RECOMMENDATION

Members are asked to note the attached Public Health Screening Programmes Annual Report from 1 April 2008 to 31 March 2009.

INTRODUCTION

This annual report presents information about the following screening programmes offered to residents across NHS Greater Glasgow and Clyde for the period 2008/09:

- Cervical Screening
- Bowel Screening
- Breast Screening
- Communicable Diseases in Pregnancy
- Down’s syndrome and other congenital anomalies
- Newborn Bloodspot
- Universal Newborn Hearing
- Diabetic Retinopathy Screening
- Pre-School Vision Screening

In addition, we have also highlighted plans for:

- the replacement of the existing Pregnancy Screening Programme offered for Down's syndrome and other congenital anomalies
- the implementation of haemoglobinopathy screening both during pregnancy and for newborn babies
- the extension of the newborn bloodspot screening programme to include screening for Medium Chain Acyl CoA Dehydrogenase Deficiency (MCADD)
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 are in place and their remit is to monitor performance, uptake and quality assurance.

Figure A illustrates the reporting and accountability lines.
Figure 1: Accountability arrangements for population screening programmes across NHS Greater Glasgow and Clyde (as at 2009)

Key:
- Direct Reports
- Network Links

Director of Public Health

Public Health Screening Unit

Pregnancy & Newborn Programmes
- Pregnancy Screening Steering Group (incl. Down's Syndrome and other congenital anomalies, Communicable Diseases in Pregnancy)
- Newborn Bloodspot Steering Group
- Universal Newborn Hearing Screening Steering Group
- Maternity Services Strategy Group

Child Screening Programme
- Preschool Vision Screening Steering Group
- Child Health Services Strategy Group

Child Health Services Strategy Group

Cancer Screening Programmes
- Bowel Screening Programme Steering Group
- Breast Screening Programme Steering Group
- Cervical Screening Programme Steering Group
- NHS GGC Cancer Advisory Group

Child Health Services Strategy Group

Diabetes Screening Programme
- Diabetic Retinopathy Screening Programme Steering Group
- Diabetes Managed Care Network

Director of Public Health

Public Health Screening Unit
In 2008/2009, approximately 247,464 NHS Greater Glasgow and Clyde residents were eligible for screening (see Table A). Table A also shows that 35.1% of the total population live in the most deprived areas of NHS Greater Glasgow and Clyde.

**Table A Total NHS Greater Glasgow and Clyde population and total number and percentage of eligible screening population**

<table>
<thead>
<tr>
<th>SIMD 2006</th>
<th>Most Deprived</th>
<th>Least Deprived</th>
<th>Total</th>
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<td>1</td>
<td>2</td>
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<td>Total GGC Population</td>
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<td>206,258</td>
<td>157,846</td>
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<tr>
<td>Target Screening Population</td>
<td>86899</td>
<td>43249</td>
<td>33585</td>
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<td>% of total GGC population</td>
<td>19.5</td>
<td>21.0</td>
<td>21.3</td>
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<td>% of target screening population</td>
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<td>17.5</td>
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Source: Small Area Population Estimates (SAPE) 2008
SIMD - Scottish Index of Multiple Deprivation

1 Target Screening - Number of people eligible for screening within 1 year
SIMD - Scottish Index of Multiple Deprivation

**Health inequalities**

As part of NHS Greater Glasgow and Clyde’s commitment to tackle inequalities to health, the Public Health Screening Unit engaged with voluntary and statutory services to identify innovative ways to encourage and promote uptake of screening programmes.

We engaged with local CH(C)P health improvement teams and voluntary groups to develop local protocols to encourage and include groups who, for various social and economic circumstances, could potentially be excluded or prevented from taking up any of our public health screening programmes.

Screening programmes stretch across the whole organisation and the successful delivery relies on a large number of individuals working in a co-ordinated manner towards common goals in a quality assured environment. It is essential that good information management systems are in place to monitor and evaluate each component and the overall performance of every screening programme offered to our residents. All the screening programmes, with the exception of Pre-school Vision Screening, have clinical standards set by NHS Quality Improvement Scotland which we strive to meet.

Equality impact assessments for each of the screening programmes are planned starting with cervical screening. The outcome of the assessments will identify any areas of the service that prevent service users from receiving equal access to services or receiving treatment when taking part in any screening programme.
CERVICAL SCREENING

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

- 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 were approximately 362,800 women aged 21 to 60 resident in NHS Greater Glasgow and Clyde in the target population. Following the exclusion of those with no cervix, approximately 345,000 women were eligible to be invited to participate in the programme over three years. Each year approximately 115,000 women are sent an invitation to attend.

- The cervical screening uptake rate as defined by NHS Quality Improvement Scotland Standards has increased in Greater Glasgow and Clyde and Scotland in the past year. The uptake rate increased in Argyll and Clyde from 76.2% to 78.7%; in Greater Glasgow from 72.9% to 75.2%; and Scotland wide from 77.9% to 79.4%. Information Services Division (ISD) data continues to be reported on the old NHS Board boundaries and the Community Health Index continues to code patients according to those.

- The increase in uptake rate was due to the intense publicity caused by Jade Goody’s illness and death from cervical cancer.

- We calculated the uptake rates of NHS Greater Glasgow and Clyde residents: the 5.5 year cervical screening uptake rate, when only the no cervix exclusion has been applied, increased from 71.9% in 2007/08 to 72.7%. This is still significantly less than the 81.5% reported in 2001.

- When exception categories allowed under the General Medical Services (GMS) contract were included, the calculated 5.5 year uptake rate increased from 82.7% in 2007/09 to 83.6% in 2008/09.

- There was a 9% difference in the uptake rate calculated for the purpose of QIS Standard and GMS contract.

- On average, 31% of women aged 21 to 60 had been excluded under one of the GMS exclusion categories. 23.7% of women have been excluded as they defaulted following invitations to take part in screening, while 5% of women have been excluded as they have no cervix.

- The uptake of cervical screening varied across different age groups. The lowest 5.5 year uptake in 2008/09 was among the 20 to 24 year at 55.1% when only no cervix exclusion was applied. When calculations were made for the purpose of General Medical Services target payments the uptake was 73%.
• The cervical screening uptake rate varied across deprivation categories. The lowest 5.5 year uptake rate in 2008/09 was seen among women resident in the most deprived neighbourhoods where the uptake rate was 68.9% while among the least deprived neighbourhoods, the uptake rate was 79.5% when only the no cervix exclusion was applied. When calculations were made for the purpose of General Medical Services target payments the uptake among women living in the most deprived neighbourhoods was 80.6%, whereas those living among the least deprived was 88.3%.

• 116,000 smear tests were processed and reported in laboratories in NHS Glasgow and Clyde in 2008/09. These included repeat smears and smears taken at colposcopy as one woman can have more than one smear test. This represents an increase of 21,674 (23%) from the number of smears processed in 2007/08.

• The proportion of results reported as abnormal smears in 2008/09, after excluding the unsatisfactory tests, was 9.9%. Abnormal smears results include: borderline, mild, moderate and severe dyskaryosis, severe dyskaryosis/invasive, glandular abnormality and adenocarcinoma.

• The cervical screening histories of women who developed invasive cervical cancer were reviewed in 2008/09. Sixty-five patients were diagnosed with invasive cervical cancer in 2008. (The number of patients diagnosed with invasive cervical cancer in 2007 was 67; 49 in 2006; and 50 in 2005.) The largest number of cervical cancers occurred in women aged between 30 and 39 years.

• Twenty-five women out of the 50 with invasive cervical cancer in 2005, 22 women of 49 in 2006, 34 women of 67 in 2007 and 31 women of 65 in 2008 had a complete smear history. Over the four years audited, 33 women out of the 231 that developed cancer had never had a smear.

• There were 23 deaths over the four years audited; 69 women were under follow up at colposcopy service and 127 were under follow up in the oncology service.

• The Scottish Cervical Call Recall System (SCCRS) implemented in 2007 provides women with a complete e-health record detailing their whole smear history. Professionals involved with the screening programme have access to this system. Since the system was implemented, the turnaround time for smears reported has reduced. The system also produces automated reports and more recently allows for individual performance data to be produced.

• In an effort to improve uptake we continue to provide comparative practice-based uptake figures to all practices and to the Community Health Care Partnerships.
A subgroup of the NHS Greater Glasgow and Clyde Cervical Screening Steering Group oversees the promotion of the cervical screening among hard to engage groups. Initiatives are aimed at women with learning difficulties, those in long term institutions, women in travelling communities, women in long term care and women abusing alcohol.

Following intense media publicity surrounding Jade Goody’s death from cervical cancer, we have seen increased awareness and participation in the programme.

A national group has been set up to oversee a new communication strategy informed by the research carried out in Scotland in which NHS Greater Glasgow and Clyde residents were sampled.

To reduce the number of unsatisfactory smears, a cervical skills update training programme will be developed and offered to all community smear takers from 2010.

BREAST SCREENING

This report represents interim data for the breast screening round May 2006 – May 2009 in NHS Greater Glasgow and Clyde.

From May 2006 to May 2009, there were 142,829 eligible women across NHS Greater Glasgow and Clyde.

102,331 women (72% of eligible women) were invited for breast screening during period reported.

72,220 women (71% of those invited) attended breast screening during the reported period.

There were 495 women who were diagnosed with breast cancer following screening.

NHS Greater Glasgow and Clyde implemented two view mammography in Clyde in May 2009 and will extend it across Greater Glasgow by March 2010.

In May 2009, a breast screening protocol for women in specific categories was approved and implemented across NHS Greater Glasgow and Clyde. The protocol aims to ensure that all groups are invited to take part in the breast screening programme and are followed up appropriately.

A sub group has recently been set up to explore the opportunity of educating women about lifestyle choices and risk factors associated with cancer during their normal screening appointment.
Colorectal (Bowel) Cancer is the third most common cancer in Scotland. Every year over 3,400 people are diagnosed with the disease.

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 implemented the bowel screening programme in April 2009. During 2008/09, detailed planning for implementation was carried out.

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 will be able to participate. Thereafter, all individuals will be routinely recalled every two years.

It is estimated that, from 1 April 2009 to 31 March 2010, 244,000 NHS Greater Glasgow and Clyde residents will have been invited to participate in the Bowel Screening programme.

All eligible individuals are sent a teaser letter two weeks before the screening kit is sent to advise them that they will be sent the bowel screening kit.

135,440 teaser letters were sent to eligible participants.

66,571 test results were reported by the Bowel Screening laboratory and this gives an estimated uptake of 50%.

1,645 patients received a positive result. This represented a positivity screening rate of 2.5%. This was higher than the national average range of 1.9% to 2.3% reported in the Scottish Bowel Screening Programme KPI reports (www.ISDscotland.org 25 August 2009).

Of the 1,645 patients screened positive, 1,457 patients were pre-assessed prior to colonoscopy. 84 patients did not respond to the offer of a colonoscopy pre-assessment.

1,040 (63.2%) patients completed colonoscopy investigations by 31 December 2009. 3.1% (46) patients refused to take up the offer of a colonoscopy. Of the total eligible population invited to take part in bowel screening, 84 (0.06%) cancers were detected.

To minimise the complication rates for colonoscopy, colonoscopy skills update training and continuous audit for screening colonoscopists are implemented.
• A bespoke information management and technology system to support the bowel screening programme was developed in-house. The data collected allows staff to monitor service performance and track patients through the process from point of referral to diagnosis and treatment for colorectal cancer.

• NHS Greater Glasgow and Clyde has implemented several initiatives to promote uptake based on experience from Breast Screening. Primary care staff and Health Promotion leads in Community Health (Care) Partnerships are involved by displaying promotional materials and engaging with local communities to promote and encourage the uptake of bowel screening.

• A TV, radio and poster campaign was commissioned by NHS Greater Glasgow and Clyde which ran from April to August 2009. The evaluation of the campaign reported that by using TV advertising, TV awareness was 46%, and the total campaign awareness was 53%.

COMMUNICABLE DISEASES IN PREGNANCY

• To comply with NHS Quality Improvement Scotland standards (Clinical Standards 2005, Pregnancy and Newborn Screening), protocols covering each of the four 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 pregnant 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.

• 16,079 pregnant women had a first booking visit at a Greater Glasgow and Clyde hospital during 2008/09. 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 communicable diseases.

• Thirteen pregnant women were identified as having HIV by the screening programme, only six of whom were previously known to be HIV positive. Seventy-three women were detected as having hepatitis B virus, 34 of whom were previously known to be chronic carriers of the virus. Fifteen women were identified by the screening programme to be positive for syphilis. Of these six were false positives, three were previously treated and only six required follow-up management.
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 2008/09, 16,079 women attended antenatal clinics across NHS Greater Glasgow and Clyde. 14,232 women were NHS Greater Glasgow and Clyde residents and 1,847 women lived outwith the Board area.

- There were two screening pathways in NHS Greater Glasgow and Clyde: first trimester combined ultrasound and biochemical testing for Down’s syndrome and 18-20 week foetal anomaly ultrasonography offered to women booking in the Clyde area of NHS Greater Glasgow and Clyde; and second trimester blood testing offered to women booking in Greater Glasgow.

- In 2008/09, the overall uptake for Down’s syndrome and neural tube defects was 63.8%. The overall percentage uptake for Down’s syndrome was 62.95%; and first trimester combined ultrasound and biochemical screening for neural tube defect was 15.3%. 0.8% of women chose to have only neural tube defect screening.

- Following the second trimester screening, 6.4% of women were assigned to the 'higher chance' of Down's syndrome group, 0.7% of women assigned to the 'higher chance' of trisomy 18 group and 2.2% of women with an elevated AFP giving a 'higher chance' of a neural tube defect.

- 460 amniocentesis tests were analysed by the Cytogenetics Laboratory. 50 abnormalities were detected (10.9% of samples) and 26 of those (5.7% of total tests) had a diagnosis of trisomy (Down’s syndrome/trisomy 18).

- 97 chorionic villus biopsies were analysed by the Cytogenetics Laboratory in 2008/09. 31 abnormalities were detected (32% of tests) and 17 of those (17.5% of tests) had a diagnosis of trisomy (Down’s syndrome/trisomy 18).

- To date, it is known that 11 cases of Down's syndrome, 2 cases of trisomy 18 and 4 cases with neural tube defects were detected antenatally by screening. Some babies born with these conditions will not be diagnosed during pregnancy as a number of women that had a “higher chance” screening result would not take up the offer of diagnostic test (amniocentesis or CVS).
From 2010, all women in NHS Greater Glasgow and Clyde will be offered combined ultrasound and biochemical screening (CUBS) in the first trimester of pregnancy and a second trimester foetal anomaly ultrasound (FAS) scan between 18 weeks, 0 days and 20 weeks, 6 days. Women who do not present early enough in their pregnancy to take advantage of first trimester screening will be offered second trimester serum screening.

NEWBORN BLOODSPOT SCREENING

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

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

- In 2008/09 of the 15,509 bloodspot samples received, 85 (0.5%) bloodspot specimens could not be analysed due to insufficient amounts of blood on the bloodspot card. This required repeat bloodspot screening tests to be carried out on babies. 61 (0.4%) samples received had taken more than 7 days to arrive at the laboratory.

- In 2008/09, 14,231 babies of NHS Greater Glasgow and Clyde residents were screened which represents 97.7% of the total eligible population of 14,563.

- There were 3 positive cases of phenylketonuria detected (a decrease of 5 from previous year); 11 babies with congenital hypothyroidism and 13 babies with cystic fibrosis. All received appropriate management within the timescale of the standard.

- The proportion of bloodspot cards with a CHI number sent for analysis increased from 66% in April 2008 to 88% in March 2009 compared to the national average of 43% in March 2008 and 63% in April 2009.
UNIVERSAL NEWBORN HEARING SCREENING

• The Universal Newborn Hearing Screening (UNHS) Programme was introduced across NHS Greater Glasgow and Clyde in 2005.

• 14,134 babies born in 2008/09 to residents of NHS Greater Glasgow and Clyde. 5,981 (42%) of babies were born to residents in the most deprived areas.

• Of the 14,134 babies born in 2008/09, 13,620 were screened for a hearing loss giving an overall uptake of 96.4%. 204 (1.5%) babies were referred to audiology and, of those, 25 were confirmed with a hearing loss. 3.2% (452) did not attend for screening and these include babies who are deceased or have moved away from their current home address or transferred to another Board area.

• NHS Greater Glasgow and Clyde has established a Universal Newborn Hearing Screening Network to enable staff to share knowledge and experiences.

• An interface between the eSP, the Community Health Index (CHI) and Child Health information systems across Scotland has been developed and the link went live on 2 November 2009. The link removes the need for manual entry of data into eSP which would provide more screening time, tracking of all babies and more importantly a failsafe for notification of births ensuring no babies are missed.

• A local IT project to allow Clyde screeners to transfer screening data electronically into eSP is being piloted by Health visitors in Greenock. It is planned that the pilot will run until Spring 2010 followed by an evaluation. If successful, the project will be implemented across all Clyde sites.

FUTURE DEVELOPMENTS -PREGNANCY AND NEWBORN BLOODSPOT SCREENING PROGRAMMES

• Since September 2009, all pregnant women are now offered foetal anomaly screening scanning when booking into antenatal care.

• It is planned that from summer 2010, all pregnant women will be offered combined ultrasound and biochemical screening in the first trimester of pregnancy. This involves measuring the biochemical markers in the mother’s blood and is combined with the ultrasound measurement of nuchal translucency in the foetus.
There are plans to introduce screening for Medium Chain Acyl CoA Dehydrogenase Deficiency (MCADD) in NHS Greater Glasgow and Clyde by summer 2010 as an addition to the current newborn bloodspot screening tests. The final implementation has still to be decided by National Services Division in consultation with NHS Boards.

MCADD leads to an inability to metabolise sufficient energy from fat during periods of stress such as fasting, intercurrent illnesses with fever or surgery.

NHS Greater Glasgow and Clyde plan to implement the Haemoglobinopathies screening programme by summer 2010.

All pregnant women will be offered screening for sickle cell disease, thalassaemia and other haemoglobinopathies.

Newborn babies will be screened for sickle cell disorders as part of the newborn bloodspot screening programme.

An IT application is being developed to support the pregnancy and newborn bloodspot screening programmes. Implementation will be phased across the hospital and community sites from November 2009 to March 2010. It is expected that the IT application will:

• remove the need for duplicating data entry and reduce data error
• have inbuilt quality assurance and audit mechanisms
• have inbuilt failsafe alert mechanisms
• facilitate automation of letters and reports
• will link a mother’s antenatal screening history with her baby’s screening record

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 digital photography was implemented in August 2006 in Argyll and Clyde. The service was introduced in Greater Glasgow in 2002 and expanded and redesigned in 2006/07.

• The screening programme takes place in a variety of settings across Greater Glasgow and Clyde (including the Argyll and Bute area). There are four mobile screening units and ten fixed site locations.
• As at May 2009 there were 52,695 people with diabetes in NHS Greater Glasgow and Clyde.

• As at May 2009, 37,560 (71.4%) people with diabetes were screened for diabetic retinopathy. At least 9.3% of patients with diabetes who were invited for screening did not take up the offer of screening. This could be an underestimate of the current situation as approximately 20% of screening appointments are reported as “did not attend” by the service. 2525 (4.8%) patients were permanently suspended from the screening programme as they were already attending an ophthalmology clinic.

• In February 2008, a review of the patient pathway was undertaken to assess the effectiveness of the referral to ophthalmology process and the completeness of feedback received following attendance at ophthalmology clinics. Following the review, the service identified control measures that should be put in place that will allow the continuous monitoring of the delivery of the administrative tasks and the provision of feedback from ophthalmology clinics. These include a “return receipt” for ophthalmology referrals and access to the Diabetic Retinopathy Screening information and management system in Ophthalmology clinics.

• Work commenced in late 2008 to develop a single Greater Glasgow and Clyde service and to integrate the diabetes information management systems by April 2009.

PRE-SCHOOL VISION SCREENING

• All children born between 1 March 2004 and 28 February 2005 were offered pre-school vision screening in 2008/09.

• 13,235 children aged between four to five years old were identified using the Community Health Index System as being eligible for pre-school vision screening.

• 10,175 children were screened out of 13,235 eligible children in 2008/09. This gives an uptake rate of 76.9%. The uptake rate varies across the geographical location from 67.2% in East Glasgow to 81.1% in Clyde.

• 604 (4.6%) of eligible children were already attending an eye clinic.

• 63 (0.5%) parents refused consent for their children to be screened.

• 8,534 children were screened in a nursery setting; that represents 83.9% of all screened children and 64.5% of all eligible children.
• Children who could not be screened in the programme at the end of the school year were invited to a hospital Orthoptic Department for screening. This represents 14.2% (1,874) of the total eligible population (13,235). This includes children resident in East Glasgow where staff shortage has had an impact on the delivery of screening in nurseries.

• Following screening, 2,761 (27.1%) children were referred for further assessments. Of these, 301 (10.9%) were referred to a Community Optometrist for further assessment. This represents 2.27% of the total eligible population.

• 7,414 (72.9%) of children screened had a normal result following screening.

