</td>
<td>6.8%</td>
<td>6.2%</td>
<td>5.9%</td>
<td>3.9%</td>
<td>n/a</td>
<td>n/a</td>
<td>4.6%</td>
<td>7.4%</td>
</tr>
<tr>
<td>2003/4</td>
<td>3.4%</td>
<td>4.6%</td>
<td>3.8%</td>
<td>6.3%</td>
<td>3.9%</td>
<td>n/a</td>
<td>n/a</td>
<td>4.8%</td>
<td>3.9%</td>
</tr>
<tr>
<td>2004/5</td>
<td>2.7%</td>
<td>2.6%</td>
<td>2.7%</td>
<td>2.2%</td>
<td>1.9%</td>
<td>n/a</td>
<td>n/a</td>
<td>2.1%</td>
<td>2.2%</td>
</tr>
<tr>
<td>2005/6</td>
<td>2.3%</td>
<td>n/a</td>
<td>2.3%</td>
<td>2.9%</td>
<td>1.6%</td>
<td>n/a</td>
<td>n/a</td>
<td>2.0%</td>
<td>2.2%</td>
</tr>
<tr>
<td>2006/7</td>
<td>2.5%</td>
<td>n/a</td>
<td>2.5%</td>
<td>3.0%</td>
<td>2.1%</td>
<td>n/a</td>
<td>n/a</td>
<td>2.5%</td>
<td>2.4%</td>
</tr>
</tbody>
</table>

VOL - stopped reporting smears taken as at quarter ending 30th Sept 2004
STOB - stopped reporting smears taken as at quarter ending 30th June 2001
VIC - stopped reporting smears taken as at quarter ending 30th Sept 2001
Source: Cervical Cytology System

Table 1.9 shows the proportion of results reported as abnormal smears in each of the cytopathology laboratories in NHSGGC, after excluding the unsatisfactory tests. Abnormal smears results include: borderline, mild, moderate and severe dyskaryosis, severe dyskaryosis/invasive, glandular abnormality and adenocarcinoma.

Table 1.9  Percentage of abnormal smear results

<table>
<thead>
<tr>
<th>Year</th>
<th>IRH</th>
<th>VOL</th>
<th>Total</th>
<th>SGH</th>
<th>GRI</th>
<th>STOB</th>
<th>VIC</th>
<th>Total</th>
<th>Scotland</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000/1</td>
<td>7.8%</td>
<td>8.6%</td>
<td>8.1%</td>
<td>10.2%</td>
<td>11.2%</td>
<td>10.1%</td>
<td>8.5%</td>
<td>10.2%</td>
<td>8.0%</td>
</tr>
<tr>
<td>2001/2</td>
<td>7.2%</td>
<td>7.4%</td>
<td>7.3%</td>
<td>7.8%</td>
<td>12.4%</td>
<td>16.5%</td>
<td>8.5%</td>
<td>10.7%</td>
<td>8.3%</td>
</tr>
<tr>
<td>2002/3</td>
<td>7.0%</td>
<td>8.3%</td>
<td>7.4%</td>
<td>5.7%</td>
<td>10.0%</td>
<td>n/a</td>
<td>n/a</td>
<td>8.5%</td>
<td>7.3%</td>
</tr>
<tr>
<td>2003/4</td>
<td>7.6%</td>
<td>10.2%</td>
<td>8.5%</td>
<td>5.2%</td>
<td>10.3%</td>
<td>n/a</td>
<td>n/a</td>
<td>8.5%</td>
<td>7.2%</td>
</tr>
<tr>
<td>2004/5</td>
<td>7.8%</td>
<td>7.4%</td>
<td>7.7%</td>
<td>6.0%</td>
<td>9.8%</td>
<td>n/a</td>
<td>n/a</td>
<td>8.4%</td>
<td>7.2%</td>
</tr>
<tr>
<td>2005/6</td>
<td>7.6%</td>
<td>n/a</td>
<td>7.6%</td>
<td>6.7%</td>
<td>10.7%</td>
<td>n/a</td>
<td>n/a</td>
<td>9.3%</td>
<td>7.4%</td>
</tr>
<tr>
<td>2006/7</td>
<td>8.2%</td>
<td>n/a</td>
<td>8.2%</td>
<td>7.6%</td>
<td>10.2%</td>
<td>n/a</td>
<td>n/a</td>
<td>9.2%</td>
<td>7.6%</td>
</tr>
</tbody>
</table>

VOL - stopped reporting smears taken as at quarter ending 30th Sept 2004
STOB - stopped reporting smears taken as at quarter ending 30th June 2001
VIC - stopped reporting smears taken as at quarter ending 30th Sept 2001
Source: ISD(D)1
ISD web site
Invasive cervical cancer audit results

The aim of the cervical screening programme is to reduce the incidence of and mortality from invasive cervical cancer. It is recognised that in order to assess the effectiveness of the cervical screening programme, the audit of the screening histories of women with invasive cervical cancer is fundamental. This audit is an important process that helps to identify variations in practice, encourages examinations of the reasons for these variations, and helps to identify the changes required to improve the service.

In 2006 we reviewed the notes of women who developed invasive cervical cancer, diagnosed in 2005 and 2006. Fifty patients were diagnosed with invasive cervical cancer in 2005 and 49 women were diagnosed with invasive cervical cancer in 2006. Table 1.10 shows the age distribution at the age of diagnosis. The largest number of cervical cancers occur in women aged between 30 and 59 years.

Table 1.10 Number of NHSGGC residents with invasive cervical cancers by age at diagnosis and year of diagnosis

<table>
<thead>
<tr>
<th>Age</th>
<th>Year of diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2005</td>
</tr>
<tr>
<td>20 - 29</td>
<td></td>
</tr>
<tr>
<td>30 - 39</td>
<td></td>
</tr>
<tr>
<td>40 - 49</td>
<td></td>
</tr>
<tr>
<td>50 - 59</td>
<td></td>
</tr>
<tr>
<td>60 - 69</td>
<td></td>
</tr>
<tr>
<td>70 - 79</td>
<td></td>
</tr>
<tr>
<td>80+</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
</tr>
</tbody>
</table>

Table 1.11 shows that 33 of 50 invasive cervical cancers in 2005, and 16 of 49 in 2006, were detected at screening with the rest of the cases presenting to the service with symptoms.

Table 1.11

<table>
<thead>
<tr>
<th>Modality of Presentation</th>
<th>Year of diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2005</td>
</tr>
<tr>
<td>Screen Detected</td>
<td></td>
</tr>
<tr>
<td>Symptomatic, last smear date &lt;5 yrs</td>
<td></td>
</tr>
<tr>
<td>Symptomatic, last smear date &gt;5 yrs</td>
<td></td>
</tr>
<tr>
<td>Symptomatic, No previous smear</td>
<td></td>
</tr>
<tr>
<td>No Details</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
</tr>
</tbody>
</table>
Some of the screen detected cancers might have had an opportunistic smear while presenting with genital tract complaints as only 25 women out of the 50 with invasive cervical cancer in 2005 and 22 women of 49 with invasive cervical cancer in 2006 had a complete smear history. Over the two years audited, 17 women out of the 99 that developed cancer had never had a smear; that represents approximately 1 in 5.2 women (see Table 1.12).

Table 1.12  Smear History of women with invasive cervical cancer

<table>
<thead>
<tr>
<th>Smear History</th>
<th>Year of diagnosis</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2005</td>
<td>2006</td>
<td></td>
</tr>
<tr>
<td>Complete</td>
<td>25</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>Incomplete</td>
<td>20</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>No Previous Smear</td>
<td>4</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Not Known</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>49</td>
<td></td>
</tr>
</tbody>
</table>

* Apart from index smear ie the abnormal smear causing referral

Table 1.13 shows the status of the women included in the audit of invasive cancer at the time when the audit was carried out. There were 16 deaths over the two years audited; 32 women were under follow up at colposcopy service and 44 were under follow up in the oncology service. Following the implementation of the Scottish Call Recall Cervical System in May 2007, women that were previously lost to follow up would now be brought back into the call recall.

Table 1.13  Follow up status of the women with invasive cervical cancer

<table>
<thead>
<tr>
<th>Status</th>
<th>Year diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2005</td>
</tr>
<tr>
<td>Lost to Colposcopy service</td>
<td>1</td>
</tr>
<tr>
<td>On Follow-up at Colposcopy</td>
<td>15</td>
</tr>
<tr>
<td>On Follow-up at Oncology/Beatson</td>
<td>23</td>
</tr>
<tr>
<td>Early Recall</td>
<td>1</td>
</tr>
<tr>
<td>Death</td>
<td>8</td>
</tr>
<tr>
<td>Unknown</td>
<td>2</td>
</tr>
<tr>
<td>No Details</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
</tr>
</tbody>
</table>

Cervical cancer registrations and death rates

The cervical screening programme is aimed at preventing cervical cancer and therefore it is useful to look at the number of cancer registrations and deaths over time.

Due to the small numbers of cervical cancers and deaths from cervical cancer, it is expected to see variations around a trend.
The data in Table 1.14 and Figure 1.4 illustrate a downward trend in the standardised rate per 100,000 population for both cervical cancer registrations and deaths.

Aggregated data for Scotland show that the number of cervical cancers registrations varied between 382 in 1996 to 262 (in 2004) with the standardised rate varying between 12.9 to 9.6 per 100,000 population.

The number of cervical cancer registrations for Greater Glasgow residents varied between 73 in 1998 to 44 in 2002 with the standardised rate varying between 14.2 to 8.5 per 100,000 population.

The number of cervical cancer registrations for the Argyll and Clyde residents varied between 45 in 1998 to 21 in 2002 with the standardised rate varying between 17.0 to 9.0 per 100,000 population.

The number of deaths from cervical cancer in Scotland varied between 154 in 1994 to 92 in 2004 with the standardised rate varying between 4.8 to 2.8 per 100,000 population.

The number of deaths from cervical cancer for Greater Glasgow residents varied between 36 in 1994 to 11 in 2004 with the standardised rate varying between 6.5 to 2.0 per 100,000 population.

The number of deaths from cervical cancer for Argyll and Clyde residents varied between 18 in 1998 to 7 in 2007 with the standardised rate varying between 5.5 to 2.6 per 100,000 population.

Age-standardisation adjusts rates taking into account how many old or young people are in the population being looked at. When rates are age-standardised, the differences in the rates over time or between geographical areas do not simply reflect variations in the age structure of the population. This is important when looking at cancer rates because cancer is a disease that predominantly affects the elderly. So if cancer rates are not age-standardised, a higher rate in one area or period of time is likely to reflect the fact that it has a greater proportion of older people.

The Confidence Interval (CI) provides a way of measuring how confident we are in the accuracy of the rate. We have used 95% CI which means that we have 95% confidence that the rate falls between the two Confidence Limits. When the CI of two rates overlap then there is no significant difference between the rates.

Confidence intervals for age-standardised rates (EASR and WASR) have been calculated using a formula which works only when numbers are sufficiently large. They are therefore set to 'not applicable' in the event of there being 50 cases or less.
### Table 1.14

#### Cervical Cancer Mortality and Registrations

<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Argyll &amp; Clyde (pre-2006)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Number</td>
<td>7</td>
<td>14</td>
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<td>18</td>
<td>12</td>
<td>7</td>
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<td>7</td>
<td>8</td>
<td>13</td>
<td>16</td>
<td>8</td>
</tr>
<tr>
<td>Standardised rate per 100,000 pop</td>
<td>2.7</td>
<td>4.8</td>
<td>4.6</td>
<td>5.4</td>
<td>5.5</td>
<td>4.4</td>
<td>3.0</td>
<td>4.0</td>
<td>2.6</td>
<td>2.7</td>
<td>4.8</td>
<td>5.3</td>
<td>3.5</td>
</tr>
<tr>
<td>Lower 95% Confidence Interval</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Upper 95% Confidence Interval</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Registrations</td>
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<td></td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Number</td>
<td>26</td>
<td>25</td>
<td>37</td>
<td>35</td>
<td>45</td>
<td>28</td>
<td>26</td>
<td>34</td>
<td>21</td>
<td>21</td>
<td>29</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standardised rate per 100,000 pop</td>
<td>11.6</td>
<td>10.6</td>
<td>15.6</td>
<td>13.5</td>
<td>17.0</td>
<td>11.3</td>
<td>10.4</td>
<td>13.9</td>
<td>8.7</td>
<td>9.0</td>
<td>12.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lower 95% Confidence Interval</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
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<td>x</td>
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<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Upper 95% Confidence Interval</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td><strong>Greater Glasgow (pre-2006)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deaths</td>
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</tr>
<tr>
<td>Number</td>
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<td>16</td>
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<td>12</td>
<td>16</td>
<td>24</td>
<td>21</td>
<td>11</td>
</tr>
<tr>
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</tbody>
</table>

Notes:
- Cancer of the cervix uteri (ICD-10 C53)
- Mortality Source: General Register Office for Scotland (GROS)
- Registrations Source: Scottish Cancer Registry, ISD
- Data extracted: August 2007
- Data extracted: April 2007

Notes:
- '-' = zero value.
- 'x' = not applicable.

ISD website
Information systems

The National Colposcopy Clinical Information Audit System (NCCIAS) was installed in all Colposcopy clinics in January 2007. The system allows Colposcopy staff to retrieve and audit colposcopy data.

During 2006-2007 we planned for the implementation of the Scottish Cervical Call Recall System (SCCRS) that went live in May 2007 across Scotland. The advantages of the new system is that women will now have a complete e-health record detailing their whole smear history which professionals involved with the screening programme will have access to. The turnaround time for smears reported is reduced since the results are now sent electronically to the smear takers and the patients are sent notification directly from SCCRS. The administrative staff resource required in the laboratories dropped significantly.

Currently there are ongoing developments, led at a national level, to improve and expand the functionality of the Scottish Cervical Call Recall System.
Initiatives to improve uptake

As part of the initiatives aimed to improve uptake, we submitted comparative practice-based uptake figures to all practices and to the Community Health Care Partnerships. In addition we submitted evidence to the Scottish Executive Health Department to request changes to the GMS contract to remove “defaulter” as an exclusion category.

In addition plans are under way to develop an awareness campaign aimed specifically at the age and social groups with lowest uptake; to promote the cervical screening programme by the Sandyford Initiative; and to take smears at termination of pregnancy clinics, if feasible. An equity audit is planned for 2007 – 2008.

Challenges and Future Priorities

In November 2007, the Scottish Government’s Public Health Wellbeing Directorate issued CEL 17 (2007) with information for NHS Boards to plan for the introduction of a human papilloma virus (HPV) immunisation programme to routinely vaccinate girls aged 12 - 13 years of age against cervical cancer, starting from September 2008 with a catch-up programme of girls under the age of 18 years. The cervical screening programme will continue after the HPV vaccine has been introduced. This is because the vaccine does not protect against all HPV types that may cause cervical cancer.