• The recruitment of Orthoptists to allow the delivery of screening in nurseries is a challenge and priority for the pre-school vision programme. In 2008, three Assistant Practitioners were appointed to the service to support Orthoptists with administrative duties.
Public Health Screening Programmes

Annual Report

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TO
31 MARCH 2009
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Key:
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----- Network Links
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**Table A Total NHS Greater Glasgow and Clyde population and total number and percentage of eligible screening population**

|                | SIMD 2006 |        |        |        |        |        |        |        |        |        |        |        |        |        |        |        |        |        |        |        |        |        |        |        |        |        |        |        |
|----------------|-----------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|        |
|                | Most Deprived | 1  | 2  | 3  | 4  | 5  | Total |
| Total GGC Population | 444,830 | 206,258 | 157,846 | 164,802 | 220,736 | 1,194,472 |
| Target Screening Population | 86,899 | 43,249 | 33,585 | 35,453 | 48,277 | 247,464 |
| % of total GGC population | 19.5 | 21.0 | 21.3 | 21.5 | 21.9 | 20.7 |
| % of target screening population | 35.1 | 17.5 | 13.6 | 14.3 | 19.5 | 100.0 |

Source: Small Area Population Estimates (SAPE) 2008
SIMD - Scottish Index of Multiple Deprivation

1 Target Screening - Number of people eligible for screening within 1 year
SIMD - Scottish Index of Multiple Deprivation

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CHAPTER 1: CERVICAL SCREENING

SUMMARY

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

- 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 were approximately 362,800 women aged 21 to 60 resident in NHS Greater Glasgow and Clyde in the target population. Following the exclusion of those with no cervix, approximately 345,000 women were eligible to be invited to participate in the programme over three years. Each year approximately 115,000 women are sent an invitation to attend.

- The cervical screening uptake rate as defined by NHS Quality Improvement Scotland Standards has increased in Greater Glasgow and Clyde and Scotland in the past year. The uptake rate increased in Argyll and Clyde from 76.2% to 78.7%; in Greater Glasgow from 72.9% to 75.2%; and Scotland wide from 77.9% to 79.4%. Information Services Division (ISD) data continues to be reported on the old NHS Board boundaries and the Community Health Index continues to code patients according to those.

- The increase in uptake rate was due to the intense publicity caused by Jade Goody’s illness and death from cervical cancer.

- We calculated the uptake rates of NHS Greater Glasgow and Clyde residents: the 5.5 year cervical screening uptake rate, when only the no cervix exclusion has been applied, increased from 71.9% in 2007/08 to 72.7%. This is still significantly less than the 81.5% reported in 2001.

- When exception categories allowed under the General Medical Services (GMS) contract were included, the calculated 5.5 year uptake rate increased from 82.7% in 2007/09 to 83.6% in 2008/09.

- There was a 9% difference in the uptake rate calculated for the purpose of QIS Standard and GMS contract.

- On average, 31% of women aged 21 to 60 had been excluded under one of the GMS exclusion categories. 23.7% of women have been excluded as they defaulted following invitations to take part in screening, while 5% of women have been excluded as they have no cervix.

- The uptake of cervical screening varied across different age groups. The lowest 5.5 year uptake in 2008/09 was among the 20 to 24 year at 55.1% when only no cervix exclusion was applied. When calculations were made for the purpose of General Medical Services target payments the uptake was 73%.
• The cervical screening uptake rate varied across deprivation categories. The lowest 5.5 year uptake rate in 2008/09 was seen among women resident in the most deprived neighbourhoods where the uptake rate was 68.9% while among the least deprived neighbourhoods, the uptake rate was 79.5% when only the no cervix exclusion was applied. When calculations were made for the purpose of General Medical Services target payments the uptake among women living in the most deprived neighbourhoods was 80.6%, whereas those living among the least deprived was 88.3%.

• 116,000 smear tests were processed and reported in laboratories in NHS Glasgow and Clyde in 2008/09. These included repeat smears and smears taken at colposcopy as one woman can have more than one smear test. This represents an increase of 21,674 (23%) from the number of smears processed in 2007/08.

• The proportion of results reported as abnormal smears in 2008/09, after excluding the unsatisfactory tests, was 9.9%. Abnormal smears results include: borderline, mild, moderate and severe dyskaryosis, severe dyskaryosis/invasive, glandular abnormality and adenocarcinoma.

• The cervical screening histories of women who developed invasive cervical cancer were reviewed in 2008/09. Sixty-five patients were diagnosed with invasive cervical cancer in 2008. (The number of patients diagnosed with invasive cervical cancer in 2007 was 67; 49 in 2006; and 50 in 2005.) The largest number of cervical cancers occurred in women aged between 30 and 39 years.

• Twenty-five women out of the 50 with invasive cervical cancer in 2005, 22 women of 49 in 2006, 34 women of 67 in 2007 and 31 women of 65 in 2008 had a complete smear history. Over the four years audited, 33 women out of the 231 that developed cancer had never had a smear.

• There were 23 deaths over the four years audited; 69 women were under follow up at colposcopy service and 127 were under follow up in the oncology service.

• The Scottish Cervical Call Recall System (SCCRS) implemented in 2007 provides women with a complete e-health record detailing their whole smear history. Professionals involved with the screening programme have access to this system. Since the system was implemented, the turnaround time for smears reported has reduced. The system also produces automated reports and more recently allows for individual performance data to be produced.

• In an effort to improve uptake we continue to provide comparative practice-based uptake figures to all practices and to the Community Health Care Partnerships.
- A subgroup of the NHS Greater Glasgow and Clyde Cervical Screening Steering Group oversees the promotion of the cervical screening among hard to engage groups. Initiatives are aimed at women with learning difficulties, those in long term institutions, women in travelling communities, women in long term care and women abusing alcohol.

- Following intense media publicity surrounding Jade Goody’s death from cervical cancer, we have seen increased awareness and participation in the programme.

- A national group has been set up to oversee a new communication strategy informed by the research carried out in Scotland in which NHS Greater Glasgow and Clyde residents were sampled.

- To reduce the number of unsatisfactory smears, a cervical skills update training programme will be developed and offered to all community smear takers from 2010.
CHAPTER 1: CERVICAL SCREENING

Background

Systematic cervical screening began in 1989 as part of the National Scottish Cervical Screening Programme (SCSP). Over the last 20 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. 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 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**
Delivery of screening programme 2007/08

Table 1.1 shows the numbers of women in the target and eligible populations for the cervical screening programme. There were approximately 362,800 women aged 21 to 60 resident in NHS Greater Glasgow and Clyde in the target population. Following the exclusion of those with no cervix, approximately 345,000 women were eligible to be invited to participate in the programme over three years. Each year approximately 115,000 women are sent an invitation to attend.

Table 1.1 NHS Greater Glasgow and Clyde Cervical Screening populations

<table>
<thead>
<tr>
<th>Year</th>
<th>Target Population</th>
<th>Eligible Population</th>
<th>Target GMS Payments</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000/01</td>
<td>360,361</td>
<td>338,068</td>
<td></td>
</tr>
<tr>
<td>2001/02</td>
<td>360,170</td>
<td>337,919</td>
<td></td>
</tr>
<tr>
<td>2002/03</td>
<td>360,069</td>
<td>338,184</td>
<td></td>
</tr>
<tr>
<td>2003/04</td>
<td>360,644</td>
<td>339,460</td>
<td>292,652</td>
</tr>
<tr>
<td>2004/05</td>
<td>358,617</td>
<td>338,291</td>
<td>273,106</td>
</tr>
<tr>
<td>2005/06</td>
<td>364,919</td>
<td>345,408</td>
<td>272,447</td>
</tr>
<tr>
<td>2006/07</td>
<td>359,436</td>
<td>340,446</td>
<td>272,104</td>
</tr>
<tr>
<td>2007/08</td>
<td>362,828</td>
<td>344,252</td>
<td>268,484</td>
</tr>
<tr>
<td>2008/09</td>
<td>362,845</td>
<td>344,882</td>
<td>251,844</td>
</tr>
</tbody>
</table>

Sources: 2000/01-2006/07 - CHI via Cervical Cytology system
2007/08 - 2008/09 - Scottish Cervical Call Recall System

1 Women aged 21 to 60 years
2 Women aged 21 to 60 years except medically exempt women, as defined in 3 and 4
3 NHS QIS Standard is the "no Cervix" and uptake
4 Target Payments excludes those women with the exclusion categories as defined in the GP Contract, implemented in 2004
5 Based on GGC Resident Population and not Practice population

Table 1.1 also shows the number of women that were considered to be eligible for cervical screening after the application of the exclusions allowed by the General Medical Services contract. 86,185 women who did not attend cervical screening after three invitations have been excluded from the eligible population under the GMS defaulters exception reporting.

The General Medical Services (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 General Medical Services 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 1.2 shows the Information & Statistics Division (ISD) published statistics for the 5.5 year cervical screening uptake rates as calculated for the NHS Quality Improvement Scotland standards and the Performance Assessment Framework target for the two areas that form Greater Glasgow and Clyde and Scotland. 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 the Community Health Index continues to code patients according to those.

Table 1.2 Uptake for Cervical Screening 1st January 1995 to 31st March 2009
Percentage uptake of females aged 20-60\(^1\) who had a record of a previous smear taken within the last 5.5 years

<table>
<thead>
<tr>
<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>Argyll &amp; Clyde</td>
<td>87</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>
<td>76.2</td>
<td>78.7</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>
<td>72.9</td>
<td>75.2</td>
</tr>
<tr>
<td>Scotland(^2)</td>
<td>86.7</td>
<td>86.5</td>
<td>86</td>
<td>85.5</td>
<td>84.6</td>
<td>83.8</td>
<td>82.6</td>
<td>77.9</td>
<td>79.4</td>
</tr>
</tbody>
</table>

Source: ISD(D)4 Legacy applications for 1995 to 2006-07 data
Source: ISD(D)4 SCCRs for 2007-08 Data

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 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 1 April to 31st March.

The cervical screening uptake rate in both Greater Glasgow and Clyde and Scotland has seen an increase in the past year. Table 1.2 illustrates that compared to 2007 – 2008, the uptake rate increased in Argyll and Clyde from 76.2% to 78.7% and in Greater Glasgow from 72.9% to 75.2%. Uptake across Scotland increased from 77.9% to 79.4%. That was due to the intense publicity caused by Jade Goody’s illness and death from cervical cancer.

To quantify how much the cervical screening uptake has been affected by the changes in the General Medical Services contract we calculated the 5.5 year cervical screening uptake rates by applying the “no cervix” exclusion and then the General Medical Services exclusion categories.
Table 1.3 shows the comparative numbers of and percentage uptake rates for NHS Greater Glasgow and Clyde residents screened by the programme in the last 5.5 years for the purpose of Quality Improvement Standards and GMS contract.

Table 1.3 Cervical Screening Uptake

<table>
<thead>
<tr>
<th>Year</th>
<th>NHS QIS Standard</th>
<th>GMS Target payments</th>
<th>5.5 year Percentage Uptake</th>
<th>GMS Target payments</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000/01</td>
<td>275,361</td>
<td></td>
<td>81.5%</td>
<td></td>
</tr>
<tr>
<td>2001/02</td>
<td>276,239</td>
<td></td>
<td>81.7%</td>
<td></td>
</tr>
<tr>
<td>2002/03</td>
<td>276,666</td>
<td></td>
<td>81.8%</td>
<td></td>
</tr>
<tr>
<td>2003/04</td>
<td>271,419</td>
<td>260,863</td>
<td>80.0%</td>
<td>92.1%</td>
</tr>
<tr>
<td>2004/05</td>
<td>268,860</td>
<td>251,457</td>
<td>79.5%</td>
<td>90.5%</td>
</tr>
<tr>
<td>2005/06</td>
<td>267,931</td>
<td>246,570</td>
<td>77.6%</td>
<td>89.4%</td>
</tr>
<tr>
<td>2006/07</td>
<td>262,604</td>
<td>243,388</td>
<td>77.1%</td>
<td>89.4%</td>
</tr>
<tr>
<td>2007/08</td>
<td>247,652</td>
<td>221,975</td>
<td>71.9%</td>
<td>82.7%</td>
</tr>
<tr>
<td>2008/09</td>
<td>250,799</td>
<td>210,605</td>
<td>72.7%</td>
<td>83.6%</td>
</tr>
</tbody>
</table>

Sources: 2000/01-2006/07 - CHI via Cervical Cytology system
2007/08 - 2008/09 - Scottish Cervical Call Recall System

1 Women aged 21 to 60 years with an adequate smear within the last 5.5 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 5.5 years
3 NHS QIS Standard is women with “no Cervix” and uptake
4 Target Payments excludes those women with the exclusion categories as defined in the GP Contract, implemented in 2004

The 5.5 year cervical screening uptake rate, when only the no cervix exclusion has been applied, increased from 71.9% in 2007/08 to 72.7%. This is still significantly less than the 81.5% reported in 2001. When exception categories allowed under the General Medical Services contract were included, the calculated 5.5 year uptake rate increased from 82.7% in 2007/08 to 83.6% in 2008/09. There is a 9% difference in the uptake rate calculated for the purpose of QIS Standard and GMS contract.

On average, 31% of women aged 21 to 60 had been excluded under one of the categories.
The data in Table 1.3 demonstrates and Figure 1.2 illustrates the difference in uptake rates calculated for the purpose of NHS Quality Improvement Scotland Standards and Performance assessment framework and General Medical Services target payment. The cervical screening uptake rates for the purpose of the General Medical Services target payments are between 9 and 12% higher than the NHS Quality Improvement Scotland standard uptake rate; the downward trend in the cervical screening uptake has seen a sharper drop following the implementation of the new General Medical Services contract while the uptake for the purpose of General Medical Services contract has initially seen a marked increase followed by a slow decline.

Figure 1.2

<table>
<thead>
<tr>
<th>% uptake</th>
<th>No Cervx</th>
<th>GMS Target Payments</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000/01</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2001/02</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2002/03</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2003/04</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2004/05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2005/06</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2006/07</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2007/08</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2008/09</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: CHI via Cervical Cytology System

Note Years 2007/08 and 2008/09: This is based on Resident Population

Table 1.4 shows that 23.75% of women have been excluded as they defaulted following invitations to take part in screening, while 5% of women have been excluded as they have no cervix.
Table 1.4 NHS Greater Glasgow and Clyde Resident Population - Cervical Screening
Number of Defaulters

<table>
<thead>
<tr>
<th></th>
<th>2007/08</th>
<th>2008/09</th>
</tr>
</thead>
<tbody>
<tr>
<td>Target Population¹</td>
<td>362,828</td>
<td>362,845</td>
</tr>
<tr>
<td>Total Defaulters</td>
<td>67,240</td>
<td>86,185</td>
</tr>
<tr>
<td>% Defaulters</td>
<td>18.53%</td>
<td>23.75%</td>
</tr>
</tbody>
</table>

Change in Target Pop 17
Change in Number of Defaulters 18,945

¹ Women aged 21 to 60 years

Table 1.5 shows the 5.5 year uptake rates of cervical screening by Community Health (Care) Partnership (CH(C)P) for the no cervix category as calculated for NHS Quality Improvement Scotland standards and the Performance Assessment Framework, and the uptake rate reached for the GMS target payment.

Table 1.5 Cervical Screening Uptake Rates by CH(C)P

<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>East Glasgow</td>
<td>80.1%</td>
<td>80.4%</td>
<td>80.3%</td>
<td>78.1%</td>
<td>78.7%</td>
<td>75.0%</td>
<td>71.1%</td>
<td>71.3%</td>
<td>82.5%</td>
<td>81.5%</td>
</tr>
<tr>
<td>North Glasgow</td>
<td>78.6%</td>
<td>78.6%</td>
<td>79.0%</td>
<td>76.7%</td>
<td>77.0%</td>
<td>73.2%</td>
<td>68.3%</td>
<td>69.1%</td>
<td>80.7%</td>
<td>79.7%</td>
</tr>
<tr>
<td>South East Glasgow</td>
<td>80.5%</td>
<td>81.1%</td>
<td>81.0%</td>
<td>80.3%</td>
<td>79.6%</td>
<td>77.1%</td>
<td>70.2%</td>
<td>70.1%</td>
<td>80.6%</td>
<td>81.0%</td>
</tr>
<tr>
<td>South West Glasgow</td>
<td>82.3%</td>
<td>82.7%</td>
<td>82.5%</td>
<td>80.4%</td>
<td>79.2%</td>
<td>76.4%</td>
<td>70.3%</td>
<td>71.1%</td>
<td>81.1%</td>
<td>83.4%</td>
</tr>
<tr>
<td>West Glasgow</td>
<td>76.8%</td>
<td>76.7%</td>
<td>77.8%</td>
<td>75.8%</td>
<td>74.8%</td>
<td>73.1%</td>
<td>64.3%</td>
<td>64.8%</td>
<td>76.0%</td>
<td>77.1%</td>
</tr>
<tr>
<td>North Lanarkshire (part)</td>
<td>82.6%</td>
<td>83.0%</td>
<td>84.3%</td>
<td>83.7%</td>
<td>83.5%</td>
<td>82.7%</td>
<td>78.9%</td>
<td>79.4%</td>
<td>86.1%</td>
<td>89.1%</td>
</tr>
<tr>
<td>South Lanarkshire (part)</td>
<td>83.6%</td>
<td>84.4%</td>
<td>84.3%</td>
<td>82.3%</td>
<td>82.2%</td>
<td>80.1%</td>
<td>76.0%</td>
<td>77.0%</td>
<td>86.6%</td>
<td>86.2%</td>
</tr>
<tr>
<td>East Dunbartonshire</td>
<td>85.0%</td>
<td>85.6%</td>
<td>85.4%</td>
<td>85.2%</td>
<td>84.8%</td>
<td>83.3%</td>
<td>78.6%</td>
<td>79.8%</td>
<td>87.6%</td>
<td>89.1%</td>
</tr>
<tr>
<td>East Renfrewshire</td>
<td>85.0%</td>
<td>85.8%</td>
<td>85.7%</td>
<td>84.6%</td>
<td>83.8%</td>
<td>81.6%</td>
<td>77.5%</td>
<td>78.8%</td>
<td>85.9%</td>
<td>88.4%</td>
</tr>
<tr>
<td>Inverclyde</td>
<td>82.1%</td>
<td>82.2%</td>
<td>81.7%</td>
<td>79.7%</td>
<td>78.9%</td>
<td>77.2%</td>
<td>74.6%</td>
<td>75.2%</td>
<td>86.2%</td>
<td>86.6%</td>
</tr>
<tr>
<td>Renfrewshire</td>
<td>83.8%</td>
<td>83.8%</td>
<td>83.5%</td>
<td>80.6%</td>
<td>80.0%</td>
<td>77.8%</td>
<td>73.9%</td>
<td>75.0%</td>
<td>83.9%</td>
<td>85.7%</td>
</tr>
<tr>
<td>West Dunbartonshire</td>
<td>82.7%</td>
<td>83.3%</td>
<td>73.1%</td>
<td>80.6%</td>
<td>80.4%</td>
<td>78.9%</td>
<td>73.5%</td>
<td>74.8%</td>
<td>84.6%</td>
<td>85.6%</td>
</tr>
<tr>
<td>NHS GG&amp;C²</td>
<td>81.5%</td>
<td>81.7%</td>
<td>81.8%</td>
<td>80.0%</td>
<td>79.5%</td>
<td>77.1%</td>
<td>71.9%</td>
<td>72.7%</td>
<td>82.7%</td>
<td>83.6%</td>
</tr>
</tbody>
</table>

Sources: 2000/01-2006/07 - CHI via Cervical Cytology system; 2007/08 - 2008/09 - Scottish Cervical Call Recall System

1 2007/08 & 2008/09 - CHP/CH(C)P has been derived by GGC Resident Population; 2000/01-2006/07 CH(C)P/CHP divided by GP Practice
2 Includes invalid & missing postcodes. Missing=not entered.Invalid=GGC postcode but incorrect or new postcode and unable to derive CHP/CH(C)P
3 Uptake based on Target Payments. Excludes those women with the exclusion categories as defined in the GP Contract, implemented in 2004

Table 1.6 shows that the uptake of cervical screening varied across different age groups. The lowest 5.5 year uptake in 2008/09 was among the 20 to 24 year at 55.1% when only no cervix exclusion was applied. When calculations were made for the purpose of General Medical Services target payments the uptake was 73%.
Table 1.6 Cervical Screening uptake by age group for NHS Greater Glasgow and Clyde residents for 2008/09

<table>
<thead>
<tr>
<th>Age Group</th>
<th>NHS QIS Standard¹</th>
<th>Target GMS Payments²</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Eligible women</td>
<td>3.5 yrs uptake</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>Total %</td>
</tr>
<tr>
<td>21-24</td>
<td>38947</td>
<td>20293</td>
</tr>
<tr>
<td>25-29</td>
<td>50015</td>
<td>29251</td>
</tr>
<tr>
<td>30-39</td>
<td>87369</td>
<td>57202</td>
</tr>
<tr>
<td>40-49</td>
<td>94873</td>
<td>66074</td>
</tr>
<tr>
<td>50-60</td>
<td>73678</td>
<td>49469</td>
</tr>
<tr>
<td>Total</td>
<td>344882</td>
<td>222289</td>
</tr>
</tbody>
</table>

Source: Scottish Cervical Call Recall System

1 Target Payments excludes those women with the exclusion categories as defined in the GP Contract, implemented in 2004

Table 1.7 shows that the cervical screening uptake rate varied across deprivation categories. The lowest 5.5 year uptake rate in 2008/09 was seen among women resident in the most deprived neighbourhoods where the uptake rate was 68.9% while among the least deprived neighbourhoods, the uptake rate was 79.5% when only the no cervix exclusion was applied. When calculations were made for the purpose of General Medical Services target payments the uptake among women living in the most deprived neighbourhoods was 80.6%, whereas those living among the least deprived was 88.3%.