The challenge will be to ensure that women understand the need for continuing cervical screening once the vaccination has been implemented.

We need to explore the uptake rates further and ensure a co-ordinated approach with the HPV vaccinations programme to avoid the creation of mixed messages with the potential to confuse women and adversely affect their health.

Conclusion

The cervical screening programme was the first screening programme introduced. The number of cervical cancer registrations and deaths from cervical cancer each year is relatively small. The uptake trend for the programme is downward and the implementation of HPV vaccination could accelerate the downward trend.
### Appendix 1.1

**Management and follow up for cytology results: post colposcopy following abnormal cytology**

<table>
<thead>
<tr>
<th>Colposcopy outcome</th>
<th>Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal colposcopy or benign biopsy</td>
<td>Smears at 6 and 18 months. If both smears are negative, return to routine recall.</td>
</tr>
<tr>
<td>CIN 1 (including untreated)</td>
<td>Smears at 6, 12 and 24 months. If negative, return to routine recall, if not, return to routine recall after 2nd negative.</td>
</tr>
<tr>
<td>CIN 2, CIN 3, Microinvasive or CGIN</td>
<td>Smears at 6 and 12 months. Then annual smears to 5 years. If negative, return to routine recall.</td>
</tr>
</tbody>
</table>

- Borderline changes in post-colposcopy follow up, repeat. Refer after 3rd.
- Any dyskaryosis in post-colposcopy follow up, refer back to colposcopy

**Post TOTAL Hysterectomy**

<table>
<thead>
<tr>
<th>No History of CIN/CGIN</th>
<th>No Recall</th>
</tr>
</thead>
<tbody>
<tr>
<td>CIN or CGIN in history</td>
<td>No recall</td>
</tr>
<tr>
<td>CIN or CGIN within last 5 years in history</td>
<td>Smear at 12 months. If negative, no further recall.</td>
</tr>
<tr>
<td>- CIN/CGIN in specimen, completely excised</td>
<td></td>
</tr>
<tr>
<td>CIN or CGIN in history</td>
<td>Smears at 6, 12 and 24 months. If negative, no further recall</td>
</tr>
<tr>
<td>- CIN/CGIN in specimen, incompletely excised</td>
<td></td>
</tr>
</tbody>
</table>
Members of Cervical Screening Steering Group
(As at September 2006)

Dr Urszula Bankowska  Clinical Director - Sandyford
Dr Margaret Burgoyne  Consultant Pathologist
Dr Laura Cassidy  Consultant Gynaecologist
Dr Mary Jo Coffield  General Practitioner
Ms Kathleen Cox  Sexual Health Co-ordinator
Ms Jeanette Crawford  Staff Grade Nurse
Dr Emilia Crighton  Consultant in Public Health Medicine (Chair)
Ms Margaret Duffy  Colposcopy Nurse
Mrs Fiona Gilchrist  Screening Manager
Dr James Kennedy  Consultant Gynaecologist
Miss Denise Lyden  Project Officer
Miss Jacqueline McFadden  Information Analyst
Ms Jane McNiven  Practice Manager
Ms Louise McTaggart  Mentoring Team Manager
Ms Cynthia Mendelsohn  Lay Member - Glasgow
Dr Alan Mitchell  Clinical Director
Dr Vaijia Rajoriya  Medical Officer
Mrs Elizabeth Rennie  Screening Manager
Dr Gour Sarkar  Consultant Gynaecologist
Dr Helen Scullion  Consultant Cytopathologist
Dr Mary Stephen  Consultant Pathologist
Dr Millicent Thomas  Consultant Pathologist
Ms Patricia Weir  Lay member - Clyde
Dr Barbara West  General Practitioner (LMC)
Ms Jackie Wright  Practice Nurse
Mr Nic Zappia  Head of Primary Care Support
Appendix 1.3

Reporting Structure:
Cervical Screening Programme

Diagram:
- Public Health Screening Unit
  - Cervical Screening Programme Steering Group
    - Chair: Dr Emilia Crighton, CPHM
    - Scottish Cervical Call Recall System (SCCRS) Group
    - Cervical Improving Uptake Group
    - SLWG Colposcopy Direct Referrals
    - Ad Hoc Groups
    - Colposcopy User Group
CHAPTER 2: BREAST SCREENING

Background

Breast cancer is the most common cancer in women in Scotland. Incidence rates continue to rise with a significant 11% increase in the last ten years. This is partly due to increased detection by the Scottish Breast Screening Programme and in the context of changes in the prevalence of known risk factors, such as age at birth of first child, and alcohol consumption. (ISD 2007)

The Scottish Breast Screening Programme (SBSP) was introduced in February 1987 following the publication of the Forrest Report (1986). Breast screening was implemented in 1988 in North Glasgow, 1991 in South Glasgow and in October 1990 in Argyll & Clyde when women aged 50 to 64 were invited for a mammogram every three years.

This report presents data for the breast screening round 2003 – 2006.

Aim of screening programme

The purpose of breast screening by mammography is to detect breast cancers at the earliest possible time so that treatment may be offered promptly. It is believed that very early detection of breast cancers in this way can result in more effective treatment, which may be more likely to reduce deaths from breast cancer.

Recommended age to perform screening

From implementation, women aged 50-64 years were invited for a routine screen once every three years, and women aged over 64 years were screened three yearly on request. The age range for invitation has been extended to include women up to the age of 70 years (women over 70 years will continue to be screened on request). In Scotland and NHS Greater Glasgow and Clyde this expansion was phased in over one three-year round of screening, beginning in 2003/04. The age extension has been implemented across NHS Greater Glasgow and Clyde in April 2003 for the women resident in the old Argyll and Clyde area and in March 2005 for women residents in the former Greater Glasgow Health Board area.

The screening test

The current screening method used consists of two mammographic views at first screen (called incident screen) and one view at subsequent screens (called prevalent screens). The test is a straightforward procedure involving X-rays being taken of each breast using an X-ray machine (also known as a mammogram). Mammography can identify small abnormalities that cannot be detected by a physical examination.
Screening setting

The West of Scotland Breast Screening Centre screens NHS Greater Glasgow and Clyde residents either in the static centre in Glasgow or in mobile van units that visit pre-established sites across the NHS Greater Glasgow and Clyde area.

Screening pathway

Every woman registered with a GP will receive her first invitation to attend for a mammogram at her local breast screening location sometime between her 50th and 53rd birthdays and then three yearly thereafter until her 70th birthday. The West of Scotland Breast Screening Centre also contacts all long-stay institutions to offer screening to eligible residents.

The mammograms taken during the screening visit are examined and the results sent to the woman and her GP within two weeks. A proportion of women attending for screening will be recalled for technical reasons (if the picture was not clear enough) or asked to go to an assessment clinic for further tests, because a potential abnormality was detected.

At the assessment clinic more tests are carried out. These include a clinical examination, more mammograms at different angles or with magnification, or examination using ultrasound. A common technique used in the clinics is core biopsy, whereby some of the breast tissue can be removed and taken away for analysis. This is always done under local anaesthetic.

About 95% of women are reported as having a normal result after the first mammogram and will be routinely invited for screening three years later. Of those recalled for further investigation, only around one in six will be found to have cancer.

If a woman is found to have cancer, she is referred to a consultant surgeon for a discussion of the options available to her. Many women have a choice about the treatment they receive depending on the type and location of their cancer. This usually involves some form of surgery: a lumpectomy where just the lump and a small amount of surrounding tissue is removed, or a mastectomy where the whole breast is removed. Surgery is likely to be followed by radiotherapy, chemotherapy or hormone therapy or a mixture of these.
The exact course of treatment will depend on the type of cancer found and the woman’s personal preferences.

**Figure 2.1 Screening pathway**

In NHS Greater Glasgow and Clyde the assessment clinics are carried out in the West of Scotland Breast Screening Centre situated in Glasgow. The surgical treatment is carried out by designated teams in Western Infirmary and Victoria Infirmary and a small proportion of women with palpable tumours are referred for treatment to local breast teams.

**Uptake of breast screening in NHS Greater Glasgow and Clyde**

**Eligible population**

The number of women eligible for breast screening across the area of Greater Glasgow and Clyde increased from approximately 104,000 in 2003 when women aged 50 to 64 were eligible for screening to more than 143,000 at the end of the round when women aged 50 to 70 were invited for screening. Eligible women were identified using the Community Health Index (CHI) system.
Table 2.1 shows the size of the eligible population of 50 to 64 and 50 to 70 year old females split by age bands and it demonstrates that the number has been increasing slightly over the years in all areas.

Table 2.1

<table>
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<th>Greater Glasgow &amp; Clyde</th>
<th>Glyde</th>
<th>A&amp;C</th>
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Source: CHI

*Note: The uptake rate for the purpose of key performance indicators (KC62) will be reported with the definition of eligible women as women aged 50-64 from 2009/10 round to allow for full implementation of age extension across Scotland. For the purpose of this report the two former Health Boards - NHS Argyll and Clyde and NHS Greater Glasgow – are reported side by side as national datasets are not yet merged.

The Breast screening programme runs over three year periods and invites the total number of eligible women over three years. Table 2.2 shows the numbers invited; numbers screened; and the uptake rate split into prevalent and incident uptake. The prevalent uptake is the uptake of the first screening episode and includes women aged 50 to 52 and incident is the consequential mammogram they receive in the screening programme. In both Argyll and Clyde and Greater Glasgow the overall uptake was over 70% - the target for the breast screening programme. Statistical data will be available for NHS Greater Glasgow and Clyde from 2006/07.
Table 2.2 Breast screening uptake

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<td>(age 50-52)</td>
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<td>No of women invited</td>
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<td>94225</td>
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<td>% Uptake</td>
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<td>(age 53-64)</td>
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<tr>
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<tr>
<td>% Uptake</td>
<td>71.53</td>
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<td>Overall uptake</td>
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<tr>
<td>(age 50-64)</td>
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<tr>
<td>No of women screened</td>
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<td>50834</td>
<td>363153</td>
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<tr>
<td>No of women invited</td>
<td>39902</td>
<td>70761</td>
<td>476571</td>
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<tr>
<td>% Uptake</td>
<td>73.2</td>
<td>71.8</td>
<td>76.2</td>
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</table>

Source: SBSP Information System, KC62 returns and Revised KC62 returns (ISD Scotland)
Provisional data, awaiting validation

Table 2.3 shows the screening uptake rates split by age group. Women over the age of 70 years old can self-refer for a mammogram, but they are not part of the screening programme. It can be seen below that there is quite an even uptake overall, with only a slight dip in the later ages.

Table 2.3 Percentage uptakes by age bands for 2003/04 to 2005/06

<table>
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<th>Age group 1</th>
<th>Argyll &amp; Clyde</th>
<th>Greater Glasgow</th>
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<tbody>
<tr>
<td></td>
<td>Number invited</td>
<td>Number screened</td>
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<tr>
<td>50-52</td>
<td>8242</td>
<td>6075</td>
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<td>53-54</td>
<td>5569</td>
<td>4064</td>
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<td>55-59</td>
<td>14066</td>
<td>10396</td>
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<td>60-64</td>
<td>12025</td>
<td>8667</td>
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<tr>
<td>65-70</td>
<td>12773</td>
<td>8659</td>
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<tr>
<td>71-74 (self referred)</td>
<td>66</td>
<td>65</td>
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<td>Over 74 (self referred)</td>
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<tr>
<td>Target Group (50-64)</td>
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<td>29202</td>
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<tr>
<td>Total All Ages</td>
<td>52741</td>
<td>37926</td>
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Source: SBSP Information System, KC62 returns and Revised KC62 returns (ISD Scotland)
Provisional data, awaiting validation
Table 2.4 and Figure 2.2 illustrate an increase in the uptake rate of the breast screening programme over successive screening rounds. That is most marked for Greater Glasgow that achieved an increase in uptake from 61.9% in the 1991-1994 round to 71.8% in the 2003-2006 round. During the same period the uptake rate increased in Argyll and Clyde from 68.8% to 73.2%

### Table 2.4 Breast screening uptake trends

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<td>Argyll &amp; Clyde</td>
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1. Only routine appointments are included in the above figures. Self /GP referral and early recall appointments are not included.
2. Women are invited to attend screening once every three years and NHS Boards are not necessarily screened evenly throughout the three year period.
3. The above figures relate to women aged 50 - 64 years.

Source : SBSP Information System, KC62 returns and Revised KC62 returns; Provisional data, awaiting validation

**Figure 2.2**

Table 2.5 shows the number of breast cancers detected through the programme. This is split into invasive and non-invasive cancers and is again reported over the three year period the programme runs for. Non-invasive (or "in situ") cancers confine themselves to the ducts or lobules and do not spread to the surrounding tissues in the breast or other parts of the body. Invasive (or infiltrating) cancers have started to break through normal breast tissue barriers and invade surrounding areas and can spread to other parts of the body.
One hundred and sixty-nine cancers were detected in Argyll and Clyde and 244 in Greater Glasgow over the three year period. In comparison, in 2004 - the most recent year for which registration data is available - there were 353 breast cancer registrations in Argyll and Clyde and 913 cancers in NHS Greater Glasgow (see Table 2.6). This equates to approximately 15% of breast cancers registered in a year being detected through screening.

Table 2.5 Numbers and rates for breast cancer detected

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<th>NHS Argyll &amp; Clyde</th>
<th>NHS Greater Glasgow</th>
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<td><strong>Invasive cancer detection rate</strong></td>
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<tr>
<td><strong>Prevalent uptake</strong></td>
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<tr>
<td>Number of Cancers</td>
<td>47</td>
<td>97</td>
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<tr>
<td>Number of Women Screened</td>
<td>8394</td>
<td>19218</td>
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<tr>
<td>Rate per 1,000</td>
<td>5.6</td>
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<tr>
<td><strong>Incident uptake</strong></td>
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<tr>
<td>Number of Cancers</td>
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<td>109</td>
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<tr>
<td>Number of Women Screened</td>
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<td>24811</td>
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<tr>
<td>Rate per 1,000</td>
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<tr>
<td><strong>Non-invasive cancer detection rate</strong></td>
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<td><strong>Prevalent uptake</strong></td>
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<tr>
<td>Number of non/micro-invasive cancers</td>
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<tr>
<td>Number of Women Screened</td>
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<tr>
<td>Rate per 1,000</td>
<td>2.6</td>
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<tr>
<td><strong>Incident uptake</strong></td>
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<tr>
<td>Number of non/micro-invasive cancers</td>
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<td>22</td>
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<tr>
<td>Rate per 1,000</td>
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Source: SBSP Information System, KC62 returns and Revised KC62 returns (ISD Scotland)
Provisional data, awaiting validation
Morbidity and mortality from breast cancer in NHS GGC

Table 2.6 and Figure 2.3 demonstrate an increase in the standardised rate of breast cancer from 95.9 per 100,000 population in 1994 to 124.1 per 100,000 population in 2004 for the area of Argyll and Clyde; from 112.1 per 100,000 population in 1994 to 118.2 per 100,000 population in 2004 for the area of Greater Glasgow. This is mirrored by a similar trend for the whole of Scotland - the rates increased from 104.4 in 1994 to 120 in 2004.