Table 1.7 Cervical Screening uptake by deprivation category for NHS Greater Glasgow and Clyde residents for 2008/09

<table>
<thead>
<tr>
<th>SIMD³</th>
<th>NHS QIS Standard¹</th>
<th>Target GMS Payments²</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Eligible</td>
<td>3.5 yr uptake</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td></td>
</tr>
<tr>
<td>Most Deprived</td>
<td>1 128638</td>
<td>77277</td>
</tr>
<tr>
<td></td>
<td>2 59214</td>
<td>37561</td>
</tr>
<tr>
<td></td>
<td>3 46583</td>
<td>30321</td>
</tr>
<tr>
<td></td>
<td>4 47996</td>
<td>32246</td>
</tr>
<tr>
<td>Least Deprived</td>
<td>5 60533</td>
<td>43723</td>
</tr>
<tr>
<td>New/Incomplete postcodes⁴</td>
<td>1918</td>
<td>1161</td>
</tr>
<tr>
<td>Total</td>
<td>344882</td>
<td>222289</td>
</tr>
</tbody>
</table>

Notes
1 NHS QIS standard is women with "no cervix" and uptake
2 Target Payments excludes those women with the exclusion categories as defined in the GP Contract, implemented in 2004
3 SIMD Quintiles 2006
4 Although incomplete these postcodes clearly fall within Greater Glasgow & Clyde boundaries
Cytopathology Laboratories Workload

Table 1.8 shows the number of tests performed in Cytopathology laboratories in the NHS Greater Glasgow and Clyde area. An essential criterion of the NHS QIS standards requires the laboratories to process a minimum of 15,000 smears annually and this has been achieved throughout the area. Approximately 116,000 smear tests were processed and reported in laboratories in NHS Glasgow and Clyde. These included repeat smears and smears taken at colposcopy as one woman can have more than one smear test. This represents an increase of 21,674 (23%) from the number of smears processed in 2007/08.

Table 1.8 Number of smear tests processed in NHS GGC Laboratories

<table>
<thead>
<tr>
<th>Year</th>
<th>IRH*</th>
<th>VOL*</th>
<th>SGH</th>
<th>GRI</th>
<th>STOB</th>
<th>VIC</th>
<th>NHSGGC</th>
<th>Scotland</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000/01</td>
<td>25,453</td>
<td>17,486</td>
<td>10,266</td>
<td>29,667</td>
<td>15,907</td>
<td>18,959</td>
<td>117,738</td>
<td>457,774</td>
</tr>
<tr>
<td>2001/02</td>
<td>27,378</td>
<td>14,973</td>
<td>23,326</td>
<td>49,162</td>
<td>190</td>
<td>7,101</td>
<td>122,130</td>
<td>471,722</td>
</tr>
<tr>
<td>2002/03</td>
<td>24,627</td>
<td>12,384</td>
<td>25,953</td>
<td>44,713</td>
<td>n/a</td>
<td>n/a</td>
<td>107,677</td>
<td>439,678</td>
</tr>
<tr>
<td>2003/04</td>
<td>23,607</td>
<td>12,052</td>
<td>25,824</td>
<td>44,422</td>
<td>n/a</td>
<td>n/a</td>
<td>105,905</td>
<td>429,522</td>
</tr>
<tr>
<td>2004/05</td>
<td>28,326</td>
<td>5,843</td>
<td>25,975</td>
<td>43,194</td>
<td>n/a</td>
<td>n/a</td>
<td>103,338</td>
<td>406,305</td>
</tr>
<tr>
<td>2005/06</td>
<td>36,166</td>
<td>n/a</td>
<td>23,160</td>
<td>44,035</td>
<td>n/a</td>
<td>n/a</td>
<td>103,361</td>
<td>410,241</td>
</tr>
<tr>
<td>2006/07</td>
<td>36,137</td>
<td>n/a</td>
<td>23,141</td>
<td>40,732</td>
<td>n/a</td>
<td>n/a</td>
<td>100,010</td>
<td>401,749</td>
</tr>
<tr>
<td>2007/08</td>
<td>30,955</td>
<td>n/a</td>
<td>23,742</td>
<td>39,684</td>
<td>n/a</td>
<td>n/a</td>
<td>94,381</td>
<td>373,340</td>
</tr>
<tr>
<td>2008/09</td>
<td>38,363</td>
<td>n/a</td>
<td>28,190</td>
<td>49,502</td>
<td>n/a</td>
<td>n/a</td>
<td>116,055</td>
<td>450,522</td>
</tr>
</tbody>
</table>

Source 2000-2007 Cervical Cytology System (CCS); 2007/09 - Labs : Telepath & SCCRs
Scotland figures from ISD Website

*IRH/VOL - includes smears tests for Argyll and Bute area
Vale of Leven stopped reporting smears taken as at quarter ending 30th September 2004
Stobhill stopped reporting smears taken as at quarter ending 30th June 2001
Victoria stopped reporting smears taken as at quarter ending 30th September 2001

Table 1.9 shows the proportion of the total cervical samples sent to each of the cytology laboratories that were reported as unsatisfactory smears in 2008/09. Following the introduction of Liquid Based Cytology testing in 2003, there has been a marked decrease in the percentage of unsatisfactory smears with only 2.7% of smears required to be repeated due to an unsatisfactory result in 2008/09.
Table 1.9 Percentage of unsatisfactory smears reported in NHS GGC Laboratories

<table>
<thead>
<tr>
<th>Year</th>
<th>IRH*</th>
<th>VOL*</th>
<th>SGH</th>
<th>GRI</th>
<th>STOB</th>
<th>VIC</th>
<th>NHSGGC Scotland</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000/01</td>
<td>6.0%</td>
<td>7.6%</td>
<td>9.1%</td>
<td>7.2%</td>
<td>7.6%</td>
<td>10.2%</td>
<td>7.7% 8.5%</td>
</tr>
<tr>
<td>2001/02</td>
<td>5.5%</td>
<td>6.3%</td>
<td>7.3%</td>
<td>10.5%</td>
<td>4.2%</td>
<td>8.5%</td>
<td>8.1% 8.8%</td>
</tr>
<tr>
<td>2002/03</td>
<td>5.9%</td>
<td>6.8%</td>
<td>5.9%</td>
<td>3.9%</td>
<td>n/a</td>
<td>n/a</td>
<td>5.2% 7.4%</td>
</tr>
<tr>
<td>2003/04</td>
<td>3.4%</td>
<td>4.6%</td>
<td>6.3%</td>
<td>3.9%</td>
<td>n/a</td>
<td>n/a</td>
<td>4.4% 3.9%</td>
</tr>
<tr>
<td>2004/05</td>
<td>2.7%</td>
<td>2.6%</td>
<td>2.2%</td>
<td>1.9%</td>
<td>n/a</td>
<td>n/a</td>
<td>2.3% 2.2%</td>
</tr>
<tr>
<td>2005/06</td>
<td>2.3%</td>
<td>n/a</td>
<td>2.9%</td>
<td>1.6%</td>
<td>n/a</td>
<td>n/a</td>
<td>2.1% 2.2%</td>
</tr>
<tr>
<td>2006/07</td>
<td>2.5%</td>
<td>n/a</td>
<td>3.0%</td>
<td>2.1%</td>
<td>n/a</td>
<td>n/a</td>
<td>2.5% 2.4%</td>
</tr>
<tr>
<td>2007/08</td>
<td>1.8%</td>
<td>n/a</td>
<td>2.7%</td>
<td>2.8%</td>
<td>n/a</td>
<td>n/a</td>
<td>2.4% 2.8%</td>
</tr>
<tr>
<td>2008/09</td>
<td>2.0%</td>
<td>n/a</td>
<td>2.7%</td>
<td>3.1%</td>
<td>n/a</td>
<td>n/a</td>
<td>2.7% 3.0%</td>
</tr>
</tbody>
</table>

Source 2000-2007 Cervical Cytology System (CCS); 2007/08 - Labs (SCCRs)
Scotland figures from ISD Website

*IRH/VOL - includes unsatisfactory smears reported for Argyll and Bute area
Vale of Leven stopped reporting smears taken as at quarter ending 30th September 2004
Stobhill stopped reporting smears taken as at quarter ending 30th June 2001
Victoria stopped reporting smears taken as at quarter ending 30th September 2001

As part of an initiative to reduce the number of unsatisfactory smears, a sub group has been set up to develop a training programme for staff to update their cytology sampling skills.

Table 1.10 shows the proportion of results reported as abnormal smears in each of the cytopathology laboratories in NHSGGC, after excluding the unsatisfactory tests between 2000/01 and 2008/09. Abnormal smears results include: borderline, mild, moderate and severe dyskaryosis, severe dyskaryosis/invasive, glandular abnormality and adenocarcinoma. 9.9% of smears were reported as abnormal in 2008/09.

Table 1.10 Percentage of abnormal smears reported in NHS GGC Laboratories

<table>
<thead>
<tr>
<th>Year</th>
<th>IRH*</th>
<th>VOL*</th>
<th>SGH</th>
<th>GRI</th>
<th>STOB</th>
<th>VIC</th>
<th>NHSGGC Scotland</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000/01</td>
<td>7.8%</td>
<td>8.6%</td>
<td>10.2%</td>
<td>11.2%</td>
<td>10.1%</td>
<td>8.5%</td>
<td>9.4% 8.0%</td>
</tr>
<tr>
<td>2001/02</td>
<td>7.2%</td>
<td>7.4%</td>
<td>7.8%</td>
<td>12.4%</td>
<td>16.5%</td>
<td>8.5%</td>
<td>9.5% 8.3%</td>
</tr>
<tr>
<td>2002/03</td>
<td>7.0%</td>
<td>8.3%</td>
<td>5.7%</td>
<td>10.0%</td>
<td>n/a</td>
<td>n/a</td>
<td>8.1% 7.3%</td>
</tr>
<tr>
<td>2003/04</td>
<td>7.6%</td>
<td>10.2%</td>
<td>5.2%</td>
<td>10.3%</td>
<td>n/a</td>
<td>n/a</td>
<td>8.5% 7.2%</td>
</tr>
<tr>
<td>2004/05</td>
<td>7.8%</td>
<td>7.4%</td>
<td>6.0%</td>
<td>9.8%</td>
<td>n/a</td>
<td>n/a</td>
<td>8.2% 7.2%</td>
</tr>
<tr>
<td>2005/06</td>
<td>7.6%</td>
<td>n/a</td>
<td>6.7%</td>
<td>10.7%</td>
<td>n/a</td>
<td>n/a</td>
<td>8.7% 7.4%</td>
</tr>
<tr>
<td>2006/07</td>
<td>8.2%</td>
<td>n/a</td>
<td>7.6%</td>
<td>10.2%</td>
<td>n/a</td>
<td>n/a</td>
<td>8.9% 7.6%</td>
</tr>
<tr>
<td>2007/08</td>
<td>8.5%</td>
<td>n/a</td>
<td>7.1%</td>
<td>11.1%</td>
<td>n/a</td>
<td>n/a</td>
<td>9.3% 7.7%</td>
</tr>
<tr>
<td>2008/09</td>
<td>9.6%</td>
<td>n/a</td>
<td>8.5%</td>
<td>10.9%</td>
<td>n/a</td>
<td>n/a</td>
<td>9.9% 8.4%</td>
</tr>
</tbody>
</table>

*IRH/VOL - includes unsatisfactory smears reported for Argyll and Bute area
VOL stopped reporting smears taken as at quarter ending 30th September 2004
STOB stopped reporting smears taken as at quarter ending 30th June 2001
VIC stopped reporting smears taken as at quarter ending 30th September 2001
Source 2000-2007 Cervical Cytology System (CCS); 2007/09 - Labs (SCCRs)
Scotland figures from ISD Website
Table 1.11 shows the detailed breakdown of smear results profile reported by NHSGGC laboratories.

Of the 116,055 smears tests received by the laboratories, 112,978 (97.3%) were processed. 90.1% of smears processed were reported to be negative; 6.2% to be borderline squamous; 2.3% mild dyskaryosis and 1.2% to have moderate to severe dyskaryosis. Appendix A shows the management and follow up advice for cytology results.
Table 1.11 Result profiles by age band: 1 April 2008 - 31 Mar 2009 (compiled from quarterly reports)
All NHS Greater Glasgow and Clyde Laboratories

<table>
<thead>
<tr>
<th>Age Band</th>
<th>Under 20</th>
<th>20 - 24</th>
<th>25 - 29</th>
<th>30 - 34</th>
<th>35 - 39</th>
<th>40 - 44</th>
<th>45 - 49</th>
<th>50 - 54</th>
<th>55 - 59</th>
<th>60 - 64</th>
<th>65+</th>
<th>Total 65+</th>
<th>% Unsatisfactory</th>
<th>% Cumulative</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Unsatisfactory</strong></td>
<td>35</td>
<td>411</td>
<td>343</td>
<td>305</td>
<td>350</td>
<td>411</td>
<td>364</td>
<td>350</td>
<td>395</td>
<td>99</td>
<td>14</td>
<td>3077</td>
<td>2.7</td>
<td>2.64</td>
</tr>
<tr>
<td><strong>Negative</strong></td>
<td>954</td>
<td>13866</td>
<td>13827</td>
<td>12368</td>
<td>13851</td>
<td>14877</td>
<td>12860</td>
<td>9952</td>
<td>7459</td>
<td>1976</td>
<td>226</td>
<td>101815</td>
<td>90.12</td>
<td>90.26</td>
</tr>
<tr>
<td><strong>Borderline Squamous</strong></td>
<td>229</td>
<td>2293</td>
<td>1391</td>
<td>815</td>
<td>761</td>
<td>693</td>
<td>454</td>
<td>245</td>
<td>135</td>
<td>49</td>
<td>6</td>
<td>7071</td>
<td>6.26</td>
<td>96.38</td>
</tr>
<tr>
<td><strong>Borderline Glandular</strong></td>
<td>0</td>
<td>2</td>
<td>9</td>
<td>9</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>54</td>
<td>0.05</td>
<td>96.43</td>
</tr>
<tr>
<td><strong>Mild Dyskaryosis</strong></td>
<td>76</td>
<td>930</td>
<td>553</td>
<td>307</td>
<td>245</td>
<td>219</td>
<td>135</td>
<td>79</td>
<td>24</td>
<td>15</td>
<td>3</td>
<td>2586</td>
<td>2.7</td>
<td>98.71</td>
</tr>
<tr>
<td><strong>Moderate Dyskaryosis</strong></td>
<td>14</td>
<td>198</td>
<td>196</td>
<td>123</td>
<td>75</td>
<td>68</td>
<td>35</td>
<td>14</td>
<td>10</td>
<td>5</td>
<td>2</td>
<td>740</td>
<td>0.66</td>
<td>99.4</td>
</tr>
<tr>
<td><strong>Severe Dyskaryosis</strong></td>
<td>1</td>
<td>123</td>
<td>192</td>
<td>112</td>
<td>83</td>
<td>71</td>
<td>32</td>
<td>18</td>
<td>9</td>
<td>3</td>
<td>1</td>
<td>645</td>
<td>0.57</td>
<td>99.9</td>
</tr>
<tr>
<td><strong>Severe Dyskaryosis/?Invasion</strong></td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>15</td>
<td>0.01</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Glandular Abnormality</strong></td>
<td>0</td>
<td>4</td>
<td>13</td>
<td>5</td>
<td>13</td>
<td>6</td>
<td>6</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>51</td>
<td>0.05</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Endocervical Adenocarcinoma</strong></td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0.00</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Other Malignancy</strong></td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0.00</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Total including unsatisfactory results</strong></td>
<td>1309</td>
<td>17627</td>
<td>16527</td>
<td>14046</td>
<td>15391</td>
<td>16156</td>
<td>13896</td>
<td>10663</td>
<td>8038</td>
<td>2150</td>
<td>252</td>
<td>116055</td>
<td>9.74</td>
<td>113741</td>
</tr>
<tr>
<td><strong>Total excluding unsatisfactory results</strong></td>
<td>1274</td>
<td>17216</td>
<td>16184</td>
<td>13741</td>
<td>15041</td>
<td>15745</td>
<td>13532</td>
<td>10313</td>
<td>7643</td>
<td>2051</td>
<td>238</td>
<td>112978</td>
<td>9.42</td>
<td>110743</td>
</tr>
</tbody>
</table>

All Ages 20-60 years

| N Abnormal       | 11163   | 10790   |
| % abnormal       | 9.88    | 9.74    |

Source: Scottish Cervical Call Recall System (SCCRS)

Report Definitions
1. Smears are those processed at a lab, independent of a woman's area of residence or where smeared
2. Smear counts for the originating lab
3. Date received into the lab is the qualification date - report won't run until all smears completed for reporting period. Date authorised may be after end of reporting period.
4. Only lab processed smears count, not white cards or other historic adjustments/additions
5. Smears must be authorised to qualify
6. If a woman has more than one smear, each one will count.
7. Result proportions are calculated excluding unsatisfactory results
8. Age is age at date of exam
Invasive cervical cancer audit

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 2008, we reviewed the notes of women who developed invasive cervical cancer. Sixty-five patients were diagnosed with invasive cervical cancer in 2008. The number of patients diagnosed with invasive cervical cancer in 2007 was 67; 49 in 2006; and 50 in 2005.

Table 1.12 shows the age distribution at the age of diagnosis for years 2005 to 2008. The largest number of cervical cancers occurred in women aged between 30 and 39 years.

Table 1.12 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>5</td>
</tr>
<tr>
<td>30 - 39</td>
<td>13</td>
</tr>
<tr>
<td>40 - 49</td>
<td>14</td>
</tr>
<tr>
<td>50 - 59</td>
<td>10</td>
</tr>
<tr>
<td>60 - 69</td>
<td>2</td>
</tr>
<tr>
<td>70 - 79</td>
<td>3</td>
</tr>
<tr>
<td>80+</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
</tr>
</tbody>
</table>

Source: NHSGGC Invasive Cancer Audit database October 2009
Table 1.13 shows the distribution of clinical stage at diagnosis over a four year period from 2005 to 2008.

Table 1.13 Total number of women with invasive cervical cancers split by diagnosis and year

<table>
<thead>
<tr>
<th>Clinical stage of diagnosis</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a1 (less than 3mm deep and &gt;=7mm wide)</td>
<td>13</td>
<td>15</td>
<td>18</td>
<td>17</td>
<td>63</td>
</tr>
<tr>
<td>1a2 (3-5mm deep and &lt;7mm wide)</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>1b (confined to cervix)</td>
<td>12</td>
<td>10</td>
<td>18</td>
<td>16</td>
<td>56</td>
</tr>
<tr>
<td>2 or greater (spread out with cervix)</td>
<td>23</td>
<td>22</td>
<td>27</td>
<td>31</td>
<td>103</td>
</tr>
<tr>
<td>No Details</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>50</strong></td>
<td><strong>49</strong></td>
<td><strong>67</strong></td>
<td><strong>65</strong></td>
<td><strong>231</strong></td>
</tr>
</tbody>
</table>

Source: NHSGGC Invasive Cancer Audit Database

Table 1.14 shows that 31 of 65 invasive cervical cancers were detected at screening in 2008; 25 of 67 in 2007; 16 of 49 in 2006 and 33 of 50 in 2006. The rest of the cases presented to the service with symptoms.

Table 1.14 Total number of women with invasive cancers split by modality of presentation and year

<table>
<thead>
<tr>
<th>Modality of Presentation</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screen Detected</td>
<td>33</td>
<td>16</td>
<td>25</td>
<td>31</td>
<td>105</td>
</tr>
<tr>
<td>Symptomatic, last smear date &lt;5 yrs</td>
<td>4</td>
<td>9</td>
<td>14</td>
<td>14</td>
<td>33</td>
</tr>
<tr>
<td>Symptomatic, last smear date &gt;5 yrs</td>
<td>7</td>
<td>9</td>
<td>19</td>
<td>13</td>
<td>48</td>
</tr>
<tr>
<td>Symptomatic, No previous smear</td>
<td>6</td>
<td>14</td>
<td>9</td>
<td>7</td>
<td>36</td>
</tr>
<tr>
<td>No Details</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>50</strong></td>
<td><strong>49</strong></td>
<td><strong>67</strong></td>
<td><strong>65</strong></td>
<td><strong>231</strong></td>
</tr>
</tbody>
</table>

Source: NHSGGC Invasive Cancer Audit database

Some of the screen detected cancers might have had an opportunistic smear while presenting with genital tract complaints.

Table 1.5 shows that 25 women out of the 50 with invasive cervical cancer in 2005, 22 women of 49 in 2006, 34 women of 67 in 2007 and 31 women of 65 in 2008 had a complete smear history.
Over the four years audited, 33 women out of the 231 that developed cancer had never had a smear.

**Table 1.15 Smear history of women with invasive cervical cancer**

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

Source: NHSGGC Invasive Cancer Audit database

* Apart from index smear ie the abnormal smear causing referral

**Table 1.16** shows the status of the women included in the audit of invasive cancer at the time when the audit was carried out. There were 23 deaths over the four years audited; 69 women were under follow up at colposcopy service and 127 were under follow up in the oncology service.

**Table 1.16 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>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>50</strong></td>
</tr>
</tbody>
</table>

Source: NHSGGC Invasive Cancer Audit database
Information systems

Scottish Cervical Call Recall System (SCCRS)

The Scottish Cervical Call Recall System (SCCRS) implemented in 2007 provides women with a complete e-health record detailing their whole smear history which professionals involved with the screening programme access. Since the system was implemented, the turnaround time for smears reported has reduced. This is because results are automatically available for the smear takers to view in SCCRS and patients are sent notification directly from Scottish Cervical Call Recall System. The system also produces automated reports and more recently allows for individual performance data to be produced.

National Colposcopy Clinical Information Audit System (NCCIAS)

The National Colposcopy Clinical Information Audit System (NCCIAS) is used by Colposcopy staff for the clinical management and audit of all colposcopy referrals.

Initiatives to improve uptake

In an effort to improve uptake we continue to provide comparative practice-based uptake figures to all practices and to the Community Health Care Partnerships.

A subgroup of the NHS Greater Glasgow and Clyde Cervical Screening Steering Group oversees the promotion of the cervical screening among hard to engage groups. Initiatives are aimed at women with learning difficulties, those in long term institutions, women in travelling communities, women in long term care and women abusing alcohol. Following intense media publicity surrounding Jade Goody’s death from cervical cancer, we have seen increased awareness and participation in the programme. A national group has been set up to oversee a new communication strategy informed by the research carried out in Scotland in which NHS Greater Glasgow and Clyde residents were sampled.

Health Inequalities

An Equality Impact Assessment was carried out in October 2009 to ensure that eligible population receive equal access to screening and services. The outcome of the assessment will be reported to the Cervical Steering Group to consider and take forward any recommendations that arise from the assessment.
Challenges and future priorities

- The human papilloma virus (HPV) immunisation programme was implemented in September 2008. The programme routinely vaccinates girls aged 12 - 13 years of age against cervical cancer. The cervical screening programme will continue because the vaccine does not protect against all HPV types that may cause cervical cancer.

- The challenge is to ensure that women understand the need for continuing cervical screening despite the HPV vaccination being introduced. The information materials developed for the vaccination campaign include the message on the need to continue to attend cervical screening.

- To reduce the number of unsatisfactory smears, a cervical skills update training programme will be developed and offered to all community smear takers from 2010.

- To complete the Equalities Impact Assessment and consider and take forward any recommendations reported.
### SMEAR REPORT MANAGEMENT

<table>
<thead>
<tr>
<th>SMEAR REPORT</th>
<th>MANAGEMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative</td>
<td>36 month recall</td>
</tr>
<tr>
<td>Negative, after borderline</td>
<td>Further repeat at 6 months Return to routine recall after 2nd negative.</td>
</tr>
<tr>
<td>Negative, after mild</td>
<td>Further repeat at 6 &amp; 18 months. Return to routine recall after 3rd negative</td>
</tr>
<tr>
<td>Unsatisfactory</td>
<td>3 month recall. Refer after third in succession.</td>
</tr>
<tr>
<td>Borderline Squamous Changes +/- HPV</td>
<td>6 month recall. Refer after third. ? High grade – Flag as such and Refer to Colposcopy on 1st.</td>
</tr>
<tr>
<td>Borderline Glandular Changes</td>
<td>6 month recall. Refer after second.</td>
</tr>
<tr>
<td>Mild dyskaryosis</td>
<td>Repeat in 6 months Refer after second. OR Refer to Colposcopy on 1st</td>
</tr>
<tr>
<td>Glandular abnormality</td>
<td>Refer to Colposcopy</td>
</tr>
<tr>
<td>Moderate Dyskaryosis</td>
<td>Refer to Colposcopy</td>
</tr>
<tr>
<td>Severe Dyskaryosis</td>
<td>Refer to Colposcopy</td>
</tr>
<tr>
<td>Severe Dyskaryosis / invasive</td>
<td>Refer to Colposcopy</td>
</tr>
<tr>
<td>Adenocarcinoma – Endocervical</td>
<td>Refer to Colposcopy</td>
</tr>
<tr>
<td>Endometrial Adenocarcinoma</td>
<td>Refer to Gynaecology (Early recall will not be triggered for such cases as the detected abnormality is not relevant to cervical screening)</td>
</tr>
</tbody>
</table>
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 2\textsuperscript{nd} 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 3\textsuperscript{rd}.
- 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>

CIN = cervical intraepithelial neoplasia
CGIN = cervical glandular intraepithelial neoplasia
Appendix 1.2

Members of Cervical Screening Steering Group
(As at April 2009)

Dr Emilia Crighton  Consultant in Public Health Medicine (Chair)
Mrs Donna Athanasopolous PERL Resources Co-ordinator
Dr Urszula Bankowska Clinical Director, Sandyford
Dr Margaret Burgoyne Head of Service, Pathology
Dr Kevin Burton Consultant Gynaecologist
Dr Laura Cassidy Consultant Gynaecologist
Mr Mark Darroch IM&T Project Manager
Dr Lorna Dunlop GP/Referrals and Protocols Advisor (to July 2008)
Mrs Fiona Gilchrist Assistant Programme Manager, Screening Dept
Dr Mary Hepburn Consultant Obstetrician/Gynaecologist
Mrs Kathy Kenmuir Primary Care Support Nurse
Dr James Kennedy Consultant Gynaecologist – MCN Cancer Network representative (to March 2009)
Dr Margaret Laing Staff Grade in Cytology/Colposcopy
Mrs Annette Little Information Analyst
Miss Denise Lyden Project Officer
Ms Lois Marshall SCI Gateway Service Delivery Manager
Ms Cynthia Mendelsohn Lay Member
Mrs Eleanor McColl Screening Service Delivery Manager
Ms Jane McNiven Practice Manager
Ms Louise McTaggart Contractor Services Manager
Dr Alan Mitchell Clinical Director Renfrewshire CHP
Mrs Elizabeth Rennie Programme Manager, Screening Dept
Ms Claire Scott Health Improvement Senior (Cancer)
Dr Mary Stephen Consultant Pathologist (to October 2008)
Dr Millicent Thomas Consultant Pathologist
Dr Cynthia Van der Horst Consultant Cytopathologist
Ms Patricia Weir Lay Member
Dr Barbara West General Practitioner
Ms Jackie Wright Practice Nurse
Appendix 1.3

Reporting Structure:
Cervical Screening Programme

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

Ad Hoc Groups

Colposcopy User Group
CHAPTER 2: BREAST SCREENING

SUMMARY

- This report represents interim data for the breast screening round May 2006 – May 2009 in NHS Greater Glasgow and Clyde.

- From May 2006 to May 2009, there were 142,829 eligible women across NHS Greater Glasgow and Clyde.

- 102,331 women (72% of eligible women) were invited for breast screening during period reported.

- 72,220 women (71% of those invited) attended breast screening during the reported period.

- There were 495 women who were diagnosed with breast cancer following screening.

- NHS Greater Glasgow and Clyde implemented two view mammography in Clyde in May 2009 and will extend it across Greater Glasgow by March 2010.

- In May 2009, a breast screening protocol for women in specific categories was approved and implemented across NHS Greater Glasgow and Clyde. The protocol aims to ensure that all groups are invited to take part in the breast screening programme and are followed up appropriately.

- A sub group has recently been set up to explore the opportunity of educating women about lifestyle choices and risk factors associated with cancer during their normal screening appointment.
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. (Information Statistics Division 2007)

The Scottish Breast Screening Programme 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 represents interim data from May 2006 to February 2008 for the breast screening round 2006 – 2009 in NHS Greater Glasgow and Clyde.

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.

Eligible population

Women residents of NHS Greater Glasgow and Clyde area who are aged 50-70 years are invited for a routine breast screen once every three years. Screening is also available to women over 70 years on request.

The screening test

The current screening method used consists of all women having both mammographic views at the first screening test (called prevalent screen). Only one mammographic view will be taken at any subsequent screening test (called incident 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).
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 birthday 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. A proportion of women attending for screening will be recalled if the picture was not clear enough or asked to go to an assessment clinic for further tests if a potential abnormality has been detected. The tests include ultrasound and core biopsies.

If a woman is found to have cancer, she is referred to a consultant surgeon to discuss the options available to her. This usually involves 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.

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 the Western Infirmary and Victoria Infirmary and a small proportion of women with palpable tumours are referred for treatment to local breast teams.
Figure 2.1 Screening pathway

- Invitation of women
- Screening by Mammography
- Film processing: read and analysed
- Results abnormal
  - Assessment will include clinical Examination which may also include:
    - Further films
    - Ultrasound
    - Core biopsy
    - on rare occasions MRI
- Results normal
  - Benign
    - Patient choice - excise
  - Malignant
    - Treatment
  - Indeterminate
    - Repeat biopsy or open biopsy
- Back to routine recall (invite 3 years later)
Delivery of screening programme 2008/09

Uptake of breast screening in NHS Greater Glasgow and Clyde

The number of women eligible for breast screening across the area of Greater Glasgow and Clyde from May 2006 to March 2009 was 142,829 (Table 2.1). Eligible women were identified using the Community Health Index and then invited for breast screening using the NHSGGC CH(C)P SAPE system.

Table 2.1 Total number of women eligible for breast screening split by age bands and CH(C)P for period May 2006 to May 2009

<table>
<thead>
<tr>
<th>CH(C)P</th>
<th>50-54</th>
<th>55-59</th>
<th>60-64</th>
<th>65-70</th>
<th>50-70</th>
<th>Screening Population per year 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>East Dunbartonshire</td>
<td>4197</td>
<td>3733</td>
<td>3571</td>
<td>3538</td>
<td>15039</td>
<td>5013</td>
</tr>
<tr>
<td>East Glasgow</td>
<td>4206</td>
<td>3435</td>
<td>3250</td>
<td>3538</td>
<td>14429</td>
<td>4810</td>
</tr>
<tr>
<td>East Renfrewshire</td>
<td>3332</td>
<td>2851</td>
<td>2809</td>
<td>2721</td>
<td>11713</td>
<td>3904</td>
</tr>
<tr>
<td>Inverclyde</td>
<td>2903</td>
<td>2685</td>
<td>2600</td>
<td>2621</td>
<td>10809</td>
<td>3603</td>
</tr>
<tr>
<td>North Glasgow</td>
<td>3031</td>
<td>2554</td>
<td>2348</td>
<td>2696</td>
<td>10629</td>
<td>3543</td>
</tr>
<tr>
<td>North Lanarkshire¹</td>
<td>683</td>
<td>615</td>
<td>603</td>
<td>538</td>
<td>2439</td>
<td>813</td>
</tr>
<tr>
<td>Renfrewshire</td>
<td>6025</td>
<td>5617</td>
<td>5354</td>
<td>5229</td>
<td>22225</td>
<td>7408</td>
</tr>
<tr>
<td>South East Glasgow</td>
<td>3164</td>
<td>2600</td>
<td>2164</td>
<td>2275</td>
<td>10203</td>
<td>3401</td>
</tr>
<tr>
<td>South Lanarkshire¹</td>
<td>2229</td>
<td>1865</td>
<td>1723</td>
<td>1697</td>
<td>7514</td>
<td>2505</td>
</tr>
<tr>
<td>South West Glasgow</td>
<td>4079</td>
<td>3035</td>
<td>2845</td>
<td>3068</td>
<td>13027</td>
<td>4342</td>
</tr>
<tr>
<td>West Dunbartonshire</td>
<td>3430</td>
<td>2893</td>
<td>2830</td>
<td>2738</td>
<td>11891</td>
<td>3964</td>
</tr>
<tr>
<td>West Glasgow</td>
<td>3982</td>
<td>3100</td>
<td>2844</td>
<td>2985</td>
<td>12911</td>
<td>4304</td>
</tr>
<tr>
<td>NHSGGC Total</td>
<td>41261</td>
<td>34983</td>
<td>32941</td>
<td>33644</td>
<td>142829</td>
<td>47610</td>
</tr>
</tbody>
</table>

Source: NHS GGC CH(C)P SAPE 2008
SAPE: Small Area Population Statistics

Note:
¹ NHS Greater Glasgow and Clyde residents only
² Screening Population - Total population divided by 3 years

Table 2.2 shows the numbers and the proportion of the eligible population invited; numbers screened; and the interim uptake rate split by Community Health (Care) Partnership (CH(C)P) area for the period May 2006 to May 2009. 102,331 (71.6%) women living in NHS Greater Glasgow and Clyde area were invited to attend breast screening.

72,220 women (71% of those invited) attended breast screening during the reported period. There were 495 women who were diagnosed with breast cancer following screening.
Table 2.2: Interim progress report of Breast Screening programme by CH(C)P area for the period May 2006 to May 2009

<table>
<thead>
<tr>
<th>CH(C)P</th>
<th>Number invited(^1)</th>
<th>Number attended(^1)</th>
<th>Number Cancers Detected(^1)</th>
<th>% Attend of those invited</th>
<th>%Cancers of those Attended</th>
</tr>
</thead>
<tbody>
<tr>
<td>East Dunbartonshire</td>
<td>7040</td>
<td>5631</td>
<td>33</td>
<td>80.0</td>
<td>0.6</td>
</tr>
<tr>
<td>East Renfrewshire</td>
<td>4933</td>
<td>3628</td>
<td>23</td>
<td>73.5</td>
<td>0.6</td>
</tr>
<tr>
<td>Glasgow East</td>
<td>11928</td>
<td>8077</td>
<td>46</td>
<td>67.7</td>
<td>0.6</td>
</tr>
<tr>
<td>Glasgow North</td>
<td>8009</td>
<td>5016</td>
<td>39</td>
<td>62.6</td>
<td>0.8</td>
</tr>
<tr>
<td>Glasgow South East</td>
<td>11341</td>
<td>8152</td>
<td>73</td>
<td>71.9</td>
<td>0.9</td>
</tr>
<tr>
<td>Glasgow South West</td>
<td>3911</td>
<td>2635</td>
<td>15</td>
<td>67.4</td>
<td>0.6</td>
</tr>
<tr>
<td>Glasgow West</td>
<td>9293</td>
<td>6292</td>
<td>43</td>
<td>67.7</td>
<td>0.7</td>
</tr>
<tr>
<td>North Lanarkshire(^2)</td>
<td>2240</td>
<td>1718</td>
<td>11</td>
<td>76.7</td>
<td>0.6</td>
</tr>
<tr>
<td>South Lanarkshire(^2)</td>
<td>4934</td>
<td>3666</td>
<td>21</td>
<td>74.3</td>
<td>0.6</td>
</tr>
<tr>
<td>Inverclyde</td>
<td>10649</td>
<td>7277</td>
<td>43</td>
<td>68.3</td>
<td>0.6</td>
</tr>
<tr>
<td>Renfrewshire</td>
<td>21895</td>
<td>15776</td>
<td>117</td>
<td>72.1</td>
<td>0.7</td>
</tr>
<tr>
<td>West Dunbartonshire</td>
<td>6158</td>
<td>4352</td>
<td>31</td>
<td>70.7</td>
<td>0.7</td>
</tr>
<tr>
<td><strong>NHSGGC Total</strong></td>
<td><strong>102331</strong></td>
<td><strong>72220</strong></td>
<td><strong>495</strong></td>
<td><strong>70.6</strong></td>
<td><strong>0.7</strong></td>
</tr>
</tbody>
</table>

Source: \(^1\) West of Scotland Breast Screening Data

Notes

\(^2\) NHS Greater Glasgow and Clyde residents only

Progress/Completion Details:


Inverclyde, Renfrewshire, West Dunbartonshire: Round completed - May 2006 to May 2009

**Health inequalities**

Work started in May 2009 to carry out an Equality Impact Assessment of the breast screening programme. The work is due to be completed by December 2009.

A sub group was set up to consider how best to identify and engage with hard to reach groups who cannot otherwise be identified by the Community Health Index, for example travellers and the homeless. The group also looked at developing a process for screening women in nursing homes and patients in long stay care establishments.

A breast screening protocol for women groups that could discriminated by the existing screening process was approved and introduced across NHS Greater Glasgow and Clyde in May 2009. The protocol aims to ensure that all groups are invited to take part in the breast screening programme and are followed up appropriately.
Promoting uptake

There have been several initiatives to promote uptake of the breast screening programme. These included inviting women from ethnic minority and learning disability groups who are approaching the eligible age range to visit the centre and familiarise themselves with the equipment. This initiative has proved to be a beneficial exercise.

There has been much in the recent literature looking at the effect of obesity and lack of physical activity as well as alcohol consumption being contributing factors to developing cancer.

A sub group has recently been set up to explore the opportunity of raising the issue with women about lifestyle choices, and risk factors associated with cancer, during their normal screening appointment.

It is planned that a staff training programme will be developed to introduce staff to Health Behaviour Change theories and Brief Intervention skills. Staff will then have the knowledge and skills to advise women who attend screening of risk factors associated with cancer and offer women the opportunity to discuss lifestyle changes, like physical activity, healthy eating, weight management; alcohol consumption and smoking. The training will also enable staff to signpost women to the appropriate services that are available. It is planned that training will be piloted and evaluated with a view to rolling out in 2010.

Two view mammography

In Scotland, women are offered two view mammography at their first screen, and a single oblique view mammogram in subsequent screens.

All Boards received funding to implement two view mammography at every screen. This was introduced in Clyde in May 2009 and is to be rolled out in Greater Glasgow by March 2010.

There had been concerns with waiting times for assessment due to radiology vacancies. However, the West of Scotland Breast Centre has now been able to recruit half of the vacant radiographic retirement posts and will continue with recruiting the remaining vacancies.

Additional mobile van is in place and the Centre has submitted a proposal for an additional mammography unit.
Future developments

Digital Mammography

Following the publication by NHS Quality Improvement Scotland (NHS QIS) of a Health Technology Assessment (HTA) on the introduction of digital mammography into the Scottish Breast Screening Programme (SBSP), work was carried out to assess the requirements for the implementation of digital mammography in the near future.

A business case was submitted to NSD to purchase a digital mammography unit.

Challenges and future priorities

To implement two view mammography in Greater Glasgow by March 2010.

To follow up on the Equality Impact Assessment for breast screening programme.

To continue to promote and encourage uptake of the screening programme through health promotion activities.

To develop and implement staff training programme to promote healthy lifestyles by 2010.
Appendix 2.1

Members of Breast Screening Steering Group
(As at March 2009)

Dr Emilia Crighton  Consultant in Public Health Medicine (Chair)
Mrs Donna Athanasopolous  PERL Resources Co-ordinator
Mrs Brenda Bellando  Business Manager
Mr Tom Clackson  GMS Contract Manager
Dr Hilary Dobson  Clinical Director
Prof David George  Consultant Breast Surgeon
Mrs Fiona Gilchrist  Assistant Programmes Manager, Screening Dept
Dr Susan Langridge  General Practitioner
Mrs Annette Little  Information Analyst
Miss Denise Lyden  Project Officer
Ms Janet Mair  Regional Registration Manager
Mrs Eleanor McColl  H&IT Service Delivery Manager
Ms Cynthia Mendelsohn  Lay Member
Dr Alan Mitchell  Clinical Director
Ms Ann Mumby  Superintendent Radiographer
Mrs Elaine Murray  Community Liaison Officer
Mrs Elizabeth Rennie  Programmes Manager, Screening Dept
Mrs Claire Scott  Senior Health Improvement Officer
Ms Patricia Weir  Lay Member
Appendix 2.2

Reporting Structure:
Breast Screening Steering Group

Key:
- - - - - Direct Reports
- - - - - Network Links
CHAPTER 3: INTERIM REPORT FOR BOWEL SCREENING PROGRAMME FOR PERIOD 1 APRIL 2009 TO 31 DECEMBER 2009

SUMMARY

- Colorectal (Bowel) Cancer is the third most common cancer in Scotland. Every year over 3,400 people are diagnosed with the disease.

- 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 implemented the bowel screening programme in April 2009. During 2008/09, detailed planning for implementation was carried.

- 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 will be able to participate. Thereafter, all individuals will be routinely recalled every two years.

- It is estimated that, from 1 April 2009 to 31 March 2010, 244,000 NHS Greater Glasgow and Clyde residents will have been invited to participate in the Bowel Screening programme.

- All eligible individuals are sent a teaser letter two weeks before the screening kit is sent to advise them that they will be sent the bowel screening kit.

- 135,440 teaser letters were sent to eligible participants.

- 66,571 test results were reported by the Bowel Screening laboratory and this gives an estimated uptake of 50%.

- 1,645 patients received a positive result. This represented a positivity screening rate of 2.5%. This was higher than the national average range of 1.9% to 2.3% reported in the Scottish Bowel Screening Programme KPI reports (www.ISDscotland.org 25 August 2009).

- Of the 1,645 patients screened positive, 1,457 patients were pre-assessed prior to colonoscopy. 84 patients did not respond to the offer of a colonoscopy pre-assessment.
• 1,040 (63.2%) patients completed colonoscopy investigations by 31 December 2009. 3.1% (46) patients refused to take up the offer of a colonoscopy. Of the total eligible population invited to take part in bowel screening, 84 (6 in 10,000) cancers were detected.

• To minimise the complication rates for colonoscopy, colonoscopy skills update training and continuous audit for screening colonoscopists are implemented.

• A bespoke information management and technology system to support the bowel screening programme was developed in-house. The data collected allows staff to monitor service performance and track patients through the process from point of referral to diagnosis and treatment for colorectal cancer.

• NHS Greater Glasgow and Clyde has implemented several initiatives to promote uptake based on experience from Breast Screening. Primary care staff and Health Promotion leads in Community Health (Care) Partnerships are involved by displaying promotional materials and engaging with local communities to promote and encourage the uptake of bowel screening.

• A TV, radio and poster campaign was commissioned by NHS Greater Glasgow and Clyde which ran from April to August 2009. The evaluation of the campaign reported that by using TV advertising, TV awareness was 46%, and the total campaign awareness was 53%.
CHAPTER 3: INTERIM REPORT FOR BOWEL SCREENING PROGRAMME FOR PERIOD 1 APRIL 2009 TO 31 DECEMBER 2009

Background

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, 434 people aged between 50 and 74 are diagnosed with bowel cancer in 2006. (Colorectal Cancer Incidence (ICD10 C18 to C20) 2006).

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 implemented the programme in April 2009.

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. In addition, the removal of precancerous lesions could lead to a reduction in the incidence of colorectal cancer.

Eligible population

The programme invites 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 would also be able to participate following NHS Greater Glasgow and Clyde local agreements. Thereafter, all eligible individuals will be routinely recalled every two years.

It is estimated that, from 1 April 2009 to 31 March 2010, 244,000 NHS Greater Glasgow and Clyde residents will have been invited to participate in the Bowel Screening programme.
The screening test

Guaiac Faecal Occult Blood test (gFOBt) testing kit is completed at home and returned to the National Bowel Screening Centre in Dundee for analysis.