The standardised death rates from breast cancer have dropped from 40.3 per 100,000 population in 1994 to 32.9 per 100,000 population in 2006 for the area of Argyll and Clyde; from 41.0 per 100,000 population in 1994 to 30.9 per 100,000 population in 2006 for the area of Greater Glasgow and from 38.1 per 100,000 population in 1994 to 28.5 per 100,000 population in 2006 for Scotland.

Table 2.6

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Notes:
Cancer of the breast (ICD-10 C50)
Mortality Source: General Register Office for Scotland (GROS)
Registrations Source: Scottish Cancer Registry, ISD
Data extracted: August 2007
Data extracted: April 2007
ISD website
Figure 2.3

Age-standardisation adjusts rates taking into account how many old or young people are in the population being looked at. When rates are age-standardised, the differences in the rates over time or between geographical areas do not simply reflect variations in the age structure of the populations. This is important when looking at cancer rates because cancer is a disease that predominantly affects the elderly. So if cancer rates are not age-standardised, a higher rate in one area or period of time is likely to reflect the fact that it has a greater proportion of older people.

The Confidence Interval (CI) provides a way of measuring how confident we are in the accuracy of the rate. We have used 95% CI which means that we have 95% confidence that the rate falls between the two Confidence Limits. When the CI of two rates overlap then there is no significant difference between the rates.

The observed increased trend in registration could partly be due to increased detection by the Scottish Breast Screening Programme in the context of changes in the prevalence of known risk factors, such as age at birth of first child, and alcohol consumption while the decrease in the death rates may be due to the synergistic action of early detection through screening, improved service standards following the implementation of the breast screening programme and the advances in diagnosis and treatment.
Future developments

In Scotland women are offered two view mammography at their first screen and a single oblique view mammogram in subsequent screens. England and Wales have implemented two view mammography at every screen in 2003 and a business case to implement two view mammography in Scotland has been approved. Additional staff will be recruited and trained and equipment will be procured to allow for the increase in activity.

NHS Quality Improvement Scotland (NHS QIS) undertook a Health Technology Assessment (HTA) at the request of the Breast and Cervical Screening National Advisory Group to assist with the proposed introduction of digital mammography into the Scottish Breast Screening Programme (SBSP). The report is due for publication in January 2008 and initial planning meetings are organised in December 2007.

Challenges and future priorities

The increase in breast screening uptake in Greater Glasgow has been achieved through intense collaboration between the West of Scotland Breast Screening Unit and the Greater Glasgow practices facilitated through a local GP re-imbursement scheme. Experience from the cervical screening programme has demonstrated the negative impact brought by changes in the GMS contract and it is essential, if we are to maintain the upward uptake trend, that we continue to provide incentives for practices to engage with the programme.

The implementation of two view mammography at incident rounds and the change in the technology brought by the introduction of digital mammography will have to be managed carefully to ensure that the high level of performance achieved by the programme is maintained.

There are ongoing issues related to data validity and analysis as well as the sharing of data collected for the prospective breast cancer audit with the national audit of screen detected breast cancers (BASO audit).

A detailed analysis of the breast screening uptake and the incidence of cancer by deprivation category will require to be done and initiatives targeted at groups with low uptake rates, taking account of the specific groups' attitudes and beliefs.
Conclusion

The breast screening programme has been implemented from 1988 - 1990; the number of women eligible for screening has increased during the 2003 - 2006 round of screening due to the implementation of the age extension and the programme achieved the target uptake rate in Glasgow for the first time since its implementation. Overall there is an up going uptake rate for the programme.

While the breast cancer registration rate has seen an increase, the mortality rate from breast cancer has been decreasing due to a combination of factors.

Recommendations

Ensure that the quality standards are maintained during the planning and implementation of two view mammography and digital mammography.
### Appendix 2.1

#### Members of Breast Screening Steering Group
(As at September 2006)

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ms Anna Baxendale</td>
<td>Health Improvement &amp; Equalities Manager</td>
</tr>
<tr>
<td>Ms Brenda Bellando</td>
<td>Business Manager</td>
</tr>
<tr>
<td>Ms Ann Boyle</td>
<td>Information Analyst</td>
</tr>
<tr>
<td>Dr Emilia Crighton</td>
<td>Consultant in Public Health Medicine (Chair)</td>
</tr>
<tr>
<td>Dr Hilary Dobson</td>
<td>Clinical Director</td>
</tr>
<tr>
<td>Mrs Fiona Gilchrist</td>
<td>Screening Manager</td>
</tr>
<tr>
<td>Ms Marian King</td>
<td>Superintendent Radiographer/Clinical Specialist</td>
</tr>
<tr>
<td>Dr Susan Langridge</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>Miss Denise Lyden</td>
<td>Project Officer</td>
</tr>
<tr>
<td>Miss Jacqueline McFadden</td>
<td>Information Analyst</td>
</tr>
<tr>
<td>Ms Fiona McGuire</td>
<td>Senior Health Promotion Officer</td>
</tr>
<tr>
<td>Ms Louise McTaggart</td>
<td>Mentoring Team Manager</td>
</tr>
<tr>
<td>Ms Janet Mair</td>
<td>Regional Registration Manager</td>
</tr>
<tr>
<td>Ms Cynthia Mendelsohn</td>
<td>Lay Member - Glasgow</td>
</tr>
<tr>
<td>Dr Alan Mitchell</td>
<td>Clinical Director</td>
</tr>
<tr>
<td>Ms Ann Mumby</td>
<td>Superintendent Radiographer</td>
</tr>
<tr>
<td>Ms Elaine Murray</td>
<td>Community Liaison Officer</td>
</tr>
<tr>
<td>Mrs Elizabeth Rennie</td>
<td>Screening Manager</td>
</tr>
<tr>
<td>Dr Eilidh Renwick</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>Ms Patricia Weir</td>
<td>Lay Member - Clyde</td>
</tr>
<tr>
<td>Mr Nic Zappia</td>
<td>Head of Primary Care Support</td>
</tr>
</tbody>
</table>
Appendix 2.2

Reporting Structure:
Breast Screening Steering Group

Key:
- - - - - - Network Links
   ______ Direct Reports

Director of Public Health

Public Health Screening Unit

Breast Screening Programme Steering Group
Chair:
Dr E Crighton, CPHM

Regional Cancer Advisory Group
CHAPTER 3: PLANNING FOR BOWEL SCREENING PROGRAMME

Background

Colorectal (Bowel) Cancer is the third most common cancer in Scotland. Every year over 3,400 people are diagnosed with the disease. In NHS Greater Glasgow and Clyde each year there are approximately 750-830 new cases registered and approximately 350 to 400 deaths (see Table 3.1 and Table 3.2).

The Scottish Bowel Screening Programme was launched in 2007 and will be fully implemented across Scotland by the end of 2009. NHS Greater Glasgow and Clyde plan to implement the programme in April 2009.

Table 3.1 Numbers of registrations for colorectal cancer between 1997-2004 for NHS Greater Glasgow and Clyde residents

<table>
<thead>
<tr>
<th>Year of Diagnosis</th>
<th>1997</th>
<th>1998</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>All ages males</td>
<td>429</td>
<td>410</td>
<td>388</td>
<td>410</td>
<td>414</td>
<td>427</td>
<td>437</td>
<td>402</td>
</tr>
<tr>
<td>All ages females</td>
<td>366</td>
<td>345</td>
<td>386</td>
<td>365</td>
<td>415</td>
<td>355</td>
<td>342</td>
<td>351</td>
</tr>
<tr>
<td>Total</td>
<td>795</td>
<td>755</td>
<td>774</td>
<td>775</td>
<td>829</td>
<td>782</td>
<td>779</td>
<td>753</td>
</tr>
</tbody>
</table>

Source: Scottish Cancer Registry, ISD
Data extracted: April 2007

Table 3.2 Numbers of deaths colorectal cancer NHS Greater Glasgow and Clyde 1997-2006

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>All ages males</td>
<td>219</td>
<td>194</td>
<td>175</td>
<td>198</td>
<td>184</td>
<td>203</td>
<td>183</td>
<td>213</td>
<td>172</td>
<td>182</td>
</tr>
<tr>
<td>All ages females</td>
<td>185</td>
<td>180</td>
<td>176</td>
<td>192</td>
<td>204</td>
<td>155</td>
<td>166</td>
<td>165</td>
<td>156</td>
<td>168</td>
</tr>
<tr>
<td>Total</td>
<td>404</td>
<td>374</td>
<td>351</td>
<td>390</td>
<td>388</td>
<td>358</td>
<td>349</td>
<td>378</td>
<td>328</td>
<td>350</td>
</tr>
</tbody>
</table>

Source: General Register Office for Scotland (GROS)
Data extracted: August 2007

Aim of the screening programme

The purpose of bowel screening by guaiac Faecal Occult Blood test (gFOBt) is to detect colorectal cancers at the earliest possible time so that treatment may be offered promptly. It is believed that very early detection of colorectal cancers in this way can result in more effective treatment, which may be more likely to reduce deaths from colorectal cancer.
**Recommended age to perform screening**

The programme will invite all men and women between the ages of 50 – 74 years registered with a General Practice. Other eligible individuals who are not registered with a General Practice such as prisoners, armed forces, homeless, and individuals in long-stay institutions will also be able to participate following NHS Greater Glasgow and Clyde local agreements. Thereafter, all individuals will be routinely recalled every two years.

**The screening test**

A guaiac Faecal Occult Blood test (gFOBt) testing kit will be sent to individuals’ homes to provide three stool samples. The test will be completed at home and returned to the National Bowel Screening Centre in Dundee for analysis.

After analysis, the National Centre will report, via an IT system, results of all test kits received to the Board. The National Centre also informs the patient by letter.

**Screening setting**

The National Bowel Screening Centre in Dundee issue screening kits to all eligible residents of NHS Greater Glasgow and Clyde to screen at home. The kits are then posted by return to the National Laboratory for processing.

**Screening pathway**

Patients with positive screening results will receive diagnostic investigations and treatment that will be integrated within the existing NHS Greater Glasgow and Clyde colorectal service. **Figure 3.1** overleaf provides an overview of the bowel screening pathway.
If the overall result is positive the individual will be referred for assessment and offered a colonoscopy, if appropriate. Robust plans for referral and fail-safe procedures will have to be agreed and implemented within NHS Greater Glasgow and Clyde.

The National Screening Co-ordinator based within NHS Scotland Screening Programmes, National Services Division will have a responsibility to monitor and co-ordinate the screening programme across Scotland. However, the screening programme will be integrated with the existing colorectal service to ensure equity for all patients.

NHS Greater Glasgow and Clyde Board will be responsible for ensuring the quality and performance of care for the patients within Greater Glasgow and Clyde area referred for further investigation and treatment.

**Eligible population**

It is estimated that 307,000 NHS Greater Glasgow and Clyde residents would be eligible to be invited to participate in the Bowel Screening programme every 2 years.

The level of uptake of 60% will prove particularly challenging for NHS Greater Glasgow and Clyde as the evaluation of the bowel screening pilot in UK demonstrated a level of uptake of 30% in deprived communities.
**Resource**

The projected workload and outcomes for NHS Greater Glasgow and Clyde can be found in Table 3.3 overleaf.

The business case submitted to the Performance Review Group on 19 September 2006 has secured the resources necessary for planning, implementation and delivery of the bowel screening programme.

**Information systems**

A bowel screening module will be developed to monitor performance and track patients through the process of diagnosis and treatment for colorectal cancer.

The system will be integrated with Patient Administration Systems, endoscopy, theatres, laboratory, pathology and radiology and will have multidisciplinary team (MDT) conference management facility. The system will be capable of producing reports, alerts and letters with results; reports on progress against quality assurance standards and NHS Quality Improvement Standards.
Table 3.3 Bowel screening programme: projected workload and outcomes for NHS Greater Glasgow and Clyde

Projected workload for Greater Glasgow and Clyde* in the Year 2006 based on 50% uptake to gFOBt test in males and 52% uptake to FOB test in females every 2 years