Screening pathway

Eligible NHS Greater Glasgow and Clyde residents that are due to be invited to take part in the bowel screening programme are sent a “teaser” letter before they are sent an invitation letter and screening kit. The letter explains the programme and encourages participants to take the test.

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.

After analysis, the National Centre reports, via an IT system, results of all positive tests to the Board. The National Centre also informs the patient and the patient’s general practitioner by letter.

Patients with positive screening results are invited to contact NHS Greater Glasgow and Clyde administrative staff to arrange for a telephone assessment and be offered a colonoscopy. If required, they are then referred for further diagnostic investigations and treatment. Figure 3.1 gives an overview of the bowel screening pathway.
Figure 3.1 Overview of bowel screening pathway

1. Identify eligible residents
2. Send teaser letter
3. Send test kit
4. Perform screening test at home
5. Process test kit and return result to patient
6. Positive: If positive – Refer to NHS Board
7. Negative: Pre-assessment
8. Other pathology
10. Follow up as agreed in failsafe
11. Recall 2 years
12. Pathology
13. Double Contrast Barium Enema (DCBE) if failed colonoscopy

Key:
- Scottish Bowel Screening centre
- NHS Greater Glasgow and Clyde
- General Practices

SCI Gateway Information Request (GPs)
Performance on uptake and delivery of service – Interim report 1 April to 31 December 2009

Since the launch of the bowel screening programme, 135,440 teaser letters have been sent to eligible participants (see Figure 3.1). 66,571 test results were reported by the Bowel Screening laboratory. This gives an estimated uptake of 50%. The uptake is encouraging as the evaluation of the bowel screening pilot in the UK demonstrated a level of uptake of 30% in deprived communities.

To meet NHS Quality Improvement Scotland’s standard level of uptake of 60% will prove particularly challenging for NHS Greater Glasgow and Clyde.

Figure 3.1: Breakdown of NHS Greater Glasgow and Clyde Bowel Screening Activity 1 April 2009 to 31 December 2009

Source: NHS Greater Glasgow and Clyde Bowel Screening IT System.
Note:
1. It was estimated that residents would complete the test within 6 weeks of teaser letter being issued. Therefore the approximate percentage uptake is based on total number of results from 1 April 2009 – 31 December 2009 against the number of teaser letters issued from 1 April 2009 – 28 November 09.

There were 1,645 patients that received a positive result, representing a positivity screening rate of 2.5%. This was higher than the national average range of 1.9% to 2.3% reported in the Scottish Bowel Screening Programme KPI reports (www.ISDscotland.org 25 August 2009).

Of the 1,645 patients screened positive, 1,457 patients were pre-assessed prior to colonoscopy. 84 patients did not respond to the offer of a colonoscopy pre-assessment.

1,040 (63.2%) patients completed colonoscopy investigations by 31 December 2009. 3.1% (46) patients refused to take up the offer of a colonoscopy. Of the total eligible population invited to take part in bowel screening, 84 (6 in 10,000) cancers were detected.

**Quality assurance and training**

To minimise the complication rates for colonoscopy, skills update training and audit for screening colonoscopists are implemented. These include:

- an audit of individual’s recent practice, number of colonoscopies and rates of completion.

- 2 day course for independent colonoscopists who have not previously attended a JAG course. The course combines elements of educational theory, basic colonoscopy skills and assessment/feedback skills.

- A one day advanced colonoscopy skills refresher course aimed at independent practising colonoscopists who have already achieved 90% completion rates (intention to treat) and wish to improve or develop their therapeutic technical skills. Endoscopic Mucosal Resection (EMR) and standard polypectomy techniques are covered. This course is particularly suited to those colonoscopists participating in bowel cancer screening programme.

**Information systems**

A bespoke information management and technology system to support the bowel screening programme was developed in-house. The data collected allows staff to monitor service performance and track patients through the process from point of referral to diagnosis and treatment for colorectal cancer.

The final phase of the development will include links to pathology, cancer MDT and cancer waiting times systems.
The application enables staff to monitor service performance, progress against quality assurance standards and NHS Quality Improvement Scotland Standards.

**Multidisciplinary staff**

The screening programme is delivered and supported by work done by different directorates.

The Screening Department has three WTE administrative staff who send teaser letters, co-ordinate, track and monitor screening patients using NHSGGC’s bespoke Bowel Screening IT application.

The colorectal service has four nurse specialists that run eight telephone pre-assessment clinics per week seeing eight patients per clinic. There are 26 screening colonoscopists to deliver in excess of eight colonoscopy sessions per week.

All screening related activity for Health Records is co-ordinated across the Board by one WTE Health Records Officer. Activity includes issuing colonoscopy appointments, bowel preparation and organising patient transport for individuals requiring it.

**Promoting uptake**

NHS Greater Glasgow and Clyde has implemented several initiatives to promote uptake based on the experience from the breast screening programme.

Teaser letters are sent to patients before they receive their bowel screening kit. The wording of the letter was agreed with the Local Medical Council (LMC).

Primary care was also involved in promoting the programme by displaying promotional materials.

In addition, general practices are involved in the delivery of the diagnostic part of the programme by sending relevant clinical information using SCI Gateway protocol.

The Keep Well programme incorporates advice and encourages eligible participants to take part in the bowel screening programme.

NHS Greater Glasgow and Clyde commissioned a TV and radio advertising and poster campaign to help raise public awareness and maximise the uptake of the bowel screening programme. The campaign ran from April to August 2009. The evaluation of the campaign reported that by using TV advertising, TV awareness was 46% and that the total campaign awareness was 53%. *(Bowel Screening Campaign, MRUK Omnibus, June 2009, The Bridge).*
It is commonly accepted, however, that any marketing campaign that relies on leaflets, posters and advertisements alone may have limited success. What works are approaches that provide information but also explore attitudes, values, and develop skills and ways of addressing barriers to uptake. Also engagement with, and empowerment of, the target group is key to a successful screening programme.

An information session was held in November 2008, inviting representatives from each Health Improvement team in the CH(C)Ps. Their engagement in promoting uptake was vital in order to engage with their own most vulnerable communities.

Subsequently a group was established with Health Improvement leads in CH(C)Ps and they each developed local health promotion plans to engage with local communities to promote bowel screening. These plans will be updated annually as roll out progresses.

In addition, the Health Improvement Team (Acute Planning) developed a cross cutting action plan for vulnerable groups of people who may experience greater inequalities.

They also worked with other partners to develop a pilot training course on Bowel Awareness and Bowel Screening. This course would be delivered to key health and care employees to increase their knowledge and skills, allowing them to talk to patients, clients and community groups. The pilot will be evaluated before deciding on future direction.

**Challenges and future priorities**

- To complete the final phase of the Bowel Screening IT application
- To complete an equality impact assessment for the bowel screening programme
- To monitor and audit the performance of the programme
- To encourage uptake of the programme through health promotion activities
### Appendix 3.2

#### Members of Bowel Screening Steering Group
(As at March 2009)

<table>
<thead>
<tr>
<th>Name</th>
<th>Position and Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Emilia Crighton</td>
<td>Consultant in Public Health Medicine, Chair</td>
</tr>
<tr>
<td>Mr John Anderson</td>
<td>Consultant Surgeon</td>
</tr>
<tr>
<td>Mrs Donna Athanasopolous</td>
<td>PERL Resources Co-ordinator</td>
</tr>
<tr>
<td>Mr Ewan Bell</td>
<td>Colorectal Nurse Endoscopist</td>
</tr>
<tr>
<td>Ms Jacqueline Carrigan</td>
<td>Head of Finance, Surgery and Anaesthetics</td>
</tr>
<tr>
<td>Mr Andrew Daly</td>
<td>Head of Financial Planning and Allocations</td>
</tr>
<tr>
<td>Dr Fraser Duthie</td>
<td>Lead Clinician for Pathology</td>
</tr>
<tr>
<td>Mr Ian Finlay</td>
<td>Consultant Surgeon - Bowel Screening Lead</td>
</tr>
<tr>
<td>Mr Patrick Finn</td>
<td>Consultant Colorectal and General Surgeon</td>
</tr>
<tr>
<td>Mrs Fiona Gilchrist</td>
<td>Assistant Programmes Manager, Screening Dept</td>
</tr>
<tr>
<td>Dr Derek Gillen</td>
<td>Lead Clinician for Endoscopy</td>
</tr>
<tr>
<td>Mr Alan Hunter</td>
<td>General Manager</td>
</tr>
<tr>
<td>Ms Heather Jarvie</td>
<td>Senior Health Promotion Officer</td>
</tr>
<tr>
<td>Mrs Maureen Kirkland</td>
<td>Lay Member</td>
</tr>
<tr>
<td>Mrs Annette Little</td>
<td>Information Analyst</td>
</tr>
<tr>
<td>Miss Denise Lyden</td>
<td>Project Officer</td>
</tr>
<tr>
<td>Miss Flora MacInnes</td>
<td>Business Analyst/ Project Lead</td>
</tr>
<tr>
<td>Mrs Eleanor McColl</td>
<td>H&amp;IT Service Delivery Manager</td>
</tr>
<tr>
<td>Ms Joyce McFadyen</td>
<td>Health Records Manager</td>
</tr>
<tr>
<td>Ms Susan McFadyen</td>
<td>Clinical Service Manager</td>
</tr>
<tr>
<td>Mrs Tricia McKenna</td>
<td>Colorectal Nurse Endoscopist</td>
</tr>
<tr>
<td>Dr John Morris</td>
<td>Consultant Gastroenterologist</td>
</tr>
<tr>
<td>Dr Kenneth O'Neill</td>
<td>Clinical Director, South West CHP</td>
</tr>
<tr>
<td>Mr Ian Pickford</td>
<td>Consultant Surgeon</td>
</tr>
<tr>
<td>Dr Fat Wui Poon</td>
<td>Lead Clinician for Radiology</td>
</tr>
<tr>
<td>Mrs Rebecca Reid</td>
<td>Clinical Service Manager</td>
</tr>
<tr>
<td>Dr Robin Reid</td>
<td>Associate Medical Director, Laboratories &amp; Diagnostics</td>
</tr>
<tr>
<td>Mrs Elizabeth Rennie</td>
<td>Programmes Manager, Screening Dept</td>
</tr>
<tr>
<td>Mrs Claire Scott</td>
<td>Senior Health Improvement Officer</td>
</tr>
<tr>
<td>Dr Maureen Smith</td>
<td>General Practitioner/LMC Representative</td>
</tr>
<tr>
<td>Ms Paula Spaven</td>
<td>Clinical Effectiveness Manager</td>
</tr>
<tr>
<td>Ms Ruth Tipling</td>
<td>Colorectal Nurse Endoscopist</td>
</tr>
<tr>
<td>Mrs Ann Wilson</td>
<td>General Manager – General Surgery, Urology and Endoscopy</td>
</tr>
</tbody>
</table>
Appendix 3.3

Reporting Structure:
Bowel Screening Programme

- Public Health Screening Unit
  - Bowel Screening Programme Steering Group
    Chair: Dr Emilia Crighton, CPHM
      - Colonoscopy Accreditation QA Sub Group
      - IM&T Sub Group
      - Communication/Health Improvement Group
      - Ad hoc Short Life Working Groups
CHAPTER 4: COMMUNICABLE DISEASES IN PREGNANCY

SUMMARY

- To comply with NHS Quality Improvement Scotland standards (*Clinical Standards 2005, Pregnancy and Newborn Screening*), protocols covering each of the four 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 pregnant 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.

- 16,079 pregnant women had a first booking visit at a Greater Glasgow and Clyde hospital during 2008/09. 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 communicable diseases.

- Thirteen pregnant women were identified as having HIV by the screening programme, only six of whom were previously known to be HIV positive. Seventy-three women were detected as having hepatitis B virus, 34 of whom were previously known to be chronic carriers of the virus. Fifteen women were identified by the screening programme to be positive for syphilis. Of these six were false positives, three were previously treated and only six required follow-up management. As the majority of the women with HIV or HBV 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 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 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. These were updated in 2008.

- 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.

**Delivery of screening programme 2008/09 - results**

16,079 pregnant women had a first booking visit at a Greater Glasgow and Clyde hospital during 2008/09. 12,428 took place at Greater Glasgow maternity units and 3,651 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 and Clyde, the total number of samples (12,561) is greater than the total number of booking visits (12,428).

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 three of the screening tests, uptake is greater than 95%.

**Table 4.1 Greater Glasgow laboratories**

<table>
<thead>
<tr>
<th></th>
<th>Samples 2008/09</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total number of samples</td>
<td>No. requesting individual test</td>
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<tr>
<td>HIV</td>
<td>12561</td>
<td>12176</td>
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<td>HBV</td>
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<td>12436</td>
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<td>Rubella</td>
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<tr>
<td>Syphilis</td>
<td>12561</td>
<td>12206</td>
</tr>
</tbody>
</table>

Notes

1 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.

2 6 of the 13 infections were previously known about

3 37 of the 71 infections were previously known about

4 Detection of antibody means that the woman is immune to rubella. No antibody detected means that the woman is susceptible to rubella and should be offered immunisation with MMR vaccine after delivery.
### Table 4.2 Clyde Laboratories

<table>
<thead>
<tr>
<th>Testing Type</th>
<th>Total number of samples</th>
<th>No. requesting individual test</th>
<th>No. not requesting individual test</th>
<th>% uptake</th>
<th>Antibody detected</th>
<th>Antibody not detected</th>
<th>Equiv</th>
<th>Insuff or not tested</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
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<td></td>
<td></td>
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<td></td>
<td></td>
<td>%</td>
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<tr>
<td>HIV</td>
<td>3877</td>
<td>3722</td>
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<td>96</td>
<td>-</td>
<td>3714</td>
<td>99.8</td>
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<td>HBV</td>
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<td>3756</td>
<td>123</td>
<td>96.8</td>
<td>2</td>
<td>3746</td>
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<tr>
<td>Rubella</td>
<td>3856</td>
<td>3832</td>
<td>24</td>
<td>99.4</td>
<td>3638</td>
<td>168</td>
<td>4.4</td>
<td>8</td>
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<tr>
<td>Syphilis</td>
<td>3877</td>
<td>3759</td>
<td>118</td>
<td>96.7</td>
<td>-</td>
<td>3749</td>
<td>99.7</td>
<td>9</td>
</tr>
</tbody>
</table>

**Notes**

1. Incomplete reporting of data from IRH lab from August and September 2008. The incomplete data is a consequence of data transfer for reporting purposes and not indicative of missed cases during the screening process.
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. Detection of antibody means that the woman is immune to rubella.
4. No antibody detected or equivocal means that the woman is susceptible to rubella and should be offered immunisation with MMR vaccine after delivery.

**Immunity to rubella**

Differences in laboratory testing and reporting of rubella results across the labs had been noted. This had consequences for the proportion of women being offered MMR vaccine after delivery. In 2008, the Pregnancy Screening for Communicable Diseases subgroup worked with the labs to standardise the reporting of results across the Board and to reduce the number of tests reported as equivocal. The percentage of women who are not immune to rubella is now broadly similar across the Board.

**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 four 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.

The IT application to support all pregnancy and newborn bloodspot screening programmes which will be rolled out in 2009/10 will see improvements in both the reporting and management of cases identified through the programme.
Future developments

The Pregnancy Screening for Communicable Diseases subgroup will continue to audit activity and outcomes against the protocols to ensure that the QIS standards are met and women identified as a result of the programme are offered appropriate treatment and care.

Challenges and future priorities

The Pregnancy Screening for Communicable Diseases 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. The audit 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 and all women identified (and their babies) are offered appropriate treatment.
Appendix 4.1

Members of Pregnancy Screening for Communicable Diseases Data and Monitoring Group

(As at March 2009)

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Gillian Penrice</td>
<td>Public Health Protection Unit (Chair)</td>
</tr>
<tr>
<td>Mrs Donna Athanasopolous</td>
<td>PERL Resources Co-ordinator</td>
</tr>
<tr>
<td>Ms Elizabeth Boyd</td>
<td>Clinical Effectiveness Facilitator</td>
</tr>
<tr>
<td>Dr Sheila Cameron</td>
<td>Consultant Clinical Scientist</td>
</tr>
<tr>
<td>Mrs Louise Carroll</td>
<td>Programme Manager HIV/STIs</td>
</tr>
<tr>
<td>Ms Cathy Harkins</td>
<td>Nursing &amp; Midwifery Manager</td>
</tr>
<tr>
<td>Ms Flora Dick</td>
<td>Special Needs (SNIPS) Midwife</td>
</tr>
<tr>
<td>Ms Catherine Frew</td>
<td>Data Analyst</td>
</tr>
<tr>
<td>Mrs Annie Hair</td>
<td>Head of Children's Services</td>
</tr>
<tr>
<td>Mrs Annette Little</td>
<td>Information Analyst</td>
</tr>
<tr>
<td>Miss Denise Lyden</td>
<td>Project Officer</td>
</tr>
<tr>
<td>Mrs Eleanor McColl</td>
<td>IT Service Delivery Manager</td>
</tr>
<tr>
<td>Mrs Gwyneth MacDonald</td>
<td>Sexual Health Advisor</td>
</tr>
<tr>
<td>Dr Alan Mathers</td>
<td>Clinical Director Obstetrics and Gynaecology</td>
</tr>
<tr>
<td>Mrs Marie-Elaine McClair</td>
<td>Clinical Nurse Manager</td>
</tr>
<tr>
<td>Mrs Harriet O'Donnell</td>
<td>Health Protection Nurse Specialist</td>
</tr>
<tr>
<td>Mrs Diane Paterson</td>
<td>Lead Midwife</td>
</tr>
<tr>
<td>Ms Linda Rhodick</td>
<td>Medical Secretary/Data Co-ordinator</td>
</tr>
<tr>
<td>Dr James Robins</td>
<td>Consultant Obstetrician &amp; Gynaecologist</td>
</tr>
<tr>
<td>Dr Tasmin Sommerfield</td>
<td>Specialist Registrar in Public Health</td>
</tr>
<tr>
<td>Dr Andrew Thomson</td>
<td>Consultant Obstetrician &amp; Gynaecologist</td>
</tr>
<tr>
<td>Mrs Janice Winter</td>
<td>Clinical Effectiveness Facilitator</td>
</tr>
<tr>
<td>Dr Roger Wong</td>
<td>Clinical Coordinator, Brownlee Centre</td>
</tr>
<tr>
<td>Mrs Irene Woods</td>
<td>Lead Midwife</td>
</tr>
</tbody>
</table>
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

SUMMARY

- 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 2008/09, 16,079 women attended antenatal clinics across NHS Greater Glasgow and Clyde. 14,232 women were NHS Greater Glasgow and Clyde residents and 1,847 women lived outwith the Board area.

- There were two screening pathways in NHS Greater Glasgow and Clyde: first trimester combined ultrasound and biochemical testing for Down’s syndrome and 18-20 week foetal anomaly ultrasonography offered to women booking in the Clyde area of NHS Greater Glasgow and Clyde; and second trimester blood testing offered to women booking in Greater Glasgow.

- In 2008/09, the overall uptake for Down’s syndrome and neural tube defects was 63.8%. The overall percentage uptake for Down’s syndrome was 62.9%; and first trimester combined ultrasound and biochemical screening for neural tube defect was 15.3%. 0.84% of women chose to have only neural tube defect screening.

- Following the second trimester screening, 6.4% of women were assigned to the ‘higher chance’ of Down’s syndrome group, 0.7% of women assigned to the ‘higher chance’ of trisomy 18 group and 2.2% of women with an elevated AFP giving a ‘higher chance’ of a neural tube defect.

- 460 amniocentesis tests were analysed by the Cytogenetics Laboratory. 50 abnormalities were detected (10.9% of samples) and 26 of those (5.7% of total tests) had a diagnosis of trisomy (Down’s syndrome/trisomy 18).

- 97 chorionic villus biopsies were analysed by the Cytogenetics Laboratory in 2008/09. 31 abnormalities were detected (32% of tests) and 17 of those (17.53% of tests) had a diagnosis of trisomy (Down’s syndrome/trisomy 18).

- To date, it is known that 11 cases of Down’s syndrome, 2 cases of trisomy 18 and 4 cases with neural tube defects were detected antenatally by screening. Some babies born with these conditions will not be diagnosed during pregnancy as a number of women that had a “higher chance” screening result would not take up the offer of diagnostic test (amniocentesis or CVS).
From 2010, all women in NHS Greater Glasgow and Clyde will be offered combined ultrasound and biochemical screening (CUBS) in the first trimester of pregnancy and a second trimester foetal anomaly ultrasound (FAS) scan between 18 weeks, 0 days and 20 weeks, 6 days. Women who do not present early enough in their pregnancy to take advantage of first trimester screening will be offered second trimester serum screening.
CHAPTER 5: DOWN’S SYNDROME AND NEURAL TUBE DEFECTS

Background

Scottish Government’s guidance CEL 31 (2008) on Changes to Pregnancy and Newborn Pregnancy programmes set out guidance for Boards to ensure all pregnant women are offered down’s syndrome and other congenital amply screening.

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 neural tube defects 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 neural tube defects 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 neural tube defects is to detect Down's syndrome and neural tube defects 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 neural tube defects in the first, second or both trimesters of their pregnancy.

Screening setting

All women are provided with information regarding Down's syndrome and neural tube defects 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 neural tube defects at the antenatal clinic. Screening is integrated into the clinical care pathway. There are seven hospitals and ten associated community clinics where women can book for their antenatal care.

The screening tests

Screening for Down's syndrome and neural tube defects 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 neural tube defect.
a) **Down’s syndrome**

There are two 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. This method has the best detection rate and the lowest false positive rate.

b) **Neural Tube Defects**

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

- Blood testing in the second trimester (AFP and total 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 greater than or equal to 1:250 or a risk of neural tube defect defined by an AFP greater or equal to 2.0 MOM are offered further investigation and management. All women with an abnormal foetal anomaly ultrasound are offered further investigations.

**The diagnostic procedures**

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

- Chorionic villus sampling: This is an invasive procedure, where a needle is used to sample the 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 overall risk of miscarriage of 1%.
The sample is sent to Glasgow Cytogenetics Laboratory to perform the Quantified Fluorescent Polymerase Chain Reaction (QF-PCR) analysis (Rapid Report) and standard culture/karyotyping.

Quantified Fluorescent Polymerase Chain Reaction is a technique used in testing for Down’s syndrome. This is a rapid and robust method that is highly automated. Testing includes the enumeration of chromosome 21 (to exclude Down’s syndrome), 18 (Edwards syndrome) and 13 (Patau’s syndrome).

Standard Culture/Karyotyping is commonly used to diagnose Down’s syndrome, other trisomies, balanced and unbalanced translocations and the sex of the fetus. It involves growing cells and then counting all chromosomes and examining their structure and shape. The main disadvantage is the long wait for results.

Screening Pathway

Throughout NHS Greater Glasgow and Clyde, there are two main screening pathways.

a) Greater Glasgow (and women in Clyde 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 neural tube defects (double test) (See Figure 5.2)
Screening For Down's Syndrome – Greater Glasgow

- Offer of screening by healthcare staff
- Informed consent
- 2nd trimester AFP and total HCG and maternal age
- Risk Assessment Calculation at screening laboratory

- Low Risk - Routine Maternity Care
- Women with high risk (>1:250) offered counselling and routine maternity
- Counselling and further diagnostic/management agreed
b) Clyde area of NHS Greater Glasgow and Clyde

The Clyde area offers all women combined screening for Down’s syndrome at 11 – 14 weeks and universal routine 18-20 week foetal anomaly ultrasonography (see Figure 5.3).

**Figure 5.3**

*Clyde: Screening For Down’s Syndrome and Neural Tube Defects*
Uptake of Down’s syndrome and neural tube defect screening in NHS Greater Glasgow and Clyde

The decision to accept screening for Down’s syndrome and neural tube defects 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 neural tube defects. 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 2008/09, 16,079 women attended antenatal clinics across NHS Greater Glasgow and Clyde. Table 5.1 shows that 14,232 women were NHS Greater Glasgow and Clyde residents and 1,847 women lived outwith the Board area.

Table 5.1 Number of women booking antenatal clinics in NHS Greater Glasgow and Clyde from 1 April 2008 to 31 March 2009

<table>
<thead>
<tr>
<th>Hospital/Clinic name</th>
<th>NHS GGC Resident</th>
<th>Non NHS GGC Resident</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Greater Glasgow:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clarkston Clinic</td>
<td>51</td>
<td>6</td>
<td>57</td>
</tr>
<tr>
<td>Easterhouse HC</td>
<td>150</td>
<td>0</td>
<td>150</td>
</tr>
<tr>
<td>Glasgow Royal Maternity</td>
<td>4622</td>
<td>1128</td>
<td>5750</td>
</tr>
<tr>
<td>Possilpark HC</td>
<td>38</td>
<td>0</td>
<td>38</td>
</tr>
<tr>
<td>Queen Mothers</td>
<td>3115</td>
<td>238</td>
<td>3353</td>
</tr>
<tr>
<td>Kilsyth HC</td>
<td>9</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Rutherglen HC</td>
<td>187</td>
<td>12</td>
<td>199</td>
</tr>
<tr>
<td>Southern General</td>
<td>2450</td>
<td>102</td>
<td>2552</td>
</tr>
<tr>
<td>Victoria Infirmary</td>
<td>307</td>
<td>8</td>
<td>315</td>
</tr>
<tr>
<td>Central Health Centre</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td><strong>Sub Total</strong></td>
<td>10933</td>
<td>1495</td>
<td>12428</td>
</tr>
<tr>
<td><strong>Clyde:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inverclyde Royal</td>
<td>1049</td>
<td>106</td>
<td>1155</td>
</tr>
<tr>
<td>Barrhead HC</td>
<td>160</td>
<td>0</td>
<td>160</td>
</tr>
<tr>
<td>Dumbarton HC</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Royal Alexandra</td>
<td>1538</td>
<td>92</td>
<td>1630</td>
</tr>
<tr>
<td>Vale of Leven</td>
<td>550</td>
<td>154</td>
<td>704</td>
</tr>
<tr>
<td><strong>Sub Total</strong></td>
<td>3299</td>
<td>352</td>
<td>3651</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>14232</td>
<td>1847</td>
<td>16079</td>
</tr>
</tbody>
</table>

Source: SMR00
**Delivery of Screening Programme 2008/09**

**Table 5.2** shows that 2,468 samples were received for first trimester combined ultrasound biochemical screening and 7,654 for second trimester Down’s syndrome and neural tube defects. 135 women chose to be tested for neural tube defects only.

**Table 5.2 Number of samples received and number of women screened in 2008 by Division for type of screening test**

<table>
<thead>
<tr>
<th>Division</th>
<th>1st trimester CUBS</th>
<th>2nd trimester DS/NTD</th>
<th>2nd trimester NTD only (with no previous CUBS)</th>
<th>Overall %</th>
<th>Total number screened</th>
<th>Number Booked</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clyde</td>
<td>2290</td>
<td>430</td>
<td>13</td>
<td>74.9%</td>
<td>2733</td>
<td>3651</td>
</tr>
<tr>
<td>Greater Glasgow</td>
<td>178</td>
<td>7224</td>
<td>122</td>
<td>60.5%</td>
<td>7524</td>
<td>12428</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>2468</td>
<td>7654</td>
<td>135</td>
<td>63.8%</td>
<td>10257</td>
<td>16079</td>
</tr>
</tbody>
</table>

*Source: West of Scotland Regional Prenatal Screening Service*

*Note:*

1. The total number of women screened may be a slight underestimate. It is estimated that 100 to 200 women who have CUB screening privately and then have an NTD only test through the maternity unit. They are not included as they have had a CUB screen.

There are currently different policies for neural tube defects screening in Greater Glasgow and in Clyde. In Clyde, all women are offered an anomaly scan at 18 – 20 weeks whereas in Greater Glasgow, neural tube defects screening is carried out by measuring maternal serum AFP in the second trimester.
In 2008/09, the overall uptake for Down’s syndrome and neural tube defects was 63.8%. The overall percentage uptake for Down’s syndrome was 62.9%; and first trimester combined ultrasound and biochemical screening for neural tube defect was 15.3%. 0.8% of women chose to have only neural tube defect screening.

Table 5.3 shows the number of women who had a foetal anomaly scan across NHS Greater Glasgow and Clyde. As data is recorded manually, the numbers of women reported to have had a foetal anomaly scan is higher than the numbers of women booking as per SMR00.

It was not possible to calculate the overall uptake of neural tube defects due to the difficulty linking the scans to women.

**Table 5.3 Total number of foetal anomaly scans by maternity unit for the period April 2008 to March 2009**

<table>
<thead>
<tr>
<th>Maternity Unit</th>
<th>Total number of women who had a Fetal Anomaly Scan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rankin Maternity Hospital</td>
<td>1075</td>
</tr>
<tr>
<td>Royal Alexandra Hospital</td>
<td>2279</td>
</tr>
<tr>
<td>Vale of Leven Hospital</td>
<td>786</td>
</tr>
<tr>
<td><strong>Clyde Subtotal</strong></td>
<td><strong>4140</strong></td>
</tr>
<tr>
<td>Princess Royal Maternity Hospital</td>
<td>1557</td>
</tr>
<tr>
<td>Queen Mother's Hospital</td>
<td>1569</td>
</tr>
<tr>
<td>Southern General Hospital</td>
<td>850</td>
</tr>
<tr>
<td><strong>Greater Glasgow Subtotal</strong></td>
<td><strong>3976</strong></td>
</tr>
<tr>
<td><strong>NHSGGC Total</strong></td>
<td><strong>8116</strong></td>
</tr>
</tbody>
</table>

Source: Manual records held across maternity units

**Notes:**
1. The number of scans include repeat scans.
2. Detailed scans offered to women with high risk pregnancies
3. Estimated figure due to incomplete records held.

Foetal anomaly scanning is offered to all pregnant women in Clyde as part of a screening programme. From September 2009 all pregnant women booking in Greater Glasgow will be offered a foetal anomaly scan. Prior to that, foetal anomaly scanning was only offered to those women at risk.
Proportion of women assigned to the ‘higher chance’ groups for Down’s syndrome, trisomy 18 and neural tube defects

Table 5.4 shows the number and proportion of women initially assigned to each of the three ‘higher chance’ groups following the first trimester CUB screening and second trimester screening.

Among those who had first trimester CUB screening, 3.5% of women were assigned to the ‘higher chance’ of Down’s syndrome group and 0.1% to the ‘higher chance of trisomy 18 group.

Following the second trimester screening, 6.4% of women were assigned to the 'higher chance' of Down's syndrome group, 0.7% of women assigned to the 'higher chance' of trisomy 18 group and 2.2% of women with an elevated AFP giving a 'higher chance' of a neural tube defect.

NHS Quality Improvement Scotland Standards: Pregnancy and Newborn Screening 2005, recommends that 5-7% screening tests for Down's syndrome should be assessed as high risk and 2-4% tests for neural tube defects. Therefore, laboratory based screening in NHS Greater Glasgow and Clyde does achieve these standards.

Table 5.4 Number and proportion of women initially assigned to the 'higher chance' groups from screening by type of screen

<table>
<thead>
<tr>
<th>Screening Type</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>CUB Screening</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Higher Chance of Down's syndrome</td>
<td>87</td>
<td>3.5</td>
</tr>
<tr>
<td>- Higher Chance of Trisomy 18/13</td>
<td>4</td>
<td>0.1</td>
</tr>
<tr>
<td>2nd Trimester Screening</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Higher Chance of Down's syndrome</td>
<td>489</td>
<td>6.4</td>
</tr>
<tr>
<td>- Higher Chance of Trisomy 18</td>
<td>52</td>
<td>0.7</td>
</tr>
<tr>
<td>- NTD risk (AFP&gt; 2.0 MOM)</td>
<td>165</td>
<td>2.2</td>
</tr>
</tbody>
</table>

Source: West of Scotland Regional Prenatal Screening Service
In 2008/09, **Table 5.5** shows that 460 amniocentesis tests were analysed by the Cytogenetics Laboratory. Some women whose indication for amniocentesis has been recorded as “age over 35” have also been screened; however, it was not possible to separate the data.

50 abnormalities were detected (10.9% of samples) and 26 of those (5.7% of total tests) had a diagnosis of trisomy (Down’s syndrome/trisomy 18).

**Table 5.5 Amniocentesis referrals and outcomes 1st April 2008 - 31st March 2009**

<table>
<thead>
<tr>
<th>Referral Type</th>
<th>Biochemical Screening</th>
<th>Maternal Age &gt;35</th>
<th>Abnormalities on Scan</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of women (= number of tests)</td>
<td>281</td>
<td>103</td>
<td>50</td>
<td>26</td>
<td>460</td>
</tr>
<tr>
<td>% total referral reasons</td>
<td>61.1%</td>
<td>22.4%</td>
<td>10.9%</td>
<td>5.7%</td>
<td></td>
</tr>
<tr>
<td>Number with normal results</td>
<td>266</td>
<td>100</td>
<td>35</td>
<td>24</td>
<td>425</td>
</tr>
<tr>
<td>Number with diagnostic trisomy</td>
<td>12</td>
<td>2</td>
<td>11</td>
<td>1</td>
<td>26</td>
</tr>
<tr>
<td>% number with diagnostic trisomy</td>
<td>4.27%</td>
<td>1.94%</td>
<td>22.00%</td>
<td>3.85%</td>
<td></td>
</tr>
<tr>
<td>Number of other non trisomy abnormalities</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Total number of abnormalities</td>
<td>15</td>
<td>3</td>
<td>13</td>
<td>2</td>
<td>33</td>
</tr>
<tr>
<td>% total number of abnormalities</td>
<td>5.34%</td>
<td>2.91%</td>
<td>26.00%</td>
<td>7.69%</td>
<td>7.17%</td>
</tr>
</tbody>
</table>

*source: Cytogenetics Laboratory*

**Table 5.6** shows that 97 chorionic villus biopsies were analysed by the Cytogenetics Laboratory in 2008/09. 31 abnormalities were detected (32% of tests) and 17 of those (17.53% of tests) had a diagnosis of trisomy (Down’s syndrome/Trisomy 18).
Table 5.5 Chorionic Villus Biopsy referrals and outcomes 1st April 2008 - 31st March 2009

<table>
<thead>
<tr>
<th>Referral Type</th>
<th>Biochemical Screening</th>
<th>Maternal Age &gt;35</th>
<th>Abnormalities on Scan</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of women (= number of tests)</td>
<td>10</td>
<td>16</td>
<td>31</td>
<td>40</td>
<td>97</td>
</tr>
<tr>
<td>% total referral reasons</td>
<td>10.3%</td>
<td>16.5%</td>
<td>32.0%</td>
<td>41.2%</td>
<td></td>
</tr>
<tr>
<td>Number with normal results</td>
<td>6</td>
<td>15</td>
<td>17</td>
<td>32</td>
<td>70</td>
</tr>
<tr>
<td>Number with diagnostic trisomy</td>
<td>4</td>
<td>1</td>
<td>11</td>
<td>1</td>
<td>17</td>
</tr>
<tr>
<td>% total with diagnostic trisomy</td>
<td>40.00%</td>
<td>6.25%</td>
<td>35.48%</td>
<td>2.50%</td>
<td>17.53%</td>
</tr>
<tr>
<td>Number of other non trisomy abnormalities</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Total number of abnormalities</td>
<td>4</td>
<td>1</td>
<td>14</td>
<td>8</td>
<td>27</td>
</tr>
<tr>
<td>% total number of abnormalities</td>
<td>40.00%</td>
<td>6.25%</td>
<td>45.16%</td>
<td>20.00%</td>
<td>27.84%</td>
</tr>
</tbody>
</table>

source: Cytogenetics Laboratory

Table 5.7 shows the number of cases of Down’s syndrome and neural tube defects detected by screening in 2008/09.

Table 5.7 Number of abnormalities detected by screening*

<table>
<thead>
<tr>
<th>Screening Test</th>
<th>Condition</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Second trimester double marker</td>
<td>Down's Syndrome</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Trisomy 18</td>
<td>1</td>
</tr>
<tr>
<td>Second Trimester APF</td>
<td>NTD</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Gastrochisis</td>
<td>1</td>
</tr>
<tr>
<td>First Trimester CUB Screening</td>
<td>Down's Syndrome</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Trisomy 18</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Trisomy 13</td>
<td>1</td>
</tr>
</tbody>
</table>

Source: West of Scotland Regional Prenatal Screening Service

*Note: The data is incomplete due to timescale (babies to women screened during this time are only just finished being born).
Turnaround time for laboratory results

The turnaround time from a sample to be received in the laboratory to when a report is available is regularly monitored. The time from sample collection until a report is available is also monitored. For 2008/09, the average time taken from sample receipt until a report to be available was 1.2 working days. In 99% of cases a report was available by 3 working days. Results which require follow-up testing are communicated to the requesting centre by fax or phone as soon as possible after the report has been checked and signed by a clinical scientist. Hard copies of all reports are sent out either by mail or by inter-hospital delivery service.

Challenges and future priorities

Women booking in NHS Greater Glasgow and Clyde are offered different screening tests for Down’s syndrome and neural tube defects. From Spring 2010, all women will be offered screening tests for Down’s syndrome and neural tube defects.

Current information systems do not allow the delivery of failsafe purposes across pregnancy screening programmes. An information management system is being developed to allow the delivery of the failsafe processes for all women working in NHS Greater Glasgow and Clyde.
CHAPTER 6: NEWBORN BLOODSPOT SCREENING

SUMMARY

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

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

- In 2008/09 of the 15,509 bloodspot samples received, 85 (0.5%) bloodspot specimens could not be analysed due to insufficient amounts of blood on the bloodspot card. This required repeat bloodspot screening tests to be carried out on babies. 61 (0.4%) samples received had taken more than 7 days to arrive at the laboratory.

- In 2008/09, 14,231 babies of NHS Greater Glasgow and Clyde residents were screened which represents 97.7% of the total eligible population of 14,563.

- There were 3 positive cases of phenylketonuria detected (a decrease of 5 from previous year); 11 babies with congenital hypothyroidism and 13 babies with cystic fibrosis. All received appropriate management within the timescale of the standard.

- The proportion of bloodspot cards with a CHI number sent for analysis increased from 66% in April 2008 to 88% in March 2009 compared to the national average of 43% in March 2008 and 63% in April 2009.
CHAPTER 6: NEWBORN BLOODSPOT SCREENING

Background

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

Newborn Screening for phenylketonuria and congenital hypothyroidism 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 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 which is found in around 1 in 8,000 babies born; congenital hypothyroidism which affects approximately 1 in 3,500; and cystic fibrosis, 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 phenylketonuria cannot metabolise an amino acid called phenylalanine which is a component of protein found in everyday 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. It is then sent to the National Newborn Screening Laboratory in Glasgow for analysis. The blood is analysed for markers of the 3 conditions phenylketonuria, congenital hypothyroidism and cystic fibrosis.

Screening pathway

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 Templeton and the paediatric service as is demonstrated in the following pathway (Figure 6.1) for phenylketonuria and congenital hypothyroidism. There is a separate cystic fibrosis pathway. (Figure 6.2) as double testing is required.

Eligible population

All newborn babies of residents in NHS Greater Glasgow and Clyde.
Figure 6.1 Newborn Screening Process – Phenylketonuria (PKU) & Congenital Hypothyroidism (CHT)

1. Baby Born
2. Information to Parents
3. Consent for Test
   - Yes: Blood spot collected
   - No: Consent for Test
4. Midwifery
5. Blood spot collected
6. Repeat specimen if necessary
7. Phen & TSH
   - Report negative
   - Report raised/repeat required
   - Report high/persistently raised
   - Telephone call to Paediatrician plus Report
8. Treatment if necessary & Follow up
9. Referred to Paediatrician
10. Result notified
11. Notification to GP, Hospital, Child Health
12. Child Health Services
13. Hospital
14. Coverage Monitored
15. Result Recorded
16. Birth Notified
17. Laboratory
18. Report
19. No further action unless clinical symptoms present. Refusal recorded at Laboratory.
Figure 6.2 Newborn Screening Process: Cystic Fibrosis
Delivery of screening programme 2008/09

Uptake of newborn bloodspot screening in NHS Greater Glasgow and Clyde

The number of babies of NHS Greater Glasgow and Clyde residents screened in 2008/09 was 14,231, 97.7% of the total eligible population of 14,563 (see Figure 6.3.)

Figure 6.3  Summary of Bloodspot Screening Uptake & Results for babies born 1 April 2008 to 31 March 2009 in NHS Greater Glasgow and Clyde

Source: SIRS

*1 Total includes 22 verifications; 1 refusal
*2 total includes 18 verifications; 1 result not in Child Health System.
*3 Total includes 6 carriers; 5 late tests; 28 verifications.

PKU = phenylketonuria
CHT = congenital hypothyroidism
Figure 6.3 illustrates uptake rates and the results of the screening programme from 1 April 2008 to 31 March 2009.

Of the 332 (2.3%) not screened, only two refused screening, 192 moved in or out of the area and 35 babies died. There were three positive cases of phenylketonuria detected (a decrease of five from previous year); 11 babies with congenital hypothyroidism and 13 babies with cystic fibrosis. All received appropriate management within the timescale of the standard.

Table 6.1 shows the percentage uptake of bloodspot screening by CH(C)P area and by deprivation category. The total percentage uptake for babies born to residents in the most deprived areas was 97.4% and 98.3% in the least deprived areas.

Table 6.1 Percentage uptake of Bloodspot Screening by CH(C)P and SIMD

<table>
<thead>
<tr>
<th>Period: 1st April 2008 to 31st March 2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>CH(C)P</td>
</tr>
<tr>
<td>--------</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>East Glasgow</td>
</tr>
<tr>
<td>East Dunbartonshire</td>
</tr>
<tr>
<td>East Renfrewshire</td>
</tr>
<tr>
<td>Inverclyde</td>
</tr>
<tr>
<td>North Lanarkshire</td>
</tr>
<tr>
<td>(GGC residents only)</td>
</tr>
<tr>
<td>North Glasgow</td>
</tr>
<tr>
<td>Renfrewshire</td>
</tr>
<tr>
<td>South East Glasgow</td>
</tr>
<tr>
<td>South Lanarkshire</td>
</tr>
<tr>
<td>(GGC residents only)</td>
</tr>
<tr>
<td>South West Glasgow</td>
</tr>
<tr>
<td>West Dunbartonshire</td>
</tr>
<tr>
<td>West Glasgow</td>
</tr>
<tr>
<td>Grand Total</td>
</tr>
</tbody>
</table>

Source: Child Health; Extracted 23 April 2009
SIMD=Scottish Index of Multiple Deprivation 2006

Table 6.2 shows that, in 2008/09 of the 15,509 bloodspot samples received, 85 (0.5%) bloodspot specimens could not be analysed due to insufficient amounts of blood on the bloodspot card. This required repeat bloodspot screening tests to be carried out on babies. 61 (0.4%) samples received had taken more than seven days to arrive at the laboratory.