<table>
<thead>
<tr>
<th>Definition of process/outcome</th>
<th>Numbers of Males</th>
<th>Numbers of Females</th>
<th>Total Numbers Over 2 years</th>
<th>Total Numbers per annum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Invited to participate</td>
<td>143,634</td>
<td>163,207</td>
<td>306,841</td>
<td>153,421</td>
</tr>
<tr>
<td>Agreed to participate</td>
<td>72837</td>
<td>85809</td>
<td>158,645</td>
<td>79,323</td>
</tr>
<tr>
<td>Completed gFOBt testing</td>
<td>71817</td>
<td>84868</td>
<td>156,685</td>
<td>78,343</td>
</tr>
<tr>
<td>Overall negative gFOBt test</td>
<td>69784</td>
<td>83646</td>
<td>153,429</td>
<td>76,7145</td>
</tr>
<tr>
<td>Overall positive gFOBt test</td>
<td>2033</td>
<td>1222</td>
<td>3,255</td>
<td>1,628</td>
</tr>
<tr>
<td>Colonoscopy undertaken</td>
<td>1736</td>
<td>1047</td>
<td>2,782</td>
<td>1,391</td>
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<tr>
<td>Incomplete colonoscopy</td>
<td>152</td>
<td>156</td>
<td>308</td>
<td>154</td>
</tr>
<tr>
<td>Complete colonoscopy</td>
<td>1580</td>
<td>889</td>
<td>2,470</td>
<td>1,235</td>
</tr>
<tr>
<td>Unknown if complete/incomplete</td>
<td>4</td>
<td>1</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>DCBE undertaken</td>
<td>105</td>
<td>121</td>
<td>227</td>
<td>114</td>
</tr>
<tr>
<td>Complete investigation</td>
<td>1681</td>
<td>1008</td>
<td>2,689</td>
<td>1,345</td>
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<tr>
<td>Incomplete investigation</td>
<td>353</td>
<td>214</td>
<td>567</td>
<td>284</td>
</tr>
<tr>
<td>Definition of process/outcome</td>
<td>Numbers of Males</td>
<td>Numbers of Females</td>
<td>Total Numbers Over 2 years</td>
<td>Total Numbers per annum</td>
</tr>
<tr>
<td>-------------------------------------------------------------------</td>
<td>------------------</td>
<td>--------------------</td>
<td>----------------------------</td>
<td>-------------------------</td>
</tr>
<tr>
<td>Most severe</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Invasive cancer (including malignant adenomas)</td>
<td>185</td>
<td>89</td>
<td>274</td>
<td>137</td>
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<tr>
<td>Polyp cancer</td>
<td>41</td>
<td>19</td>
<td>59</td>
<td>30</td>
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<tr>
<td>Other pathology</td>
<td>424</td>
<td>286</td>
<td>710</td>
<td>355</td>
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<tr>
<td>Normal colon</td>
<td>340</td>
<td>339</td>
<td>679</td>
<td>190</td>
</tr>
<tr>
<td>Adenoma (high, intermediate and low risk)</td>
<td>723</td>
<td>295</td>
<td>1,018</td>
<td>509</td>
</tr>
<tr>
<td>No further investigation conducted</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i.e. refused further treatment, unfit, DNA, cancelled, gone private, deceased, interrupted investigation</td>
<td>309</td>
<td>185</td>
<td>494</td>
<td>247</td>
</tr>
<tr>
<td>Unknown (includes non-diagnostic results)</td>
<td>11</td>
<td>9</td>
<td>21</td>
<td>11</td>
</tr>
<tr>
<td>Further treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>187</td>
<td>88</td>
<td>275</td>
<td>138</td>
</tr>
<tr>
<td>Oncological referral</td>
<td>referred to oncology</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oncological treatment</td>
<td>i.e. chemotherapy/radiotherapy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adenoma risk classification</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High risk adenoma</td>
<td>102</td>
<td>19</td>
<td>121</td>
<td>61</td>
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<tr>
<td>intermediate risk adenoma</td>
<td>333</td>
<td>152</td>
<td>485</td>
<td>243</td>
</tr>
<tr>
<td>low risk adenoma</td>
<td>250</td>
<td>118</td>
<td>368</td>
<td>184</td>
</tr>
<tr>
<td>Unclassifiable risk adenomas</td>
<td>37</td>
<td>7</td>
<td>44</td>
<td>22</td>
</tr>
</tbody>
</table>
NOTE:

1. These projections are based on numbers resulting from the first round pilot, using this information for subsequent rounds of bowel screening is likely to overestimate numbers.


3. These projections assume the 70-74 year old population will behave in a similar way to the 50-69 population in terms of colonoscopies undertaken, cancers detected, surgery undergone, etc when this may not necessarily be the case (more abnormalities may be expected in older age groups but lower numbers of people may attend colonoscopy/surgery).

4. These projections do not take into account any variations in lifestyle, etc between health boards which may cause the numbers gathered in the pilot health boards (Fife, Grampian and Tayside) to be unrepresentative for other areas across Scotland.

5. Percentage uptake is based on numbers of people who complete enough gFOBt kits to have a final 'positive' or 'negative' result, numbers of people 'agreeing to participate' will be higher as not everyone who completed at least one gFOBt kit will have a final positive/negative result.

6. In some cases a diagnosis may be made despite the fact that the investigation technique (i.e. colonoscopy) was determined to be incomplete.

* Glasgow and Highland population projections have been amended to include estimations of previous Argyll & Clyde population.

** BSG Guidelines were used to assign risk categories to adenomas detected through the screening programme.
**Appendix 3.1**

**Members of Bowel Screening Steering Group**  
(as at September 2006)

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ms Sharon Adamson</td>
<td>Lead Service Manager (until Sept 06)</td>
</tr>
<tr>
<td>Mr John Anderson</td>
<td>Consultant Surgeon</td>
</tr>
<tr>
<td>Dr Emilia Crighton</td>
<td>Consultant in Public Health Medicine (Chair)</td>
</tr>
<tr>
<td>Ms Carol Findlay</td>
<td>Head of Finance - Surgery &amp; Anaesthetics</td>
</tr>
<tr>
<td>Mrs Maureen Kirkland</td>
<td>Lay Member</td>
</tr>
<tr>
<td>Miss Denise Lyden</td>
<td>Project Officer</td>
</tr>
<tr>
<td>Mr Jim McCourtney</td>
<td>Consultant Surgeon</td>
</tr>
<tr>
<td>Ms Mary McGinley</td>
<td>General Manager - General Surgery &amp; Urology</td>
</tr>
<tr>
<td>Dr John Morris</td>
<td>Consultant Gastroenterologist</td>
</tr>
<tr>
<td>Ms Rebecca Morrison</td>
<td>Clinical Service Manager</td>
</tr>
<tr>
<td>Mr Ian Pickford</td>
<td>Surgical Consultant</td>
</tr>
<tr>
<td>Prof Robin Reid</td>
<td>Associate Medical Director for Diagnostics</td>
</tr>
<tr>
<td>Ms Ruth Tipling</td>
<td>Colorectal Nurse</td>
</tr>
<tr>
<td>Mr Tom Walsh</td>
<td>Acute Planning Manager (until Sept 06)</td>
</tr>
</tbody>
</table>
Appendix 3.2

Reporting Structure: Bowel Screening Programme
PREGNANCY AND NEWBORN SCREENING PROGRAMMES
CHAPTER 4: COMMUNICABLE DISEASES IN PREGNANCY

Background

HIV screening in pregnancy was introduced in Scotland in 2003. This is an addition to the existing integrated programme of antenatal screening to limit risk for a number of communicable diseases - hepatitis B, syphilis, rubella as well as HIV.

Aim of screening programme

The primary aim of screening women for these conditions is to ensure a plan for treatment and management for affected individuals and their babies. It allows treatment to be given, which can reduce the risk of mother to child transmission, improve the long-term outcome and development of affected children, and ensure that women, their partners and families are offered appropriate referral, testing and treatment.

Eligible population

The programme is offered universally to all pregnant women at the first booking visit and is opt-out. Women are offered the test, not because they have been at risk, but because they are pregnant.

The screening test

Testing for infection with HIV, hepatitis B, syphilis and immunity to rubella are carried out on serum obtained from a single blood sample normally taken at the first antenatal booking visit. Occasionally a second blood sample may be requested for technical reasons.

Screening pathway

The following protocols for communicable diseases screening in pregnancy were approved by the Pregnancy Screening Group in June 2007 and will be reviewed in July 2008 by the Pregnancy Screening for Communicable Diseases in Pregnancy Protocols and Data Monitoring sub group chaired by Dr Gillian Penrice, Consultant in Public Health Medicine in the Public Health Protection Unit.

- Offering routine antenatal communicable diseases test
- Protocol for significant laboratory results for hepatitis B
- Protocol for significant laboratory results for HIV
- Protocol for significant laboratory results for non immune rubella infection
- Protocol for significant laboratory results for syphilis
The protocols set out the pathways for antenatal screening for communicable diseases in order to meet NHS QIS Standard 3a1. Following approval, these protocols were widely disseminated to all staff within NHS Greater Glasgow and Clyde involved with this national screening programme.

**Delivery of screening programme 2006/07 - results**

15,327 pregnant women had a first booking visit at a Greater Glasgow and Clyde hospitals during 2006/07. 11967 took place at Greater Glasgow maternity units and 3,360 at Clyde maternity units. This includes all first booking visits at hospital, at a clinic outside of hospital, including community outreach and at GP surgeries or at home.

All women are offered screening for the four communicable diseases, and receive an information leaflet about the screening tests prior to attendance at their first booking visit. However, the number of women booking cannot be used to accurately calculate uptake of the individual screening tests as the laboratory data below includes ‘repeat samples’, i.e. second samples taken from the same woman. Within Greater Glasgow, the total number of samples (12,365) is greater than the total number of booking visits (11,967). In addition in Greater Glasgow, the syphilis serology is sent to, tested at and reported from three local bacteriology laboratories and data transfer for reporting purposes is incomplete.

An estimate of the percentage uptake of each of the tests has been calculated by dividing the number requesting the test by the total number of samples. When screening is offered to the woman, the tests are accepted or refused individually. Consent is obtained and documented in the woman’s notes.

The Table 4.1 below of results shows that for all four screening tests, uptake is greater than the target uptake of 95%.

**Table 4.1 Greater Glasgow laboratories**

<table>
<thead>
<tr>
<th></th>
<th>Samples 2006/07</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total number of samples</td>
<td>No. requesting individual test</td>
</tr>
<tr>
<td>HIV</td>
<td>12365</td>
<td>11805</td>
</tr>
<tr>
<td>HBV</td>
<td>12365</td>
<td>12137</td>
</tr>
<tr>
<td>Rubella</td>
<td>12365</td>
<td>12335</td>
</tr>
<tr>
<td>Syphilis</td>
<td>10404⁶</td>
<td>10404</td>
</tr>
</tbody>
</table>

**Notes**

¹ Equivocal - on initial testing, the result cannot be reported as positive or negative. A repeat sample will be needed
² Insufficient or not tested – Although the test was requested, for various reasons, e.g. sample volume too small, the test could not be carried out. A repeat sample will be needed.
³ HIV - these 6 cases were detected for the first time by antenatal screening
⁴ HBV - 34 new cases were detected by antenatal screening. 4 were already known about.
Detection of antibody means that the women is immune to rubella. No antibody detected or equivocal means that the woman is susceptible to rubella and should be offered immunisation with MMR vaccine after delivery.

Incomplete data available for antenatal syphilis testing. This is because, syphilis serology is tested, managed and reported via local bacteriology laboratories in Glasgow. The incomplete data is a consequence of data transfer for reporting purposes and not indicative of missed cases during the screening process.

### Table 4.2 Clyde laboratories

<table>
<thead>
<tr>
<th></th>
<th>Samples 2006/07</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total number of samples</td>
<td>No. requesting individual test</td>
</tr>
<tr>
<td>HIV</td>
<td>2400</td>
<td>2308</td>
</tr>
<tr>
<td>HBV</td>
<td>2400</td>
<td>2352</td>
</tr>
<tr>
<td>Rubella</td>
<td>1894</td>
<td>1807</td>
</tr>
<tr>
<td>Syphilis</td>
<td>1894</td>
<td>1811</td>
</tr>
</tbody>
</table>

**Notes**

1. Incomplete reporting of data from Clyde labs for 2006-2007. The incomplete data is a consequence of data transfer for reporting purposes and not indicative of missed cases during the screening process. Computerised results which could be reported were available from Royal Alexandra Hospital from July 2006 – March 2007, Vale of Leven from October 2006 – March 2007 and Inverclyde Royal Hospital from November 2006 – March 2007.

2. Insufficient or not tested – Although the test was requested, for various reasons, e.g. sample volume too small, the test could not be carried out. A repeat sample will be needed.

3. 1 new case of HIV detected by screening

4. 1 new case of HBV detected by screening

5. Detection of antibody means that the women is immune to rubella. No antibody detected or equivocal means that the woman is susceptible to rubella and should be offered immunisation with MMR vaccine after delivery.

### Information systems

While the protocols have been integrated across the Greater Glasgow and Clyde health board area, there is not a single information system, which facilitates routine reporting.

Antenatal samples are tested at a total of seven laboratories across the Greater Glasgow and Clyde area and this brings challenges of data collection and reporting. However, there are excellent communication links with laboratory staff who provide the necessary monitoring data when requested.

### Future developments

The Pregnancy Screening for Communicable Diseases Protocols and Data Monitoring subgroup will continue to audit activity and outcomes against the protocols to ensure that the QIS standards are met and patient care is optimum.
Challenges and future priorities

The Pregnancy Screening for Communicable Diseases Protocols and Data Monitoring subgroup will work with the laboratories to identify and resolve the minor data anomalies and improve routine reporting so that ongoing audit and identification of any problems with protocol compliance are noticed and rectified in a timely manner.

Although after care of women and their children identified through screening is not strictly a screening function, the management, treatment and care of such individuals should be considered as a consequence of the screening programme. There are well-established follow-up protocols for babies born to mothers infected with hepatitis B and regular audits are carried out to ensure effectiveness. For those mothers and their children affected by HIV, there is an annual HIV clinical audit, which reviews those HIV cases detected via the screening programme and examines where the protocol has been particularly successful or requires amendment.

Conclusion

The results indicate that this screening programme is successful as the uptake of the four screening tests is high (>95%) and all women identified (and their babies) are offered appropriate treatment. However, a programme of audit will continue to ensure protocol compliance with the screening programme itself and the ongoing management of women identified as a result of the programme.
Appendix 4.1

Members of Pregnancy Screening for Communicable Diseases Data and Monitoring Group
(As at November 2006)

Dr Vevanne Biggs       Lead Consultant in Clyde
Dr Sheila Cameron      Consultant Clinical Scientist, Regional Virus Lab
Dr Catherine Chiang    CPHM, Public Health Protection Unit (Chair until May 07)
Mrs Louise Carroll     R & D Officer for BBVs, PHPU
Sr Flora Dick          Clinical Lead Midwife SNIPS
Dr Francois de Villiers Consultant in Bacteriology, Clyde
Ms Catherine Frew      Data Analyst, Regional Virus Lab
Ms Cathy Harkins       Lead Midwife, Clyde
Dr Maggie Lachlan      CPHM PH Screening Unit
Miss Denise Lyden      Project Officer
Sr Marie-Elaine McClair Lead Midwife PRMH
Dr Alan Mathers        Clinical Director - Obstetrics
Ms Gwyneth MacDonald   Sexual Health Advisor, Sandyford
Miss Jack McFadden      Information Analyst Officer
Sr Roisin McPherson    Midwife
Ms Linda Munn          Clinical Lead Midwife, SGH
C/N Martin Murchie     Health Adviser Sandyford Initiative
Mrs Hattie O’Donnell   Health Protection Nurse Specialist
Mrs Diane Paterson     Clinical Lead Midwife, QMH
Ms Linda Rhodick       Medical Secretary, Regional Virus Lab
Ms Jo Scobie           Clinical Lead Midwife
Dr Bishan Thakker      Consultant in Microbiology GRI
Deborah Wardle         Consultant GUM Physician Russell Institute
Dr Andrew Winter       Consultant GUM Physician Sandyford Initiative
Mrs Janice Winter      Clinical Effectiveness Facilitator
Appendix 4.2

Reporting Structure:
Pregnancy Screening for Communicable Diseases Protocols and Data Monitoring Sub Group

Key:
_______ Direct Reports
CHAPTER 5: DOWN’S SYNDROME AND NEURAL TUBE DEFECTS

Background

Guidance on antenatal screening for Down’s syndrome and neural tube defects (NTDs) is led by the National Screening Committee (NSC) on a UK wide basis. Current policy advice from the NSC is that Down’s syndrome screening programmes should provide the highest quality screening method, ideally in the first trimester. The NSC Good Practice Guidelines currently recommend that a detection rate of 90% with a false positive rate of less than 2% to be achieved by 2010.

In Scotland, the Quality Improvement Scotland Standards: Pregnancy and Newborn Screening 2005 doesn’t give guidance on the screening method for Down’s syndrome. These standards, as well as The Framework for Maternity Services Scotland, and the NHS QIS Health Technology Assessment 2004 do recommend that all women should be offered routine 18-20 week foetal anomaly ultrasonography for NTDs and other foetal anomalies.

a) Down’s syndrome

Down’s syndrome is a congenital condition which causes moderate to severe learning difficulties, impaired physical growth, characteristic facial appearance and is associated with a number of other physical problems such as cardiac abnormalities.

The Scottish Perinatal and Infant Mortality and Morbidity Report 2006 shows the rate of Down’s syndrome in Scotland for 2001 – 2005 was 1.71 per 1000 births (including prenatal diagnosis) with some 61 babies born with the syndrome. Over the same time period, the rates for Down’s syndrome for Greater Glasgow were 1.19 per 1000 and 0.86 per 1000 in the former NHS Argyll and Clyde.

b) Neural Tube Defects

Neural tube defects (NTDs) are congenital malformations, which arise during the development of the brain and spinal cord. It can result in spina bifida (incomplete closure of the lower spine – this can be open or closed depending on whether or not there is tissue covering the lower spine), which causes walking difficulties as well as problems with bowel and bladder control; or anencephaly when the skull and brain are not properly formed.
Scottish Perinatal and Infant Mortality and Morbidity Report 2006 shows the rate of NTDs Syndrome in Scotland for 2001-2005 was 0.98 per 1000 (including prenatal diagnosis) with some 18 babies born with spina bifida and 3 with anencephaly. Over the same time period, the rates for NTDs for Greater Glasgow was 0.75 per 1000 births and 0.65 per 1000 in the former NHS Argyll and Clyde.

**Aim of screening programme**

The purpose of antenatal screening for Down's syndrome and NTDs is to detect Down's syndrome and NTDs in the antenatal period. This provides women and their partners with informed choice regarding continuation of pregnancy. It also allows, where appropriate, management options (such as cardiac surgery or delivery in a specialist unit) to be offered in the antenatal period.

**Eligible population**

All pregnant women who book for antenatal care in NHS Greater Glasgow and Clyde are offered antenatal screening for Down's syndrome and NTDs in the first, second or both trimesters of their pregnancy.

**Screening setting**

All women are provided with information regarding Down's syndrome and NTDs prior to attending the antenatal clinic, allowing them to make an informed decision regarding screening tests.

All pregnant women are offered antenatal screening for Down's syndrome and NTDs at the antenatal clinic. Screening is integrated into the clinical care pathway. There are 6 hospitals and 10 associated community clinics where women can book for their antenatal care.

**The screening tests**

Screening for Down’s syndrome and NTDs can be carried out using a number of different screening methods. The screening tests, together with maternal risk factors are used to derive an overall risk of having a baby with Down’s syndrome or a NTD.

a) *Down’s syndrome*

There are 2 different screening tests for Down’s syndrome used in NHS Greater Glasgow and Clyde:

- Blood testing in the second trimester (AFP and total beta HCG) and maternal age. It is carried out at 15-20 weeks.
• Combined test: This uses a combination of ultrasound measurements of foetal nuchal translucency (NT); measurements of maternal blood markers: free beta HCG and PAPP-A); age and other maternal factors. It is carried out at 11-14 weeks. The National Screening Committee report that this method has the best detection rate and the lowest false positive rate.

b) Neural Tube Defects

There are 2 different screening methods for neural tube defects used in NHS Greater Glasgow and Clyde:

• Blood testing in the second trimester (AFP and $\beta$HCG measured at around 16 weeks) and maternal age.

• 18-20 week foetal anomaly ultrasonography (which also assesses other foetal anomalies).

Throughout NHS Greater Glasgow and Clyde, all women who are found to have a risk of Down's syndrome or NTDs greater than or equal to 1:250 are offered further investigation and management. All women with an abnormal foetal anomaly ultrasound are offered further investigations.

The diagnostic tests

Further diagnostic investigation for Down's syndrome and neural tube defects in pregnancy include:

• Detailed ultrasonography by a foetal medicine specialist.

• Chorionic villus sampling. This is an invasive procedure, where a needle is used to sample the foetal placenta. It is usually performed between 11 to 13 weeks and has a miscarriage rate of 2%.

• Amniocentesis: This is an invasive procedure, where a needle is used to sample the fluid around the foetus. It is usually performed after 15 weeks gestation and has an additional overall risk of miscarriage of 1%.
Screening Pathway

Currently, throughout NHS Greater Glasgow and Clyde, there are 3 main screening pathways.

a) Queen Mother’s Hospital (QMH)

Women booking at the Queen Mother’s Hospital are offered combined screening for Down’s in the first trimester and uses second trimester bloods (double test) for NTDs (see Figure 5.1).

Figure 5.1
Queen Mother’s Hospital: Screening For Down’s Syndrome And Neural Tube Defects

![Screening Pathway Diagram](image-url)
b) **Clyde area of NHS Greater Glasgow and Clyde**

The Clyde area offers all women combined screening for Down’s syndrome and universal routine 18-20 week foetal anomaly ultrasonography (see Figure 5.2).

**Figure 5.2**

*Clyde: Screening For Down's Syndrome And Neural Tube Defects*
c) **All others areas of NHS Greater Glasgow and Clyde and Late bookers**
(women who book too late in their pregnancy to have first trimester screening)

These women are offered second trimester blood testing for Down’s syndrome and NTDs (double test) (See Figure 5.3)

**Figure 5.3**
Screening For Down's Syndrome
All other areas and late bookers in NHS Greater Glasgow and Clyde

```
<table>
<thead>
<tr>
<th>Offer of screening by healthcare staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informed consent</td>
</tr>
<tr>
<td>2nd trimester AFP and total HCG and maternal age</td>
</tr>
<tr>
<td>Risk Assessment Calculation at screening laboratory</td>
</tr>
</tbody>
</table>

Low Risk:-
Routine Maternity Care

Normal

Women with high risk (>1:250) offered counselling and routine maternity

Abnormal

Counselling and further management agreed (incl. possible termination of pregnancy)
```
Uptake of Down’s syndrome and NTD screening in NHS Greater Glasgow and Clyde

The decision to accept screening for Down's syndrome and NTDs raises particular moral and ethical issues for women. Uptake therefore depends on whether women would wish further investigation or management of Down’s syndrome or NTDs. This is reflected in the uptake rate of testing, although uptake of foetal ultrasonography at any stage is virtually 100%.

At present, assessment of uptake of screening is based on laboratory data only. In the year 2006/2007 there were a total of 15,327 booking at antenatal clinics across NHS Greater Glasgow and Clyde. It is estimated that 15% of these booked in the second or third trimester (late bookers).

The following table shows the number of women who have booked into antenatal clinics in the areas with different screening tests. Using data from the West of Scotland regional Prenatal Screening service for Down’s syndrome and neural tube defects, it was possible to estimate the uptake in each area.

Table 5.1 Estimated uptake of laboratory testing for Down’s syndrome and NTDs (April 06 – March 07):

<table>
<thead>
<tr>
<th>Area</th>
<th>No of Women having 1st trimester screening</th>
<th>No of women having 2nd trimester screening</th>
<th>Total No of women screened</th>
<th>Total Number of women booking</th>
<th>% Uptake</th>
</tr>
</thead>
<tbody>
<tr>
<td>QMH</td>
<td>1,956</td>
<td>579</td>
<td>2,535</td>
<td>3,401</td>
<td>74.54%</td>
</tr>
<tr>
<td>All other areas of Glasgow¹</td>
<td>91</td>
<td>5,472</td>
<td>5,563</td>
<td>8,566</td>
<td>64.94%</td>
</tr>
<tr>
<td>Clyde (Apr – Dec)²</td>
<td>0</td>
<td>1,404</td>
<td>1,404</td>
<td>2,550</td>
<td>55.01%</td>
</tr>
<tr>
<td>Clyde (Jan – Mar)²</td>
<td>344</td>
<td>305</td>
<td>649</td>
<td>810</td>
<td>80.12%</td>
</tr>
<tr>
<td>Total</td>
<td>2,391</td>
<td>7760</td>
<td>10,151</td>
<td>15,327</td>
<td>66.23%</td>
</tr>
</tbody>
</table>

¹ Princess Royal Maternity Hospital, Southern General Hospital and associated community clinics.
² Pre- and post- introduction of CUBS
First trimester combined testing for Down’s syndrome has been routinely offered in the Clyde area of NHS Greater Glasgow and Clyde since January 2007. Uptake during the period January 2007 –March 2007 only reflects 3 months of monitoring during which time there was overlap of the two screening pathways - this may skew the results. Uptake rates across NHS Greater Glasgow and Clyde will continue to be monitored.

First trimester combined testing for Down’s syndrome is carried out for clinical reasons in a small number of women in areas of NHS Greater Glasgow and Clyde which do not routinely offer it (e.g. for twin pregnancies).

All women who book in NHS Greater Glasgow and Clyde after the first trimester are offered second trimester blood testing for Down’s syndrome and NTDs.

**Delivery of Screening Programme 2006/07**

Table 5.2 shows data from the West of Scotland Regional Prenatal Screening service for Down’s syndrome and neural tube defects on follow up rate.

**Table 5.2: percentage of tests in the high risk category**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Screening Test</th>
<th>%of all tests which are high risk¹</th>
</tr>
</thead>
<tbody>
<tr>
<td>Down’s syndrome</td>
<td>Combined test</td>
<td>4.9%</td>
</tr>
<tr>
<td></td>
<td>Second trimester blood testing</td>
<td>6.2%</td>
</tr>
<tr>
<td>NTD (open spina bifida)²</td>
<td>Second trimester blood testing</td>
<td>2.6%</td>
</tr>
</tbody>
</table>

1. The high-risk category is ≥1:250 risk
2. Screening is most effective at detecting open spina bifida. Almost 100% of anencephaly cases are detected in routine first trimester scans.

NHS Quality Improvement Scotland Standards: Pregnancy and Newborn Screening 2005, recommends that screening tests for Down’s syndrome should have 5-7% of tests returning as high risk and they expect that tests for NTD’s have 2-4%. Therefore, laboratory based screening in NHS Greater Glasgow and Clyde does achieve these standards.

The proportion of women who decide to take a diagnostic test following a high risk screening result is 70% for women screened in the first trimester (approximately 1/4 having CVS and 3/4 having amniocentesis) and 60% for women screened in the second trimester (all having amniocentesis).
Table 5.3 shows data from the West of Scotland Regional Prenatal Screening Service for Down’s syndrome and neural tube defects on detection rate. The detection rate is percentage of cases of Down’s syndrome and NTD which were detected by the laboratory.

Table 5.3: Percentage of cases which were detected by laboratory screening during pregnancy

<table>
<thead>
<tr>
<th>Condition</th>
<th>Screening Test</th>
<th>Detected by laboratory screening</th>
</tr>
</thead>
<tbody>
<tr>
<td>Down’s syndrome</td>
<td>Combined test</td>
<td>88%</td>
</tr>
<tr>
<td></td>
<td>Second trimester blood testing</td>
<td>66%</td>
</tr>
<tr>
<td>Neural tube defects</td>
<td>Second trimester blood testing</td>
<td>85%</td>
</tr>
</tbody>
</table>

NHS Quality Improvement Scotland Standards: Pregnancy and Newborn Screening 2005, recommends that screening tests for NTD’s should have a detection rate of at least 85% in the first trimester and at least 60% by the second. They expect that laboratory tests for NTD’s have a detection rate of 80-90% of pregnancies. Therefore, laboratory based screening in NHS Greater Glasgow and Clyde does achieve these standards.

Resource

The screening programme is embedded within maternity care – ie Women’s and Children’s and Diagnostic Laboratory Directorates.

Future Developments

The priority for the programme is to achieve an equitable and integrated programme for Down’s syndrome and neural tube defects throughout NHS Greater Glasgow and Clyde which not only meets the NHS QIS standards but adheres to NSC good practice guidelines. The good practice guidelines recommend a detection rate of 90% with a false positive rate of less than 2% to be achieved by 2010. The proposed model of care, at this stage, is to offer the first trimester combined test and the 18-20 week foetal anomaly ultrasonography. Late bookers will have access to second trimester quadruple serum testing for NTDs and foetal anomaly scanning.
CHAPTER 6: NEWBORN BLOODSPOT SCREENING

Background

Newborn bloodspot screening is offered to parents/guardians of all live infants resident in Greater Glasgow, Clyde and Argyll and Bute.

Newborn Screening for phenylketonuria (PKU) and congenital hypothyroidism (CHT) has been in progress since 1965 and 1979 respectively. Newborn screening for cystic fibrosis was added in Scotland in February 2003.

Aim of screening programme

The aim of the screening programme is to identify, as early as possible, abnormalities of body chemistry (metabolism) in newborn babies which can lead to problems with growth and development, so that they may be offered appropriate management for the condition detected. The diseases screened for are phenylketonuria (PKU), which is found in around 1 in 8,000 babies born; congenital hypothyroidism (CHT), which affects approximately 1 in 3,500; and cystic fibrosis (CF), an inherited condition affecting 1 in 2,500 babies born in Scotland.

Benefits of programme

The benefits of the programme are that serious conditions may be detected before symptoms appear and treatment is offered at an early stage when it is likely to be more effective. For example, babies born with PKU cannot metabolise an amino acid called phenylalanine which is a component of protein found in every day foods including milk. Toxic levels of phenylalanine may build up causing irreversible brain damage unless the baby is urgently started on a special diet. With prompt treatment the baby is very likely to develop normally.

Recommended Age to Perform Screen

The bloodspot sample should be taken on day 5 of life whenever possible. There are separate protocols in place for screening babies who are ill, transfused or born prematurely and when repeat testing is required.
The screening test

Blood is taken by the community midwife from the baby’s heel using a blood letting device and collected on a bloodspot card consisting of special filter paper which is posted by freepost to the National Newborn Screening Laboratory in Glasgow. The blood is analysed for markers of the 3 conditions phenylketonuria, congenital hypothyroidism and cystic fibrosis.

Eligible Population

All newborn babies of residents in NHS Greater Glasgow and Clyde.