National standards require that 95% of positive cases of congenital hypothyroidism and phenylketonuria are to start treatment by 14 days of age and of cystic fibrosis by 35 days of age. Therefore, the time from when a test is taken to the time of arrival at the laboratory is important.
### Table 6.2 Specimen test outcomes for Greater Glasgow and Argyll and Clyde for period 1st April 2008 and 31st March 2009

<table>
<thead>
<tr>
<th>Health Board</th>
<th>Argyll &amp; Clyde</th>
<th>Glasgow</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Refused</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Partial Refusal (CF)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Insufficient</td>
<td>21</td>
<td>64</td>
<td>85</td>
</tr>
<tr>
<td>Unsatisfactory</td>
<td>2</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Expired cards</td>
<td>4</td>
<td>19</td>
<td>23</td>
</tr>
<tr>
<td>Updated info</td>
<td>71</td>
<td>110</td>
<td>181</td>
</tr>
<tr>
<td>IRT Tested late (total)</td>
<td>14</td>
<td>25</td>
<td>39</td>
</tr>
<tr>
<td>IRT tested late (born in Scotland)</td>
<td>1</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>&gt;7 days to reach lab</td>
<td>21</td>
<td>40</td>
<td>61</td>
</tr>
<tr>
<td>Ref PKU</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Ref TSH</td>
<td>5</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td>Ref CF</td>
<td>4</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Ref Carrier (CF)</td>
<td>1</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td><strong>TOTAL TESTS</strong></td>
<td><strong>4549</strong></td>
<td><strong>10960</strong></td>
<td><strong>15509</strong></td>
</tr>
</tbody>
</table>

Insufficient as % of total | 0.5 | 0.6 | 0.5
Unsatisfactory as % of total | 0.04 | 0.06 | 0.06
Expired cards as % of total | 0.09 | 0.17 | 0.15
IRT tested late (born in Scotland) as % of total | 0.02 | 0.06 | 0.05
>7 days to reach lab as % of total | 0.5 | 0.4 | 0.4

Source: National Newborn Screening Laboratory

### Notes
- **Refused** = parents refused all tests
- **Insufficient** = insufficient blood to perform all tests
- **Unsatisfactory** = specimen damaged or of poor quality
- **Updated information** = cards that were received with incorrect or missing details. Results are not issued until the relevant information is received
- **IRT Tested Late** = baby was more than 6 weeks of age when specimen was taken. The test for Cystic Fibrosis is not reliable after 6 weeks
- **>7 days to reach the lab** = more than 7 days from specimen collection to receipt at the laboratory

- **Ref PKU** = babies with high or persistently raised levels of phenylalanine that were referred to paediatricians for further investigations. Some of these may not be confirmed as cases of PKU
- **Ref TSH** = babies with high or persistently raised levels of TSH that were referred to paediatricians for further investigations. Some of these may not be confirmed as cases of Congenital Hypothyroidism
- **Ref CF** = babies suspected of having Cystic Fibrosis or babies referred for Sweat testing. Some of these cases may not be confirmed as cases of CF
- **Ref Carrier CF** = babies referred as probable carriers of Cystic Fibrosis
- **Total Tests** = Total number of specimens received
In 2008/09, there was a continued increase in the use of the patient identifier number (called the Community Health Index (CHI)) on bloodspot cards.

**Figure 6.4** compares the number of bloodspot cards with a CHI number received by Greater Glasgow and Argyll and Clyde with the rest of Scotland. It shows that Greater Glasgow and Argyll and Clyde’s CHI compliance was above the national average consistently from April 2008 until March 2009. The number on bloodspot cards with a CHI sent for analysis increased from 66% in April 2008 to 88% in March 2009 compared to the national average of 43% in 2008 and 63% in 2009.

**Figure 6.4 Percentage of bloodspot screening sample cards received with and without a Community Health Index number**

Information systems

Information on Pregnancy and Newborn Bloodspot screening tests is provided by the National Laboratory’s Information Management System and data is reported on the old former NHS Greater Glasgow and NHS Argyll and Clyde basis.

The results of the Bloodspot test are recorded against the individual child’s record held within the Scottish Immunisation and Recall System (SIRS).
Challenges and future priorities

The newborn bloodspot screening programme will see the addition of the haemoglobinopathy and MCCAD screening (see Chapter 8) that will require the development of information materials for parents and training for staff as well as changes to the request cards.

By March 2009, 88% of the bloodspot screening request cards had the Community Health Index recorded. This was a significant increase compared to the previous year’s 65%. Work will continue to support the units to achieve a target of 97% CHI compliance.
Appendix 6.1

Members of Newborn Bloodspot Screening Steering Group
As at March 2009

Dr Emilia Crighton  Consultant in Public Health Medicine (chair)
Mrs Betty Adair  Clinical Lead Midwife
Mrs Donna Athanasopolous  PERL Resources Co-ordinator
Ms Elizabeth Callander  Lead Midwife
Dr Anne Devenny  Consultant Paediatrician
Mrs Dorothy Finlay  Consultant Midwife
Mrs Fiona Gilchrist  Assistant Programme Manager, Screening Dept
Mrs Annie Hair  CHP Children’s Services Lead
Mrs Annette Little  Information Analyst
Miss Denise Lyden  Project Officer
Mrs Joan MacKenzie  Laboratory Newborn Screening Co-ordinator
Ms Katie McEwan  Clinical Service Manager, Neonatology
Ms Marie-Elaine McClair  Lead Midwife PRM (to September 2008)
Mrs Eleanor McColl  Screening Service Delivery Manager
Mrs Julie Mullin  Assistant Programme Manager, Screening Dept
Mrs Diane Paterson  Lead Midwife
Dr Andrew Powls  Consultant Neonatologist
Ms Sara Reynolds  HI&T Project Manager
Ms Liz Terrace  Lead Midwife
Mrs Janice Winter  Clinical Effectiveness Manager
Ms Irene Woods  Lead Midwife
CHAPTER 7: UNIVERSAL NEWBORN HEARING SCREENING

SUMMARY

- The Universal Newborn Hearing Screening (UNHS) Programme was introduced across NHS Greater Glasgow and Clyde in 2005.

- 14,134 babies born in 2008/09 to residents of NHS Greater Glasgow and Clyde. 5,981 (42%) of babies were born to residents in the most deprived areas.

- Of the 14,134 babies born in 2008/09, 13,620 were screened for a hearing loss giving an overall uptake of 96.4%. 204 (1.5%) babies were referred to audiology and, of those, 25 were confirmed with a hearing loss. 3.2% (452) did not attend for screening and these include babies who are deceased or have moved away from their current home address or transferred to another Board area.

- NHS Greater Glasgow and Clyde has established a Universal Newborn Hearing Screening Network to enable staff to share knowledge and experiences.

- An interface between the eSP, the Community Health Index (CHI) and Child Health information systems across Scotland has been developed and the link went live on 2 November 2009. The link removes the need for manual entry of data into eSP which would provide more screening time, tracking of all babies and more importantly a failsafe for notification of births ensuring no babies are missed.

- A local IT project to allow Clyde screeners to transfer screening data electronically into eSP is being piloted by Health visitors in Greenock. It is planned that the pilot will run until Spring 2010 followed by an evaluation. If successful, the project will be implemented across all Clyde sites.
CHAPTER 7: UNIVERSAL NEWBORN HEARING SCREENING

Background

The Universal Newborn Hearing Screening (UNHS) Programme was introduced across NHS Greater Glasgow and Clyde in 2005.

The screening tests are carried out in maternity units for Greater Glasgow residents and in the community for Clyde and Argyll and Bute residents of NHS Highland.

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.

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 first and second screening stages. In the community model OAEs are used for the first screening stage and both OAE and AABR are used for the second stage of screening.

Screening setting

There are two strands to the Greater Glasgow and Clyde screening protocol. In Greater Glasgow, the majority of screening takes place in the maternity unit at the mother’s bedside. In the Clyde, 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 second screen, 6 hour discharges, home births, and 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 the NHS Greater Glasgow and Clyde Universal Newborn Hearing Screening programme, bilateral hearing impairment was identified on average at 17 months. Since the programme’s introduction, the age of identification has been lowered to less than three months allowing appropriate intervention to take place before the critical age of six months.

Screening pathway

In Greater Glasgow, the hearing screen is carried out by dedicated hearing screeners, based in the maternity units, when the baby is one to two days of age. 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 the Royal Hospital for Sick Children (RHSC) for diagnostic testing.

In Clyde, the hearing screen is carried out by health visitors in the baby’s home within six to 12 days of birth. If babies do not obtain clear responses in both ears at this stage they are referred to the UNHS hub in 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.

There is also a pathway for risk factor identification and ongoing surveillance for the Special Care baby Units and Neonatal Intensive Care Units and this is incorporated into the clinical staff training programme.

Delivery of the screening programme 2008/09

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 six months. Babies who are resident from other NHS Board areas but are born in NHS Greater Glasgow and Clyde are also screened by NHSGGC screeners.

Table 7 shows that there were 14,134 babies born in 2008/09 to residents of NHS Greater Glasgow and Clyde. 5,981 (42%) of babies were born to residents in the most deprived areas.
A breakdown of the number of babies born split by CHCP area and by deprivation category is shown in Table 7.

Table 7 Total number and percentage of live babies born to NHS Greater Glasgow and Clyde residents split by CHCP area and by deprivation category from 1 April 2009 to 31 March 2009 2008/09

<table>
<thead>
<tr>
<th>CH(C)P</th>
<th>SIMD</th>
<th>Most deprived</th>
<th></th>
<th></th>
<th></th>
<th>Total</th>
<th>Total%</th>
</tr>
</thead>
<tbody>
<tr>
<td>East Glasgow</td>
<td></td>
<td>1074</td>
<td>179</td>
<td>108</td>
<td>78</td>
<td>32</td>
<td>1471</td>
</tr>
<tr>
<td>East Dunbartonshire</td>
<td></td>
<td>76</td>
<td>164</td>
<td>114</td>
<td>150</td>
<td>474</td>
<td>978</td>
</tr>
<tr>
<td>East Renfrewshire</td>
<td></td>
<td>83</td>
<td>76</td>
<td>96</td>
<td>86</td>
<td>481</td>
<td>822</td>
</tr>
<tr>
<td>Inverclyde</td>
<td></td>
<td>393</td>
<td>120</td>
<td>70</td>
<td>166</td>
<td>78</td>
<td>827</td>
</tr>
<tr>
<td>North Lanarkshire</td>
<td></td>
<td>32</td>
<td>26</td>
<td>69</td>
<td>108</td>
<td>30</td>
<td>265</td>
</tr>
<tr>
<td>North Glasgow</td>
<td></td>
<td>925</td>
<td>74</td>
<td>65</td>
<td>112</td>
<td>93</td>
<td>1269</td>
</tr>
<tr>
<td>Renfrewshire</td>
<td></td>
<td>635</td>
<td>322</td>
<td>362</td>
<td>282</td>
<td>320</td>
<td>1921</td>
</tr>
<tr>
<td>South East Glasgow</td>
<td></td>
<td>523</td>
<td>439</td>
<td>191</td>
<td>236</td>
<td>78</td>
<td>1467</td>
</tr>
<tr>
<td>South Lanarkshire</td>
<td></td>
<td>248</td>
<td>134</td>
<td>94</td>
<td>158</td>
<td>88</td>
<td>722</td>
</tr>
<tr>
<td>South West Glasgow</td>
<td></td>
<td>844</td>
<td>314</td>
<td>158</td>
<td>74</td>
<td>82</td>
<td>1472</td>
</tr>
<tr>
<td>West Dunbartonshire</td>
<td></td>
<td>414</td>
<td>344</td>
<td>161</td>
<td>92</td>
<td>32</td>
<td>1043</td>
</tr>
<tr>
<td>West Glasgow</td>
<td></td>
<td>734</td>
<td>258</td>
<td>200</td>
<td>141</td>
<td>213</td>
<td>1546</td>
</tr>
<tr>
<td>Grand Total</td>
<td></td>
<td>5981</td>
<td>2450</td>
<td>1688</td>
<td>1683</td>
<td>2001</td>
<td>14134</td>
</tr>
<tr>
<td>% of Grand Total</td>
<td></td>
<td>42</td>
<td>17</td>
<td>12</td>
<td>12</td>
<td>14</td>
<td></td>
</tr>
</tbody>
</table>

Source: ESP

NOTE:
1. 331 patients included in total - unable to define CH(C)P or SIMD due to incomplete or incorrect postcode given
2. Only residents of NHS Greater Glasgow and Clyde

Uptake of the screening programme

Of the 14,134 babies born in 2008/09, 13,620 were screened for a hearing loss giving an overall uptake of 96.4%. 204 (1.5%) babies were referred to audiology and, of those, 25 were confirmed with a hearing loss. 3.2% (452) did not attend for screening and these include babies who are deceased or have moved away from their current home address or transferred to another Board area (Figure 7.1).

Figure 7.2 illustrates the activity for the service in Greater Glasgow and Figure 7.3 illustrates the activity for the service delivered in Clyde.
Figure 7.1

Summary of Uptake and results of 1 April 2008 - 31 March 2009: Greater Glasgow & Clyde

Definitions
1st Stage - is first AABR for Glasgow and the first OAE for Clyde
2nd Stage - is the second AABR for 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
Incomplete/Not Completed - all those babies we cannot complete a screen for ie DNA's, deceased, transferred out or moved away etc
Clear Response - is a pass, though some have follow up but majority don’t
Outcomes - as agreed with undefined being better wording for the possible hearing loss and incompletes including DNA, deceased and pendings etc.

Live Births
14134
(100%)

Completed Screening Programme (CSP)
13620
(96.4% of Live Births)

Not Completed Screening Programme (NCSP)
514
(3.6% of Live Births)

1st Stage

Clear Response
12060
(88.5% of CSP)

Required 2nd Stage
1560
(11.5% of CSP)

2nd Stage

Clear Response
1331
(85.3%)
(9.8% of CSP)

DNA
25
(1.6%)
(0.2% of CSP)

Refers to Audiology
204
(13.1%)
(1.5% of CSP)

Bilateral Referrals
52
(25.5%)
(0.4% of CSP)

Unilateral Referrals
152
(74.5%)
(1.1% of CSP)

Bilateral Outcomes
Hearing satisfactory with surveillance - 17
Hearing satisfactory without surveillance - 11
Confirmed Hearing Loss - Bilateral - 11
Confirmed Hearing Loss - Unilateral - 1
Hearing under assessment - 8
Incomplete - 4

Unilateral Outcomes
Hearing satisfactory with surveillance - 24
Hearing satisfactory without surveillance - 90
Confirmed Hearing Loss - Bilateral - 1
Confirmed Hearing Loss - Unilateral - 12
Hearing under assessment - 18
Incomplete - 7

Incomplete
87
(16.9% of NCSP)

DNA
427
(83.1% of NCSP)

Total DNAs = 452
3.2% of Live Births
Summary of Uptake and results of 1 April 2008 - 31 March 2009: Greater Glasgow

Live Births
10546
(100%)

Completed Screening Programme (CSP)
10079
(95.6% of Live Births)

Not Completed Screening Programme
467
(4.4% of Live Births)

1st Stage

Clear Response
9049
(89.8% of CSP)

Required 2nd Stage
1030
(10.2% of CSP)

DNA
402
(86%)
(3.8% of live births)

Incomplete/Not Completed
65
(14%)
(0.6% of live births)

2nd Stage

Clear Response
892
(86.6%)
(8.9% of CSP)

Refers to Audiology
138
(13.4%)
(1.4% of CSP)

Bilateral Referrals
37
(26.8%)
(0.4% of CSP)

Unilateral Referrals
101
(73.2%)
(1% of CSP)

Bilateral Outcomes
- Hearing satisfactory with surveillance - 9
- Hearing satisfactory without surveillance - 11
- Confirmed Hearing Loss - unilateral - 1
- Confirmed Hearing Loss - Bilateral - 7
- Hearing Under assessment - 7
- Incomplete - 2

Unilateral Outcomes
- Hearing satisfactory with surveillance - 13
- Hearing satisfactory without surveillance - 60
- Confirmed Hearing Loss - unilateral - 7
- Confirmed Hearing Loss - Bilateral - 1
- Hearing Under assessment - 15
- Incomplete - 5

Definitions

1st Stage - is first AABR for Glasgow and the first OAE for Clyde

2nd Stage - is the second AABR for 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

Incomplete/Not Completed - all those babies we cannot complete a screen or diagnostic assessment for ie DNA's, deceased, transferred out or moved away etc

Clear Response - is a pass (though some have followed up due to risk factors)

Hearing under assessment - all babies who have referred from the screen and their diagnostic assessment is ongoing
Summary of Uptake and results of 1 April 2008 - 31 March 2009: Clyde

### Definitions
- **1st Stage** - is first AABR for Glasgow and the first OAE for Clyde
- **2nd Stage** - is the second AABR for 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
- **Incomplete** - all all those babies we cannot complete a screen for ie DNA's, deceased, transferred out or moved away etc
- **Clear Response** - is a pass, though some have follow up but majority don’t
- **Outcomes** - as agreed with undefined being better wording for the possible hearing loss and incompletes including DNA, deceased and pendings etc.

### Live Births
- **3588**
- (100%)

### Completed Screening Programme (CSP)
- **3541**
- (98.7% of live births)

#### 1st Stage
- **Clear Response**
  - 3011
  - (85% of CSP)
- **Required 2nd Stage**
  - 530
  - (14.9% of CSP)

#### 2nd Stage
- **Clear Response**
  - 439 (82.8%)
  - (12.4% of CSP)
- **DNA**
  - 25 (53.2%)
  - (0.7% of live births)
- **Incomplete**
  - 22 (46.8%)
  - (0.6% of live births)

### Not Completed Screening Programme
- **47**
- (1.3% of live births)

#### DNA
- **25** (53.2%)
- (0.7% of live births)

#### Incomplete
- **22** (46.8%)
- (0.6% of live births)

### Clear Response
- **3011**
- (85% of CSP)

### Required 2nd Stage
- **530**
- (14.9% of CSP)

### DNA
- **25** (53.2%)
- (0.7% of live births)

### Incomplete
- **22** (46.8%)
- (0.6% of live births)

### Clear Response
- **439 (82.8%)**
- (12.4% of CSP)

### Required 2nd Stage
- **530 (14.9%)**
- (0.7% of live births)

### DNA
- **25 (53.2%)**
- (0.7% of live births)

### Incomplete
- **22 (46.8%)**
- (0.6% of live births)

### Clear Response
- **3011**
- (85% of CSP)

### Required 2nd Stage
- **530**
- (14.9% of CSP)

### DNA
- **25** (53.2%)
- (0.7% of live births)

### Incomplete
- **22** (46.8%)
- (0.6% of live births)

### Bilateral Referrals
- **15** (22.7%)
- (0.4% of CSP)

### Unilateral Referrals
- **51 (77.3%)**
- (1.4% of CSP)

### Bilateral Outcomes
- Hearing satisfactory with surveillance - **8**
- Hearing satisfactory without surveillance - **0**
- Confirmed Hearing Loss - unilateral - **0**
- Confirmed Hearing Loss - bilateral - **4**
- Hearing Under Assessment - **1**
- Incomplete - **2**

### Unilateral Outcomes
- Hearing satisfactory with surveillance - **11**
- Hearing satisfactory without surveillance - **30**
- Confirmed Hearing Loss - unilateral - **5**
- Confirmed Hearing Loss - bilateral - **0**
- Hearing Under Assessment - **3**
- Incomplete - **2**

### Definitions
- **1st Stage** - is first AABR for Glasgow and the first OAE for Clyde
- **2nd Stage** - is the second AABR for 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
- **Incomplete** - all all those babies we cannot complete a screen for ie DNA’s, deceased, transferred out or moved away etc
- **Clear Response** - is a pass, though some have follow up but majority don’t
- **Outcomes** - as agreed with undefined being better wording for the possible hearing loss and incompletes including DNA, deceased and pendings etc.
Performance against NHS QIS Standards


The report data is based on the former NHS Greater Glasgow and NHS Argyll and Clyde Health Board codes denoted as “GLA” and “ACL”. “GLA” only Greater Glasgow residents where as “ACL” include residents from Clyde and Argyll and Bute areas, the latter belonging NHS Highland.

All babies are to be offered a hearing screening within the first four weeks of life, unless born prematurely or ill, and complete the process by ten weeks of age. (*NHS Quality Improvement Scotland Clinical Standards for Pregnancy and Newborn Screening: Standard 5 – Newborn Hearing Screening (p46)*)

Figure 7.4 shows the percentage of babies recorded on eSP that were offered screening. It shows that Argyll and Clyde is slightly below the national standard.

**Figure 7.4** Outcome set (screening offered) as a percentage of all records on eSP from 2007/08 to 2008/09

Figure 7.5 shows that the percentage of babies that completed the hearing screening programme by ten weeks. At the time of the report being written, Argyll and Clyde had met the standard of 97% but as the data had not been entered on eSP the outcome was shown as approximately 80%. The service in Greater Glasgow has met the standard.

**Figure 7.5** Screen outcome set by 10 weeks corrected age as a percentage of records on eSP (well babies and NICU)


**Universal Newborn Hearing Screening Network**

Following a recommendation of the *Audit of Paediatric Audiology and Associate Universal Neonatal Hearing Screening, Medical, Early Intervention and Family Support Services (2007)*, NHS Greater Glasgow and Clyde has established a Universal Newborn Hearing Screening Network to enable staff to share knowledge and experiences.

**Information systems**

The hearing screening programme has a national IT system – eScreener Plus (eSP) Northgate Newborn Hearing Screening 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 to ensure all babies are offered hearing screening.
An interface between the eSP, the Community Health Index (CHI) and Child Health information systems across Scotland has been developed and the link went live on 2 November 2009. The link reduces the need for manual entry of data into eSP which would provide more screening time, tracking of all babies and more important a failsafe for notification of births ensuring no babies are missed.