Delivery of screening programme 2006/07

Guidelines for newborn bloodspot Screening have been developed for use across NHS Greater Glasgow and Clyde. (ref: NHS Greater Glasgow and Clyde Neonatal Guidelines: Neonatal Bloodspot Screening, 2007). These include:

- Informing the parents/carers
- Consent
- Timing of the test
- Repeat testing for sick and premature infants
- Requirements for the test
- Method for heel prick testing
- Documentation

The screening process requires excellent communication and co-ordination between the hospital and community midwifery service, the National Laboratory at Yorkhill, the screening department at Gartnavel and the paediatric service as is demonstrated in the following pathway (Figure 6.1) for PKU and CHT. There is a separate CF pathway as double testing is required.
FIGURE 6.1: NEWBORN SCREENING PROCESS: Phenylketonuria (PKU), Congenital Hypothyroidism (CHT)

MIDWIFERY

Baby born → Information to Parents

Consent for Test

Yes → Blood spot collected

No further action unless clinical symptoms present. Refusal recorded at laboratory

"Test declined" recorded

Repeat specimen if necessary

LABORATORY

Blood spot test

Report

High/persistently raised

raised/repeat required

Report

Report

Telephone call to Paediatrician plus Report

SCREENING DEPT, GARTNAVEL

Birth Notified → Coverage Monitored

Result recorded

Result notified

Notification to GP, Hospital, Child Health

Referred to Paediatrician

Treatment if necessary and follow up

HOSPITAL
A national leaflet explaining the tests is distributed soon after the birth. The heel prick blood sample is generally taken by the community midwife on the 5th day and the bloodspot card sent by freepost to the National Newborn Screening Laboratory in Yorkhill. Currently across NHS Greater Glasgow and Clyde there is a variation in the devices used to prick the heel. The costs and benefits of the devices are currently being reviewed and by early 2008 the steering group will recommend that all of NHS Greater Glasgow and Clyde uses the same type of device causing the least distress and the least unsatisfactory results so avoiding repeat testing for all babies.

There is an urgency to begin the management of all babies found to have any of the 3 conditions as soon as possible. The standards require 95% of positive cases of CHT and PKU to have started treatment by 14 days of age and of CF within 35 days of age. The delivery of the programme within the timescale is also dependent on the postal service delivering the bloodspot samples to the Newborn Screening Laboratory. Arrangements are in place to courier the samples to the laboratory if necessary.

Normally 95% of samples arriving at the National Laboratory are reported within two working days as required by the clinical standards. However in 2006 for Scotland this fell to 91%. This is the first year the laboratory has not managed to meet the standard. This was due to equipment problems and staff shortages at critical periods of the year. The equipment problems appear to be resolved and National Services Division is funding two new members of staff and therefore this should improve turn around times for 2007.

**Delivery of Screening Programme 2006/07**

The number of babies of NHS Greater Glasgow and Clyde residents screened in 2006 was 13,458, 96% of the total eligible population of 14,015. Figure 6.2 illustrates uptake rates and the results of the screening programme from 1 April 2006 to 31 March 2007.

Of the 4% (557) not screened, only 9 refused screening, 412 moved in or out of the area and 30 babies died. From 1 April 2006 to 31 March 2007 there was one positive case of PKU detected, 7 of CHT and 13 of cystic fibrosis. All received appropriate management within the timescale of the standard.
Figure 6.2

Summary of Bloodspot Screening Uptake and Results for babies born 1 April 2006 – 31 March 2007

Total Eligible for Screening
14015 (100%)

<table>
<thead>
<tr>
<th></th>
<th>Live Births to NHSGGC resident</th>
<th>Babies who moved into the area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Screened</td>
<td>13422 (95.8%)</td>
<td>593 (4.2%)</td>
</tr>
</tbody>
</table>

Screened

YES

13458 (96%)

NO

557 (4%)

Refused

<table>
<thead>
<tr>
<th>Babies moved into area, but not born here</th>
<th>Babies died after birth</th>
<th>Babies moved out after birth</th>
<th>To be investigated</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>451</td>
<td>30</td>
<td>6</td>
</tr>
</tbody>
</table>

Results

PKU

<table>
<thead>
<tr>
<th>Positive</th>
<th>Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>13457</td>
</tr>
</tbody>
</table>

THY

<table>
<thead>
<tr>
<th>Positive</th>
<th>Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>13448*1</td>
</tr>
</tbody>
</table>

CF

<table>
<thead>
<tr>
<th>Positive</th>
<th>Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>13395*2</td>
</tr>
</tbody>
</table>

*1 total to include 2 Incomplete screens and 1 verified

*2 Total to include 9 carriers, 39 incompletes and 2 verified

Source: SIRS
Information systems

Information on Pregnancy and Newborn screening tests is provided by the National Laboratory’s Information Management System. The results of the Bloodspot test are recorded against the individual child’s record held within the Scottish Immunisation and Recall System (SIRS).

Since June 2006 there has been a national requirement for all medical samples to be marked with the Community Health Index (CHI) number. A national audit (see Figure 6.3) over several weeks during the summer 2007 shows marked variation in the use of CHI on bloodspot cards across Health Boards. The low percentage of CHI marked cards in NHS Greater Glasgow and Clyde (less than 20%) is unacceptable. It is currently being monitored by the Steering group and will be addressed by the appropriate Service Managers.

Figure 6.3

% CHI on Blood Spot Card on Random dates in May/Jul/Aug 2007

Source: National Newborn Screening Laboratory
Challenges and future priorities

- To ensure the programme meets the pregnancy and newborn screening clinical standards
- To standardise the heel prick device used across Greater Glasgow and Clyde
- To ensure the CHI number is used on all bloodspot samples
- To ensure the bloodspot samples are delivered to the laboratory in the most efficient and timely way recognising the tight timescales required.

Conclusion

An overarching principle of newborn screening as described in the pregnancy and newborn screening clinical standards states

“The aim is to offer treatment at an early stage when it is likely to be more effective. The emphasis should be on performing high quality blood spot and hearing tests, with rapid reporting, as key components of the programme so that repeat tests are minimised and parents have confidence in the value of the process.” (NHS Quality Improvement Scotland, Clinical Standards – October 2005, Pregnancy and Newborn, p12)

The Newborn Bloodspot Steering Group (Appendix 6.1) and all involved in the NHS Greater Glasgow and Clyde bloodspot programme have worked hard to achieve this and are continuing to address the few areas of the programme where the clinical standards are not met.
Appendix 6.1

Members of Newborn Bloodspot Screening Steering Group
(as at January 2007)

Mrs Donna Athanasopolous PERL Resources Co-ordinator
Ms Dorothy Cafferty Planning Officer
Mrs Jacquie Campbell General Services Manager
Mrs Diane Paterson Lead Midwife
Dr Anne Devenny Consultant Paediatrician
Mrs Fiona Gilchrist Screening Manager
Mrs Annie Hair CHP Children’s Services Lead
Dr Margaret Lachlan Consultant in Public Health Medicine
Miss Denise Lyden Project Officer
Mrs Joan MacKenzie Newborn Laboratory
Ms Marie-Elaine McClair Lead Midwife PRM
Miss Jacqueline McFadden Information Analyst
Ms Julie Mullin Deputy Screening Manager
Dr Andrew Powls Consultant Neonatologist
Ms Jo Scobie Clinical Lead Midwife
Ms Audrey Taggart Lead Midwife
Marion McLoone Quality and Effectiveness Manager (until Nov 06)
Mrs Janice Winter Clinical Effectiveness Manager (from Jan 07)
CHAPTER 7: Universal Newborn Hearing Screening

Background

Universal Newborn Hearing Screening Programmes were introduced to NHS Argyll and Clyde in April 2005 and NHS Greater Glasgow in October 2005. Full reports on the delivery and results for the first year of these programmes demonstrating how the Clinical Standards for pregnancy and newborn screening are met are available on the Public Health Screening Unit website under the publications section [www.nhsggc.org.uk/phsu](http://www.nhsggc.org.uk/phsu).

During 2006 at the formation of NHS Greater Glasgow and Clyde, the two programmes were integrated and share a common steering group, however the actual screening test carried out continues to be maternity based for Greater Glasgow residents and community based for Clyde and Argyll and Bute residents of NHS Highland with whom we have a service level agreement.

One to two babies in every 1,000 are born with a hearing loss in one or both ears. It is not easy to identify that a young baby has a hearing loss. The objective hearing screening test allows those babies who do have a profound hearing loss to be identified early. Early identification is known to be important for the development of the child. It also means that support and information can be provided to parents at an early stage.

Aim of screening programme

The aim of the screening programme is the early detection of permanent congenital hearing impairment, greater than 40 decibels in the better ear. In addition, babies with mild and unilateral losses are also being identified and receive ongoing review.

Recommended age to perform screen

The hospital based hearing screen is carried out at around 1-2 days of age by dedicated hearing screeners who are based in the maternity units. The community based hearing screen is carried out at 6-21 days by health visitors in the baby’s home.

The screening test

There are two types of equipment used to screen babies hearing in the Greater Glasgow and Clyde area. Automated Auditory Brainstem Response (AABR) is used in the hospital setting and Otoacoustic Emissions (OAE) are used in the community setting. In the hospital setting an AABR is used for both the 1st and 2nd screening stages. In the community model OAE’s are used for the 1st screening stage and both OAE and AABR are used for the 2nd stage of screening.
Screening setting

There are two strands to the Greater Glasgow and Clyde screening protocol. In the Greater Glasgow area the majority of screening takes place in the maternity unit at the mother’s bedside and in the Clyde area most of the screening takes place in the baby’s home. There are outpatient clinics at each of the 3 maternity units and also in Paisley, Lomond and Inverclyde which cover any baby who requires a 2nd screen, 6 hour discharges, home births, transfers into the area.

Benefits of programme

Evidence suggests that early identification and treatment of babies with hearing loss is beneficial and the programme is being continuously evaluated to confirm this. Prior to the introduction of UNHS, bilateral hearing impairment was identified in Argyll and Clyde on average at 33 months and in Greater Glasgow on average at 17 months. Since UNHS the age of identification has been lowered to less than 3 months allowing appropriate intervention to take place before the critical age of six months.

Screening pathway

In the Greater Glasgow area the hearing screen is carried out by dedicated hearing screeners who are based in the maternity units. If babies do not obtain clear responses in both ears at this stage they are re-screened either whilst still in the maternity unit or at an outpatient clinic. If no clear responses are obtained again then at this stage babies are referred on to the audiology department at Royal Hospital for Sick Children (RHSC) for diagnostic testing.

In the Clyde area the hearing screen is carried out by health visitors in the baby’s home. If babies do not obtain clear responses in both ears at this stage they are referred to the UNHS hub at Royal Alexandra Hospital for further testing. If no clear responses are obtained again at this stage then babies are referred on to their local Audiology department for further testing.

Eligible population

The screening programme covers all babies born to Greater Glasgow and Clyde residents and any babies moving into the area who are aged less than 6 months. In addition, Greater Glasgow hospital screeners screened babies from other health board areas. There were 2,403 births from other health boards of which 1,994 were screened. The Clyde programme provides the service to residents of Argyll and Bute. There were 544 births in Argyll and Bute of which 540 were screened.
Delivery of screening programme 2006/07

Summary of uptake and results 1 April 2006 – 31 March 2007: Clyde

**Figure 7.1**

**Live Births**
- 3790 (100%)

**Completed Screening Programme**
- 3733 (98.49%)

**Not Completed Screening Programme**
- 57 (1.5%)
  - DNA 37 (0.97%)

**1st Stage**

**Clear Response**
- 455 (12%)

**requiring 2nd Stage**
- 513 (13.5%)

**2nd Stage**

**Clear Response**
- 503 (11.6%)

**Refers to Audiology**
- 62 (1.43%)
  - diagnostic 27 (0.6%)

**Bilateral Referrals**
- 19 (0.5%)
  - Diagnostic testing 12 (0.31%)

**Unilateral Referrals**
- 38 (1%)
  - Diagnostic testing 13 (0.34%)

**Bilateral Outcomes**
- Hearing satisfactory with surveillance: 7
- Hearing satisfactory with no surveillance: 1
- Confirmed Hearing Loss: 9
- Severe/profound sensory neural: 2
- Conductive: 6
- Unilateral: 1
- Hearing Undefined: 0
- Incomplete: 2

**Unilateral Outcomes**
- Hearing satisfactory with surveillance: 6
- Hearing satisfactory no surveillance: 19
- Hearing satisfactory with surveillance: 3
- Confirmed Hearing Loss: 7
- Hearing Undefined: 0
- Incomplete: 2

**Median age at Audiology referral for babies with bilateral severe/profound loss (2) - 40 days**

**Definitions**
- 1st Stage – is first AABR for Greater Glasgow and the first OAE for Clyde
- 2nd Stage – is the second AABR for Greater Glasgow and the second OAE and first AABR for Clyde
- Results pending – includes all those babies who we are still trying to complete the screen
- Not completed – are all those babies we cannot complete a screen for i.e. DNAs, deceased, transferred out or moved away etc.
- Clear Response – is a pass (though some are followed up due to risk factors)
- Outcomes – as agreed with Hearing undefined being better wording for the possible hearing loss) and Incompletes including DNA, deceased and pendings etc.
Figure 7.2
Summary of uptake and results 1 April 2006 – 31 March 2007: Greater Glasgow

Live Births
10031
100%

Completed Screening Programme
9562
95%

Not Completed Screening Programme
469 (5%)
DNA 306 (3%)

1st Stage

Clear Response
8745
87%

Requiring 2nd stage
817
8%

2nd Stage

Clear Response
764
7.5%

Refers to Audiology
53
0.5%

Bilateral Referrals
28
0.3%

Unilateral Referrals
25
0.2%

Bilateral Outcomes
Hearing satisfactory with surveillance 4
Hearing satisfactory with no surveillance 5
Confirmed Hearing Loss – unilateral 1
Confirmed Hearing Loss – Bilateral 11
Hearing under assessment 5
Incomplete 2

Unilateral Outcomes
Hearing satisfactory with surveillance 4
Hearing satisfactory with no surveillance 12
Confirmed Hearing Loss – Unilateral 2
Confirmed Hearing Loss – Bilateral 0
Hearing Under assessment 5
Incomplete 2

The median age of diagnosis of the 11 bilateral loss babies was 55 days

Definitions
1st Stage – is first AABR for Greater Glasgow and the first OAE for Clyde
2nd Stage – is the second AABR for Greater Glasgow and the second OAE and first AABR for Clyde
Results pending – includes all those babies who we are still trying to complete the screen
Not completed – are all those babies we cannot complete a screen or diagnostic assessment for i.e. DNAs, deceased, transferred out or moved away etc.
Clear Response – is a pass (though some are followed up due to risk factors)
Hearing Under assessment – all babies who have referred from the screen and their diagnostic assessment is ongoing.
Resource

The annual budget for delivery of the hearing screening programme in Greater Glasgow and Clyde is approximately £550,000.

The Greater Glasgow and Clyde screening programme includes 11 whole time equivalent (WTE) dedicated hearing screeners, 1 screening manager and a clinical lead audiologist, administrative support and healthcare colleagues working with the Clyde community setting eg Health Visitor led teams and administrative staff.

Information systems

The hearing screening programme has a national IT system – eSP (escreener plus) which is a web based database into which all screening results and demographic data are entered. The Child Health Surveillance Programme system is also an important feature of the screening programme and is used as a failsafe for checking on any missed babies.

Future developments

There are discussions at national level to consider how the stand alone eSP Northgate IT Newborn Hearing screening system links with the Community Health Index (CHI) and Child Health information systems across Scotland. Currently the manual entry of data into eSP is time consuming and open to risk through data errors. A link will provide more screening time plus an important failsafe for notification of births ensuring no babies are missed. There should also be consideration of this link being extended to allow the population of the Child Health Information System with the outcome of the screening test.

Outstanding issues

Information to parents/carers given in the antenatal period needs further development based on the outcomes of the audit of parental satisfaction with the screen. This issue is currently being addressed with plans to expand the Maternity Services Strategy Group’s draft pregnancy care schedules to include at what stage and how information is given to parents/carers.

There are many service changes occurring which may impact on the programme. For example, the recent review of health visiting may affect the ability and suitability of health visitors to carry out the initial screen in the Clyde area. The remarkably low numbers in the Clyde area who fail to complete the screening programme suggest it is very beneficial to provide the service in the community. However there must be on-going analysis and comparison of the costs and benefits of the different methods of programme delivery.
Future priorities

- Put in place a rolling replacement programme for screening equipment
- Develop a clearer pathway for risk factor identification and ongoing surveillance for the Special Care baby Units and Neonatal Intensive Care Units
- Develop electronic transfer of screening data in the Clyde area
- Ensure information pathways are complete. For example, outpatient results of the hearing screen are to be included in babies’ hospital notes
- Work at national level to develop the Northgate eSP system to link with child health information systems and use the eSP system to its full potential
- Continue to provide appropriate training for all involved in the programme
- Deliver information on the programme to parents and carers at appropriate stages in accordance with maternity strategy and to meet standards
- Consider the screening modalities across Greater Glasgow and Clyde in light of the Health Visitors review and other service changes

Conclusion

Since October 2006, all aspects of the former NHS Greater Glasgow and NHS Argyll & Clyde programmes have been integrated into the NHS Greater Glasgow and Clyde UNHS programme apart from the different operational methods of the screening test. The programme is a success measured objectively in terms of meeting and exceeding the required clinical standards set by NHS QIS and subjectively by the many involved in the running of the programme.
Appendix 7.1

Universal Newborn Hearing Screening Programme Steering Group
(as at October 2006)

Mr Michael Bradnam  Head of Clinical Physics
Ms Elizabeth Callander  Lead Midwife
Mrs Patricia Carmichael  UNHS Programme Manager
Ms Gail Carroll  Assistant Technical Officer
Mrs Elizabeth Denny  Lead Nurse
Ms Frances Dolan  Family Support
Mrs Fiona Gilchrist  Screening Manager
Mrs Annie Hair  CHP Children’s Services Lead
Mrs Leigh Hamilton  Hearing Screening Manager
Dr Ruth Hamilton  Clinical Scientist
Mr James Harrigan  Head of Audiology
Ms Brenda Kirk  Acting Directorate Team Leader
Dr Margaret Lachlan  Consultant in Public Health Medicine
Mr Forbes Lauder  Head of Audiology
Miss Denise Lyden  Project Officer
Ms Gillian McBride  Finance Manager
Ms Marian McLoone  Quality & Effectiveness Manager
Miss Jacqueline McFadden  Information Analyst
Dr Juan Mora  Consultant Audiological Physician
Mrs Julie Mullin  Deputy Screening Manager (Glasgow)
Dr Andrew Powls  Consultant Neonatologist
Dr Lucy Reynolds  Consultant Paediatrician
Ms Jo Scobie  Clinical Lead Midwife
Ms Mags Simpson  Practice Development Nurse
Ms Pat Tyrrell  Lead Nurse Argyll & Bute
Ms Maureen Saunders  Health Visitor
Ms Fiona Van der Meer  Lead Nurse
Dr Madeline White  Consultant Neonatologist
Ms Heather Young  Family Support
Appendix 7.2

Reporting Structure:
Universal Newborn Hearing Screening Steering Group

Key:

Direct Reports

Network Links
DIABETIC RETINOPATHY SCREENING
CHAPTER 8: DIABETIC RETINOPATHY SCREENING

Background

Diabetic Retinopathy is a complication of diabetes affecting blood vessels of the retina and is the biggest single cause of blindness and visual impairment amongst working age people in Scotland. Retinopathy is symptom-free until its late stages and programmes of retinal screening can reduce the risk of blindness on diabetic population by detecting retinopathy at a stage at which it may be effectively treated. If it is detected early enough, laser treatment can prevent the progression of the disease and save sight for many years in most patients.

Currently in NHS Greater Glasgow and Clyde Diabetic Retinopathy Screening is provided by two separate services, one covering the former Greater Glasgow area and the other covering the former Argyll and Clyde area. The service started screening in August 2006 in Argyll and Clyde. Retinopathy screening service in Greater Glasgow started screening in 2002 but to cope with screening all diabetics resident in Greater Glasgow, the service capacity was expanded in 2006 and 2007.

Aim of screening programme

The primary aim of the programme is the detection of referable (sight-threatening) retinopathy.

A secondary aim is the detection of lesser degrees of diabetic retinopathy. This can have implications for the medical management of people with diabetes.

Recommended age to perform screen

People with diabetes aged 12 and over.

The screening test

Digital photography of the individual's retina.

Clinic Setting

The screening programme takes place in a variety of settings; this can either be at a fixed site or within a mobile screening unit, which visits health centres and other locations around the area. Currently across Greater Glasgow and Clyde (including the Argyll and Bute area) there are three mobile screening units and six fixed site locations.
**Foreseen benefits of programme**

To identify and treat sight threatening diabetic retinopathy.

**Screening Pathway**

**Delivery of Screening Programme 2006/07**

Table 8.1 shows that there are approximately 35,000 people with diabetes in Greater Glasgow and 15,600 in Argyll and Clyde; the estimated uptake rate for the programme is 47.18% for Argyll and Clyde area and 37.97% for Glasgow area and nearly a quarter of appointments offered for screening (22% and 23%) are missed.

**Table 8.1 Uptake of Screening in NHS Greater Glasgow and Clyde**

<table>
<thead>
<tr>
<th>Area</th>
<th>Number eligible</th>
<th>Number Invited</th>
<th>Number Screened</th>
<th>Uptake</th>
<th>DNA %</th>
<th>Ophthalmology Referral %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Argyll and Clyde</td>
<td>15,603</td>
<td>10,630</td>
<td>7,363</td>
<td>47.18%</td>
<td>23%</td>
<td>3.5%</td>
</tr>
<tr>
<td>Greater Glasgow</td>
<td>35,000</td>
<td>21,100</td>
<td>13,291</td>
<td>37.97%</td>
<td>22%</td>
<td>6%</td>
</tr>
</tbody>
</table>

Source: SCI-DC
Resource

The Argyll and Clyde Area Diabetic Retinal Screening Service budget for 2006/07 was £211,100. In 2006/07 the Greater Glasgow Diabetic Retinal Screening Service budget was £771,778.

In 2006/07 Argyll & Clyde Area was part of a regional administrative programme with NHS Lanarkshire and NHS Dumfries & Galloway. The administration centre had 4 whole time equivalent (WTE) clerical staff to provide call/recall for the three services. The Greater Glasgow Diabetic Retinal Screening Service has a total of 3.53 WTE administrative & clerical staff.

Information systems

There are two main information sets used in the provision of Diabetic Retinopathy Screening. SOARIAN provides the call/recall, image capture, grading, quality assurance and result delivery.

SCI-DC is an essential component for effective Diabetic Retinopathy Screening. This will provide the diabetes population register for the call/recall for DRS and it will hold the results of the Diabetic Retinopathy Screening which will be available to clinical staff involved in the care of patient with diabetes.

Soarian is a new database and initially operational problems were experienced which have now been resolved. Improved functionality for reporting is still to be developed.

There are still some problems with the interface between Soarian and SCI-DC, which have still to be resolved.

Future developments

In Argyll and Clyde part of the service there are plans to expand the number of fixed site clinics, which will also provide slit lamp examinations as well as retinal photography.

Glasgow currently has one mobile screening unit and is planning to commission a second mobile unit during 2007/08. The Glasgow service is also planning to provide a slit lamp service from their 4 hospital sites during 2007/08 for those patients who are not suitable for retinal photography.

Outstanding issues

Argyll and Clyde – to examine the causes of technical failures at screening. Glasgow – to reduce the time taken to report results to patients.

Both - IT issues
Challenges and future priorities

- Integration of the services
- Increasing numbers of people with diabetes
- Reducing the high DNA rate

Conclusion

This new service experienced some teething problems in 2006/07 mainly around the introduction of the new screening software and also the slower than expected expansion of the Greater Glasgow service to full operating capacity. It is anticipated that all eligible patients in Greater Glasgow and Clyde, and Argyll and Bute, will be offered retinal screening in 2007/08.

Recommendations

To meet the challenges and future priorities outlined above and to try and achieve fully QIS compliant diabetic retinal screening services.
Appendix 8.1

Members of Diabetic Retinopathy Screening Steering Group
As at September 2006

Dr Emilia Crighton, Consultant in Public Health Medicine (Chair)
Elizabeth Rennie, Screening Manager, Primary Care Support
Keith Redpath, Director, West Dunbartonshire CHP
Patricia Morrison, DRS Manager, Clyde
Michael Craig, Diabetes MCN Manager, Acute Planning
David Sawers, DRS Service Manager, West Dunbartonshire
Karen Ross, MCN and CDM Planning Manager

(as at May 2007)

Mr Cliff Baister IM &T Manager
Mr Michael Craig Diabetic MCN Manager
Dr Emilia Crighton Consultant in Public Health Medicine (Chair)
Mrs Eileen Fergusson Lay Member
Mrs Fiona Gilchrist Screening Manager
Dr Michelle Gillies Specialist Registrar
Ms Marianne Hayward MCN Diabetes Manager
Ms Fiona Heggie Retinal Screening Coordinator
Ms Gale Leslie Optometrist
Miss Denise Lyden Project Officer
Dr Fraser MacLeod General Practitioner
Miss Chris McNeill Head of Health & Community Care
Mr Eddie McVey Optometric Advisor
Ms Patricia Morrison DRS Manager, Clyde
Dr Gerry O’Kane General Practitioner
Dr Alasdair Purdie Consultant Ophthalmologist
Mr Keith Redpath Director - West Dunbartonshire CHP
Mrs Elizabeth Rennie Screening Manager
Ms Karen Ross MCN & CDM Planning Manager
Mr David Sawers DRS Service Manager, West Dunbartonshire
Mr Graham Tytler IT Project Manager
Dr William Wykes Ophthalmologist
Appendix 8.2

Reporting Structure:
Diabetic Retinopathy Screening Steering Group

Director of Public Health

Public Health Screening Unit

Breast Screening Programme Steering Group
Chair: Dr E Crighton, CPHM

Diabetic Managed Care Network

Key:
- - - - - - Network Links
- - - - - Direct Reports
PRE-SCHOOL VISION SCREENING
CHAPTER 9 : PRE-SCHOOL VISION SCREENING

Background

This is the first annual report for the Pre-school Vision Screening Programme. In 2006 NHS Greater Glasgow and Clyde extended the orthoptic, nursery based, Pre-school Vision Screening to cover the whole area. The programme was implemented in NHS Argyll and Clyde in 2002. The decision was based on the recommendations of the UK National Screening Committee Child Health Sub-Group Report on Vision Screening (May 2005) that states that “All children should be screened for visual impairment between four and five years of age” and the Scottish Executive Health Department guidance on implementation of Health for All Children 4 in Scotland (April 2005) advises that “All children should be screened by an Orthoptist in their preschool year, between the ages of four and five years”.

Amblyopia is a condition caused by the brain receiving different images from the two eyes. In an adult, receiving two images causes double vision, but a child compensates for the difficulty by suppressing one of the images. Amblyopia can be caused by either a squint (strabismus) or differences in the focusing power of each eye (refractive error). If this defect goes untreated this leads to reduced vision in one or, in some cases, both eyes. The screening programme can also detect reduced vision due to structural abnormality or disease of the media, fundi or visual pathways.

Amblyopia and strabismus affects 3-6% of children, and although obvious squints are easily detected, refractive error and subtle squints often go undetected and thus amblyopia develops. Amblyopia can be treated using spectacle lenses to correct any refractive error and occlusion therapy - mainly eye patches. These treatments can be used alone or in combination. Treatment is most effective when the brain is still developing (in young children), and when the child cooperates in wearing the patch and/or glasses.

Aim of vision screening programme

The aim of the screening programme is to detect reduced visual acuity, the commonest causes of which are amblyopia and refractive error.

There is emerging evidence that good screening and treatment result in lower incidence of significant permanent vision loss.

Recommended age to perform screen

All children should be screened for visual impairment between four and five years of age in the pre-school year (HALL 4).
Screening setting

The screening takes place in a child’s nursery setting as experience from other Health Boards (NHS Ayrshire and Arran, and the former Argyll and Clyde Health Board) has shown that it greatly improved coverage of screening. Children that are not registered with nurseries are screened in a secondary care setting.

The screening test

The basic screen is a visual acuity test where children are asked to match a line of letters or pictures to a key card or to describe a line of pictures.

Screening pathway

The list of eligible children (the school intake cohort for the following year), with dates of birth between 1 March 2002 and 28 February 2003, were downloaded from CHI and matched against the lists received from nurseries.

In the Greater Glasgow area, nurseries were requested to submit lists of pre-school children attending to the screening department; to pass on screening information and consent forms to parents; collect the consent forms and return them to the screening office. In Clyde the orthoptists delivering screening collected the consent forms from nurseries at the time of screening.

The vision screening clinic took place in the nursery setting. The pre-school children that did not attend nursery, those whose nursery was unknown to the screening programme and the children that missed their appointment within the nursery were invited to the hospital Orthoptic Department to have their vision screened.

A number of children had to be referred for screening to the Community Optometrists due to staff shortages that prevented the delivery of screening in agreed settings.

Following screening, a proportion of children required further testing. They were referred to secondary care for further assessment in the Orthoptic Department that was in the same geographical sector as the nursery, unless the parent wished for the child to be seen in another Orthoptic Department that was closer to their home. A proportion of children requiring “further assessments” that comply with existing protocols were referred to the community optometrists. The assessment appointment involved a fuller vision examination. At that stage the examination determined if the screen was a false positive and no further action was required, or if the screen was positive and if so the specific disorder identified and treated.
Eligible population

Approximately 15,000 children, resident in NHS Greater Glasgow and Clyde, aged between 4 – 5 years old in 2006/2007, were identified using the CHI system.

Table 9.1 shows the number of children eligible for screening for each geographical area allocated to Orthoptic Departments; the number of children identified in nursery lists within each geographical area; the number of children whose nursery is not known (or do not attend a nursery) and the number of refused consent.

10,573 children were on nursery lists across NHS Greater Glasgow and Clyde. The proportion of children attached to a nursery across geographical areas varied and was dependent on the nurseries returning the children lists to the screening department. The low return rate of nursery lists was due to the cumbersome administrative process set up at the beginning of the programme that could not be met within the resource constraints in a large number of nurseries. Since then the administrative process has been simplified and a high return rate has been achieved for 2007-08.

3,189 (22.9%) of the eligible children were not on nursery lists submitted to the screening department. The lowest nursery returns was seen in the East where only 32.24% of children were on returned nursery lists.

Only 62 (0.45%) parents refused consent for their children to be screened.

Table 9.1 Eligible Population for pre-school vision screening

<table>
<thead>
<tr>
<th></th>
<th>North</th>
<th>South</th>
<th>East</th>
<th>West</th>
<th>RAH*</th>
<th>IRH*</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of</td>
<td>1839</td>
<td>4071</td>
<td>1101</td>
<td>2540</td>
<td>3320</td>
<td>1043</td>
<td>3320</td>
</tr>
<tr>
<td>children (CHI download)</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Number of children</td>
<td>1267</td>
<td>2819</td>
<td>355</td>
<td>1777</td>
<td>3320</td>
<td>1035</td>
<td>10573</td>
</tr>
<tr>
<td>attached to nurseries</td>
<td>68.90%</td>
<td>69.25%</td>
<td>32.24%</td>
<td>69.96%</td>
<td>100%</td>
<td>100%</td>
<td>75.99%</td>
</tr>
<tr>
<td>Children not</td>
<td>547</td>
<td>1175</td>
<td>739</td>
<td>728</td>
<td>0</td>
<td>8</td>
<td>3189</td>
</tr>
<tr>
<td>attending nursery or</td>
<td>29.74%</td>
<td>28.86%</td>
<td>67.12%</td>
<td>28.66%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>22.92%</td>
</tr>
<tr>
<td>with unknown nursery</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consent denied</td>
<td>3</td>
<td>31</td>
<td>3</td>
<td>17</td>
<td>0</td>
<td>8</td>
<td>62</td>
</tr>
<tr>
<td></td>
<td>0.16%</td>
<td>0.76%</td>
<td>0.27%</td>
<td>0.67%</td>
<td>0.00%</td>
<td>0.77%</td>
<td>0.45%</td>
</tr>
</tbody>
</table>

* Includes mop up clinics at Inverclyde Royal Hospital, Royal Alexandra Hospital, Vale of Leven District General Hospital and Dumbarton Health Centre
Delivery of screening programme 2006/07

Table 9.2 shows, by geographical sector, the total number of children screened and the split between nursery based screening and hospital based screening; the number and rate of children referred to be screened by community based optometrist due to the lack of screening staff; and the overall uptake rate.

10,890 children have been screened out of 15,194 eligible children in 2006-07. This gives an uptake rate of 68.43%. The uptake rate varies across the geographical location from 32.79% in the East (due to lack of staff required to deliver the screening programme) to 84.94% in Royal Alexandra Hospital.

The children who could not be screened in the programme at the end of the school year were referred to community optometry for screening. This represents 5% (721) of the total eligible population (15914). Of the 721 not screened, 91% (660) of children were from East Glasgow.

9,864 children have been screened in a nursery setting; that represents 91% of all screened children and 62% of all eligible children. 1,026 children were screened in hospital that represents 6% of eligible children.

Table 9.2 Uptake rates

<table>
<thead>
<tr>
<th></th>
<th>North</th>
<th>South</th>
<th>East</th>
<th>West</th>
<th>RAH*</th>
<th>IRH*</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number screened in Nursery</td>
<td>1267</td>
<td>2819</td>
<td>355</td>
<td>1777</td>
<td>2820</td>
<td>826</td>
<td>9864</td>
</tr>
<tr>
<td>Number screened in Hospital</td>
<td>223</td>
<td>465</td>
<td>6</td>
<td>332</td>
<td>0</td>
<td>0</td>
<td>1026</td>
</tr>
<tr>
<td>Total number screened</td>
<td>1490</td>
<td>3284</td>
<td>361</td>
<td>2109</td>
<td>2820</td>
<td>826</td>
<td>10890</td>
</tr>
<tr>
<td>Did not attend hospital screening</td>
<td>226</td>
<td>434</td>
<td>4</td>
<td>294</td>
<td>N/A</td>
<td>N/A</td>
<td>958</td>
</tr>
<tr>
<td>Referred to Optometrist for screening</td>
<td>51</td>
<td>5</td>
<td>660</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>721</td>
</tr>
<tr>
<td>Proportion referred to Optometrist for screening</td>
<td>3%</td>
<td>0%</td>
<td>60%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>5%</td>
</tr>
<tr>
<td>Number of eligible</td>
<td>1839</td>
<td>4071</td>
<td>1101</td>
<td>4540</td>
<td>3320</td>
<td>1043</td>
<td>15914</td>
</tr>
<tr>
<td>Uptake rate</td>
<td>81.02%</td>
<td>80.67%</td>
<td>32.79%</td>
<td>46.45%</td>
<td>84.94%</td>
<td>79.19%</td>
<td>68.43%</td>
</tr>
</tbody>
</table>

* Includes mop up clinics at Inverclyde Royal Hospital, Royal Alexandra Hospital, Vale of Leven Hospital and Dumbarton Health Centre
Table 9.3 shows the results of screening split by screening settings for which data is available and geographical area.

7,411 (62.5%) children screened had a normal result following screening and 2,496 (21%) children have been referred for further assessments.

Table 9.3: Screening Outcomes

<table>
<thead>
<tr>
<th>Outcomes by screening location</th>
<th>North</th>
<th>South</th>
<th>East</th>
<th>West</th>
<th>RAH*</th>
<th>IRH*</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal Result (NAD) Nursery</td>
<td>834</td>
<td>1961</td>
<td>196</td>
<td>1050</td>
<td>2225</td>
<td>532</td>
<td>6801</td>
</tr>
<tr>
<td>Normal Result (NAD) Hospital</td>
<td>122</td>
<td>285</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>610</td>
</tr>
<tr>
<td>Referred for assessment by nursery</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referred for assessment by hospital</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other outcomes</td>
<td>228</td>
<td>434</td>
<td>63</td>
<td>262</td>
<td>0</td>
<td>0</td>
<td>759</td>
</tr>
<tr>
<td>Total number children screened</td>
<td>1490</td>
<td>3284</td>
<td>361</td>
<td>2109</td>
<td>2820</td>
<td>826</td>
<td>10890</td>
</tr>
</tbody>
</table>

* Includes mop up clinics at Inverclyde Royal Hospital, Royal Alexandra Hospital, Vale of Leven Hospital and Dumbarton Health Centre

The results of the assessments following screening referrals are not available at the time of publishing this report and work is ongoing to address the reporting capability of the information system that supports vision screening.

The Programme Resources

a) **Orthoptic Resource**

Greater Glasgow

Orthoptic screening for children in their pre-school year commenced in October 2006 with the full complement of 2.5 additional orthoptists required for the service having been recruited. Unfortunately the orthoptist recruited for the screening service and based at Glasgow Royal Infirmary left at the end of December with a resulting gap that could not be filled in the service provided to parts of East Glasgow north of the Clyde.

The number of sessions devoted to screening Greater Glasgow for the pre-school intake in August 2006 can be seen in the table below. “Hospital” sessions refer to children called for screening to the local hospital because they were absent from nursery when the orthoptist was present and also those children not attached to a nursery. This does not include referrals from the screening service to either the Hospital Eye Service HES or to the child’s own optometrist.
Table 9.4: Orthoptic Sessions

<table>
<thead>
<tr>
<th>Orthoptic Sessions</th>
<th>North</th>
<th>West</th>
<th>South</th>
<th>East</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursery</td>
<td>175</td>
<td>186</td>
<td>299</td>
<td>28*</td>
</tr>
<tr>
<td>Hospital</td>
<td>34</td>
<td>42</td>
<td>78</td>
<td>0</td>
</tr>
<tr>
<td>Total sessions</td>
<td>209</td>
<td>228</td>
<td>377</td>
<td>28</td>
</tr>
</tbody>
</table>

* Until December 2006

Orthoptic waiting times for new patients referred to the Hospital Eye Service (HES) at Stobhill and Glasgow Royal Infirmary were also severely compromised by the length of time taken to advertise the optometry post which was not filled until the end of August 2007.

Clyde Division

The programme of pre-school nursery screening which has been in place for 2002 within Clyde was continued without change in 2006/7.

Clyde Division is fully resourced having 2.00 WTE orthoptists carrying out screening in nurseries across the area. There is also a full complement of optometrists supporting the service within the hospital setting. In addition an orthoptic support worker has been recruited to help with the administrative duties arising from the current process of using the locally designed database.

b) Optometry Resource

Additional optometry resources were appointed to four out of five of the Greater Glasgow hospital sites to support the screening programme, with the exception of Gartnavel.

Table 9.5: Optometry Sessions

<table>
<thead>
<tr>
<th>Hospital Clinic</th>
<th>No of Optometry sessions per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>West</td>
<td>2.3</td>
</tr>
<tr>
<td>North</td>
<td>0.5</td>
</tr>
<tr>
<td>East</td>
<td>0.5</td>
</tr>
<tr>
<td>South*</td>
<td>2.0</td>
</tr>
<tr>
<td>Total</td>
<td>5.3</td>
</tr>
</tbody>
</table>

* A number of children are being absorbed into existing symptomatic clinics with no additional specific resource dedicated for this.
c) **Administrative and clerical resource**

Currently there are 1.75 wte Band 2 (AfC) posts working for the screening programme and this is insufficient to cover the amount of work generated. It is anticipated that an additional 2 wte posts are required to deliver this aspect of the service for whole of NHS Greater Glasgow and Clyde.

**Information systems**

The administration of the vision screening programme requires a sound information management system. The Royal Alexandra Hospital and Inverclyde Royal Hospital service uses a local ACCESS database to call children by nursery school and register results.

The VisualWorks system, purchased to facilitate the delivery of the programme in the Greater Glasgow area has proven to be extremely laborious to the user and has required significant enhancement to allow it to be of a workable standard. VisualWorks needs to be of a standard that it can support a high level of populations across several sectors. With ongoing development of the VisualWorks system from October 2006, it has now become a clinical system.

Administrative & Clerical staff use VisualWorks to manage pre-school children data, nursery data, organise clinics, generate appointments, results and referral letters, store results (both screening and secondary care), and as a minor audit tool. Clinical staff use VisualWorks as an information base for the patients within their sector, to record all appropriate screening results and secondary care appointment results, and as a workload monitoring tool.

**Future developments**

A business case has been submitted to expand the administrative resource that would allow the full integration of Clyde and Greater Glasgow service.

Future development of VisualWorks include: the development of an interface with the Child Health Surveillance Programme – Pre School (CHSP-PS) system in order to transfer data, for example, date of screen and result; the development of service monitoring capacity and generation of audit reports by The Solution Works. At present there is limited functionality within the VisualWorks system.
Outstanding issues

Clerical support is required for call, recall, recording and informing parents of results as currently it is done by orthoptists in Clyde.

The service capacity for the delivery of the whole programme has to be continually pursued. As an interim measure part time orthoptic staff throughout the city will be asked if they are willing and/or able to work additional sessions to help with the shortfall.

The knock on effect to the Hospital Eye Service at all sites in NHS Greater Glasgow and Clyde in terms of children requiring follow up treatment over a period of months or years will also require audit through the database on VisionWorks. It is anticipated that the additional work generated will require further funding for more staff both orthoptic and administrative in the future.

Challenges and future priorities

The challenges and priorities for pre-school vision screening programme are:

- The development of a more mature IT system
- The integration of the services across NHS Greater Glasgow and Clyde
- The recruitment of staff to allow the delivery screening as agreed
- Improving the submission of the list of children attending individual nurseries.

Conclusion

This service was introduced in the Greater Glasgow area having run in Argyll and Clyde for a number of years. In spite of the difficulties faced by any new programme, 68.43% of children were screened.
Members of Pre-school Vision Screening Steering Group
(as at March 2007)

Mrs Joan Ballantyne Head Orthoptist
Ms Angela Carson Lead Optometrist
Dr Emilia Crighton Consultant in Public Health Medicine (Chair)
Mrs Maggie Darroch Optometrist
Ms Liz Denny Lead Nurse
Mrs Fiona Gilchrist Screening Manager
Ms Susan Groom General Manager, Ophthalmology & ENT Surgery
Ms Shogufa Haq Health Promotion Officer - Child Health & Parenting
Ms Bernadine Hegarty Optometrist
Mrs Marian Hodgson Head of Pre-Five Children Strategy Section
Ms Gale Leslie Optometrist
Miss Denise Lyden Project Officer
Miss Jacqueline McFadden Information Analyst
Mr Stephen McLeod Planning Manager
Mrs Elizabeth Rennie Screening Manager
Mrs Diane Russell Head Orthoptist
Mrs Elaine Salina Optometrist
Appendix 9.2

Reporting Structure:
Pre-School Vision Screening Steering Group

Key:
- Direct Reports
- Network Links
Acknowledgments

This annual report was prepared by the Public Health Screening Unit in collaboration with members from the screening programmes steering groups, Public Health Protection Unit, Jacqueline McFadden, Annette Little, Ann Boyle, Mark Menzies and Frances Paton from Information Services.

Also a special thank you to Screening Department staff at Gartnavel Royal.

Many thanks go to all the healthcare professionals and support staff for helping to deliver the screening services across NHS Greater Glasgow and Clyde.

The programmes have also benefited from the close links held with the Child Health Surveillance Programme (CHSP), Maternity Services Strategy Group, Regional Cancer Advisory Group and the Diabetes Managed Care Network.