A local IT project to allow Clyde screeners to transfer screening data electronically into eSP is being piloted by Health visitors in Greenock. It is planned that the pilot will run until Spring 2010 followed by an evaluation. If successful, the project will be implemented across all Clyde sites.

**Challenges and future priorities**

To improve service performance to ensure that all babies are offered a hearing screening test within first four weeks of life, and complete screening within 10 weeks of age.
Appendix 7.1

Universal Newborn Hearing Screening Programme Steering Group
(As at March 2009)

Dr Emilia Crighton  Consultant in Public Health Medicine (Chair)
Mrs Betty Adair  Lead Midwife
Mrs Donna Athanasopolous  PERL Resource Manager
Mrs Angela Bonomy  National Audiology Services Manager
Ms Elizabeth Callander  Lead Midwife
Mrs Patricia Carmichael  Paediatric Audiology Services Manager
Ms Gail Carroll  Assistant Technical Officer
Mrs Fiona Gilchrist  Assistant Programme Manager, Screening Dept
Mrs Annie Hair  CHP Children’s Services Lead
Mrs Leigh Hamilton  Newborn Hearing Screening Manager
Mr James Harrigan  Head of Audiology
Mr Forbes Lauder  Head of Audiology
Mrs Annette Little  Information Analyst
Miss Denise Lyden  Project Officer
Mrs Eleanor McColl  Screening Service Delivery Manager
Dr Juan Mora  Consultant Audiological Physician
Mrs Julie Mullin  Assistant Programme Manager, Screening Dept
Mrs Debbie Murray  Senior Support Officer/Secretary
Dr Andrew Powls  Consultant Neonatologist
Ms Janice Winter  Clinical Effectiveness Manager
Dr Madeline White  Consultant Neonatologist
Ms Heather Young  Family Support
Reporting Structure:
Universal Newborn Hearing Screening Steering Group

Key:
- - - - - - - Network Links
________ Direct Reports

Director of Public Health

Public Health Screening Unit

Universal Newborn Hearing Screening Programme Steering Group
Chair:
Dr Emilia Crighton, CPHM

Child Health Surveillance Programme

Maternity Services Strategy Group
CHAPTER 8: FUTURE DEVELOPMENTS - PREGNANCY AND NEWBORN BLOODSPOT SCREENING PROGRAMMES

SUMMARY

- Since September 2009, all pregnant women are now offered foetal anomaly screening scanning when booking into antenatal care.
- It is planned that from summer 2010, all pregnant women will be offered combined ultrasound and biochemical screening in the first trimester of pregnancy. This involves measuring the biochemical markers in the mother’s blood and is combined with the ultrasound measurement of nuchal translucency in the fetus.
- There are plans to introduce screening for Medium Chain Acyl CoA Dehydrogenase Deficiency (MCADD) in NHS Greater Glasgow and Clyde by summer 2010 as an addition to the current newborn bloodspot screening tests. The final implementation has still to be decided by National Services Division in consultation with NHS Boards.
- MCADD leads to an inability to metabolise sufficient energy from fat during periods of stress such as fasting, inter current illnesses with fever or surgery.
- NHS Greater Glasgow and Clyde plan to implement the Haemoglobinopathies screening programme by summer 2010.
- All pregnant women will be offered screening for sickle cell disease, thalassaemia and other haemoglobinopathies.
- Newborn babies will be screened for sickle cell disorders as part of the newborn bloodspot screening programme.
- An IT application is being developed to support the pregnancy and newborn bloodspot screening programmes. Implementation will be phased across the hospital and community sites from November 2009 to March 2010. It is expected that the IT application will:
  - remove the need for duplicating data entry and reduce data error
  - have inbuilt quality assurance and audit mechanisms
  - have inbuilt failsafe alert mechanisms
  - facilitate automation of letters and reports
  - will link a mother’s antenatal screening history with her baby’s screening record
CHAPTER 8: FUTURE DEVELOPMENTS - PREGNANCY AND NEWBORN BLOODSPOT SCREENING PROGRAMMES

Scottish Government’s CEL 31 (2008) on Changes to Pregnancy and Newborn Pregnancy programmes sets out guidance for Boards to:

- to ensure all pregnant women are offered Down’s syndrome and other congenital anomaly screening.
- extend the newborn bloodspot screening to include screening for Medium Chain Acyl CoA Dehydrogenase Deficiency (MCADD).
- introduce haemoglobinopathy screening during pregnancy and for newborn babies.

The Pregnancy and Newborn Implementation Group was set up to lead the planning and implementation of the changes to the pregnancy and newborn bloodspot screening programmes.

A short life working was also set up to develop a local training programme for staff. An initial training session took place in September 2009 to inform midwives of the changes to the Down’s syndrome and other congenital anomaly screening. Additional training on the changes to the other pregnancy and newborn bloodspot screening programmes will be offered to midwives in 2010.

Down’s syndrome and other congenital anomaly screening

From September 2009, all woman first bookers are now offered foetal anomaly screening scanning in the second trimester.

It is planned that, from summer 2010, all pregnant women will be offered Combined Ultrasound and Biochemical Screening in the first trimester of pregnancy. This involves taking a measurement of biochemical markers in the mother’s blood and is combined with the ultrasound measurement of nuchal translucency in the fetus.

Women who do not present early enough in their pregnancy to take advantage of first trimester screening are offered second trimester serum screening. This will be strengthened by the addition of measurements of 2 additional biochemical markers (quadruple test) which will refine the risk assessment available to them.

By December 2009, the Laboratory will start offering quadruple screening for Down’s syndrome to all women in Glasgow, and to all late bookers after the implementation of CUBS.
Newborn bloodspot screening for Medium Chain Acyl CoA Dehydro-genase Deficiency (MCADD).

It has been proposed that screening for MCADD will be introduced in NHS Greater Glasgow and Clyde by summer 2010. However, the implementation date is still to be confirmed by National Services Division.

What is MCADD?

MCADD is an inherited metabolic disorder which occurs with roughly the same incidence as phenylketonuria, for which newborn babies are already offered screening.

The abnormality leads to an inability to metabolise sufficient energy from fat during periods of stress such as fasting, inter current illnesses with fever or surgery. It is a recognised cause of unexpected death in infancy and of acute encephalopathy in infancy requiring intensive care, which has significant subsequent morbidity and mortality. Although rare, a significant proportion of individuals with MCADD die or have serious longer term outcomes.

Aim of the screening programme

The aim of offering this screening programme is to reduce mortality of newborns by implementing relatively straight forward interventions when cases are detected. Early recognition allows the introduction of appropriate feeding regimes which can be supplemented during periods of stress, as well as early implementation of appropriate management should the child require hospitalisation.
Haemoglobinopathies screening programme

NHS Greater Glasgow and Clyde plan to implement the new screening programme by March 2011.

Background

The haemoglobinopathies are a large group of inherited blood disorders which affect the haemoglobin (oxygen carrying) component of blood. They fall into two main groups:

- the haemoglobin variants (such as sickle cell disorders) which are associated with the production of abnormal forms of haemoglobin, and
- thalassaemia in which there is an abnormality in the amount of haemoglobin produced.

Many haemoglobinopathies are of no clinical significance whereas others are associated with severe morbidity and mortality, most notably sickle cell disorders and beta thalassaemia major. Sickle cell disorders, caused by a variant haemoglobin, often result in severe life threatening clinical symptoms. Those with beta thalassaemia major require regular blood transfusions to maintain life.

Though no haemoglobinopathy is exclusive to any single ethnic group, the frequency of these disorders varies considerably in different ethnic groups. These disorders originated in areas of the world where malaria is, or was, endemic because their occurrence conferred a survival advantage to those living in such areas. Thus, though haemoglobinopathies may be encountered in northern Europe, they are mainly associated with populations whose ancestry originated in Africa, Asia or around the Mediterranean.

A large number of haemoglobin variants are detected using current screening methods.

Those for which there is evidence that early intervention is likely to be beneficial and are therefore specified as part of the national screening programme are the following:
Table 7.1: Sickle cell disorders

<table>
<thead>
<tr>
<th>Disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sickle cell anaemia (Hb SS)</td>
</tr>
<tr>
<td>Hb SC disease</td>
</tr>
<tr>
<td>Hb S/β-thalassaemia*</td>
</tr>
<tr>
<td>Hb S/DPunjab</td>
</tr>
<tr>
<td>Hb S/OArab</td>
</tr>
<tr>
<td>Hb S/HPFH</td>
</tr>
</tbody>
</table>

Notes:
1 *This is inclusive of Hb S/β+, Hb S/β0,Hb S/ β and Hb S/Lepore.
2 It is not possible at birth to differentiate with certainty between sickle cell anaemia (Hb SS), Hb S/β0-thalassaemia and Hb S with Hereditary Persistence of Foetal haemoglobin (Hb S/HPFH), since all of these conditions produce only Hb F and Hb S on analysis. For the purpose of this programme it is essential to detect and report all such cases as ‘sickle cell disease’ without further detail in order to facilitate follow-up and diagnostic testing.
3 Although in general Hb S/HPFH is regarded as a much milder condition than the other sickling disorders, it is policy that for the purposes of this screening programme that Hb S/HPFH should be included as a form of sickle cell disease and follow-up offered.
4 Since there are many Hb ‘D’ variants and characterisation of the variant may take time, it is recommended that all ‘D’ haemoglobins are assumed to be the only clinically significant variant DPunjab(also called DLos Angeles). DNA analysis or mass spectrometry can then be used to elucidate the diagnosis. In addition to the sickle cell disorders, there is another set of conditions which are likely to be detected by the programme and in which the patient can benefit from follow-up.

These are shown in Table 7.2 as other clinically significant haemoglobinopathies. When these conditions are detected, the infants should be referred for clinical follow-up.

Table 7.2: Other clinically significant haemoglobinopathies

<table>
<thead>
<tr>
<th>Disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>ß-thalassaemia major</td>
</tr>
<tr>
<td>ß-thalassaemia intermedia</td>
</tr>
<tr>
<td>Hb H disease</td>
</tr>
<tr>
<td>Hb E/ß-thalassaemia</td>
</tr>
<tr>
<td>Hb SE</td>
</tr>
</tbody>
</table>

Whilst the purpose of this programme is to detect infants with sickle cell disease, the analytical procedures currently utilised will also detect compound heterozygotes for a variety of haemoglobinopathies and carriers for Hb S and the other common haemoglobin variants (C, DPunjab, OArab and E) and in addition some of the rarer variants. Results of infants who are found to be compound heterozygotes or heterozygous for a common haemoglobin variant will be reported and follow-up counselling offered.

Due to the diversity of haemoglobin variants and thalassaemia syndromes, there will always be some situations that require further tests on different specimens or family studies before a conclusive clinical diagnosis can be achieved.
Aim of the screening programme

The aim of offering screening during the antenatal period is to identify couples who are at risk of having an affected child and thereby offer them information on which to base reproductive choices. It is important that screening is offered early so that the results of the screening tests and any prenatal diagnosis are available sufficiently early for couples to be able to make timely informed choices. Screening for sickle cell disorders and thalassaemia should be offered to all women as early as possible in pregnancy, and ideally by 10 weeks.

Neonatal screening is intended to confirm or identify newborns that are affected with sickle cell disorders so that penicillin prophylaxis and comprehensive care is promptly given. This has been shown to reduce morbidity and mortality.

Eligible population

Pregnancy

All pregnant women will be screened for sickle cell disease, thalassaemia and other haemoglobinopathies.

Newborn

Newborn babies will be screened for sickle cell disorders as part of the newborn bloodspot screening programme.

The screening tests

Pregnancy

The pregnant woman and her partner will be asked to complete a family origin questionnaire. The information from the questionnaire will be used to assess the risk of either parent being a carrier for sickle cell and other haemoglobin variants.

Screening will then be offered if either the woman or the baby's father fall into a high risk group.

A blood test is taken to screen the woman for sickle cell, thalassaemia and other haemoglobin variants. Where testing shows that the woman is a carrier, the baby's father is offered a screening test.

Newborn

The community midwife will take blood from a newborn baby’s heel using a blood letting device to screen for Sickle Cell and thalassaemia as part of the
newborn bloodspot screening programme. (See Chapter 6 for information on the current newborn bloodspot screening programme.)

The Family Origin questionnaire completed by the mother during pregnancy will be used to assess the risk status for sickle cell or other haemoglobinopathy variants.

For infants with sickle cell disorders, diagnostic testing should be undertaken before 2 months of age. Where required, testing of parents should be carried out at the same time.

Blood samples for diagnostic testing for sickle cell disease will be sent to a specialist laboratory that has expertise in haemoglobinopathy analysis. Two types of analysis can be used: high performance liquid chromatography or iso-electric focusing.

**Screening pathway**

**Current process**

A mapping exercise of the current service was recently carried out to determine what screening is offered to pregnant women and newborn babies across NHS Greater Glasgow and Clyde. Meaningful data on haemoglobinopathy screening could not be collected as this is not held centrally.

The gestational age at booking appointment is generally between 10 and 16 weeks. Routine bloods are tested for full blood count and mean cell haemoglobin and turnaround for results vary between hospitals from 24 hours to over two weeks.

Routine screening for thalassaemia is not conducted unless the pregnant women and/or her partner originate from a geographic area identified as having a high prevalence for thalassaemia or an alert is generated by the laboratory through blood test results.

The ancestry questionnaire in the hand held record is completed by the midwife in consultation with the pregnancy woman.

Screening for sickle cell disease appears to be contingent on blood results and consultant haematologist review where a recommendation will be made that screening for sickle cell disease be offered.

In some instances the consultant obstetrician will offer screening if the woman and/or her partner are identified from an ethnic group at risk.

All pregnant women are given a leaflet which gives basic general information about haemoglobinopathies and, in some cases, is supplemented by an explanation from midwives.
If screening is positive for thalassaemia or sickle cell disease, a return appointment with the consultant obstetrician is made for the woman and her partner to discuss next steps and possible options.

Neonatal bloodspot screening for sickle cell disease is not routinely conducted.

Future process

The future screening pathways for sickle disease and thalassaemia in pregnant women and newborn babies are illustrated in Figures 8.1 and 8.2.
Fig. 8.1 Antenatal Screening
Fig. 8.2 Neonatal Screening

NEONATAL SCREENING FOR SICKLE CELL & THALASSAEMIA

Suggested Professional Midwife

Midwife

Midwife

Midwife

Health Information Dept.

Info Counselor/Practitioner

Info Counselor/Practitioner

Info Counselor/Practitioner

Info Counselor/Practitioner

Info Counselor/Practitioner

No Action Required

No Action Required

No Action Required

No Action Required

Healthcare Team

Healthcare Team

Healthcare Team

Healthcare Team

Healthcare Team

Neonatal sample taken
Test carried out by BCH

Information leaflet

UNAFFECTED CARRIER

AFFECTED

Results given to parents by Info Team
Results to GP & HV

Pediatric Care
Initiate at BCH
Shared local care

Results to GP & HV

 conheent,

Results to Info Team

Record in red book
Record on blood spot card
Record in mother's notes

Check parental status and prenatal diagnosis results

Information given neonatal test offered

decline

accept

5 days

6 days

8 days

28 days
PREGNANCY AND NEWBORN (BLOODSPOT) SCREENING IT SYSTEM

The pregnancy screening programme will be supported by an information and management system which is currently being developed by our in-house developers. The information system will:

- allow the implementation of a failsafe approach for all screening during pregnancy and the monitoring of the performance against existing standards

- have inbuilt quality assurance and audit mechanisms

- have inbuilt failsafe alert mechanisms

- facilitate automation of letters and reports

- remove the need for duplicating data entry and reduce data error

- will link a mother’s antenatal screening history with her baby’s screening record

There will be a phased roll out of the application starting in November 2009 in Clyde maternity sites and then March in Greater Glasgow hospital and community maternity sites.
CHAPTER 9: DIABETIC RETINOPATHY SCREENING

SUMMARY

- 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 digital photography was implemented in August 2006 in Argyll and Clyde. The service was introduced in Greater Glasgow in 2002 and expanded and redesigned in 2006/07.

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

- As at May 2009 there were 52,695 people with diabetes in NHS Greater Glasgow and Clyde.

- As at May 2009, 37,560 (71.4%) people with diabetes were screened for diabetic retinopathy. At least 9.3% of patients with diabetes who were invited for screening did not take up the offer of screening. This could be an underestimate of the current situation as approximately 20% of screening appointments are reported as "did not attend" by the service. 2525 (4.8%) patients were permanently suspended from the screening programme as they were already attending an ophthalmology clinic.

- In February 2008, a review of the patient pathway was undertaken to assess the effectiveness of the referral to ophthalmology process and the completeness of feedback received following attendance at ophthalmology clinics. Following the review, the service identified control measures that should be put in place that will allow the continuous monitoring of the delivery of the administrative tasks and the provision of feedback from ophthalmology clinics. These include a “return receipt” for ophthalmology referrals and access to the Diabetic Retinopathy Screening information and management system in Ophthalmology clinics.

- Work commenced in late 2008 to develop a single Greater Glasgow and Clyde service and to integrate the diabetes information management systems by April 2009.
CHAPTER 9: 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.

In 2008/09 the NHS Greater Glasgow and Clyde Diabetic Retinopathy Screening was provided by two separate services, one covering the Greater Glasgow area and the other covering the Argyll and Clyde area. The screening service using digital photography was implemented in August 2006 in Argyll and Clyde. The service was introduced in Greater Glasgow in 2002 and expanded and redesigned in 2006/07.

The service level agreement in place with NHS Highland for NHS Greater Glasgow and Clyde to offer the diabetic retinopathy screening programme to residents in Argyll and Bute was terminated on 31 March 2009.

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.

Eligible population

All people with diabetes aged 12 and over who are resident in the NHS Greater Glasgow and Clyde area.

The screening test

In the first instance a digital photograph is taken of the individual’s retina. If the photograph cannot be graded then a further slit lamp examination will be performed.
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. In 2008/09 across Greater Glasgow and Clyde (including Argyll & Bute) there were ten fixed site locations and four mobile screening units which visited 27 locations.

The Glasgow service also provides a slit lamp service from their four hospital sites for those patients who are not suitable for retinal photography.

Foreseen benefits of programme

To identify and treat sight threatening diabetic retinopathy.

Screening Pathway

[Diagram of the screening pathway with steps such as Maintain Diabetes Register, Update Call/recall database, Invite patient, Attend, Image capture, Grading and reporting, Communicate to patient & healthcare professionals, Generate recall date, and Diagnosis and treatment.]
**Delivery of Screening Programme 2008/09**

Table 9.1 shows the number of people with a diagnosis of diabetes by age group and CH(C)P area of residence. There were 52,695 people with diabetes in NHS Greater Glasgow and Clyde as at 6 May 2009. This represents an increase of 9% (4335) from the previous year 2007/08. At present the current prevalence of diabetes for NHSGGC is 4%.

Table 9.1 Eligible population for DRS screening split by CH(C)P and age group

<table>
<thead>
<tr>
<th>CH(C)P</th>
<th>12 - 19</th>
<th>20 - 29</th>
<th>30 - 39</th>
<th>40 - 49</th>
<th>50 - 59</th>
<th>60 - 69</th>
<th>70 - 79</th>
<th>80 - 89</th>
<th>90 - 99</th>
<th>100+</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>East Glasgow</td>
<td>71</td>
<td>149</td>
<td>233</td>
<td>663</td>
<td>1213</td>
<td>1581</td>
<td>1535</td>
<td>567</td>
<td>62</td>
<td>1</td>
<td>6075</td>
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<tr>
<td>North Glasgow</td>
<td>51</td>
<td>103</td>
<td>187</td>
<td>504</td>
<td>854</td>
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<td>1147</td>
<td>417</td>
<td>49</td>
<td></td>
<td>4376</td>
</tr>
<tr>
<td>South East Glasgow</td>
<td>40</td>
<td>122</td>
<td>263</td>
<td>573</td>
<td>1032</td>
<td>1045</td>
<td>918</td>
<td>385</td>
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<td></td>
<td>4409</td>
</tr>
<tr>
<td>South West Glasgow</td>
<td>56</td>
<td>118</td>
<td>239</td>
<td>649</td>
<td>1134</td>
<td>1315</td>
<td>1338</td>
<td>499</td>
<td>43</td>
<td></td>
<td>5391</td>
</tr>
<tr>
<td>West Glasgow</td>
<td>52</td>
<td>181</td>
<td>243</td>
<td>561</td>
<td>964</td>
<td>1225</td>
<td>1200</td>
<td>575</td>
<td>65</td>
<td></td>
<td>5066</td>
</tr>
<tr>
<td>East Dunbartonshire</td>
<td>58</td>
<td>82</td>
<td>141</td>
<td>362</td>
<td>733</td>
<td>1065</td>
<td>1096</td>
<td>496</td>
<td>42</td>
<td>1</td>
<td>4076</td>
</tr>
<tr>
<td>West Dunbartonshire</td>
<td>45</td>
<td>103</td>
<td>169</td>
<td>416</td>
<td>852</td>
<td>1101</td>
<td>994</td>
<td>398</td>
<td>42</td>
<td></td>
<td>4120</td>
</tr>
<tr>
<td>East Renfrewshire</td>
<td>44</td>
<td>66</td>
<td>112</td>
<td>329</td>
<td>612</td>
<td>831</td>
<td>880</td>
<td>404</td>
<td>40</td>
<td></td>
<td>3318</td>
</tr>
<tr>
<td>Renfrewshire</td>
<td>95</td>
<td>152</td>
<td>308</td>
<td>769</td>
<td>1386</td>
<td>1953</td>
<td>1851</td>
<td>730</td>
<td>60</td>
<td>2</td>
<td>7306</td>
</tr>
<tr>
<td>Inverclyde</td>
<td>50</td>
<td>75</td>
<td>135</td>
<td>358</td>
<td>678</td>
<td>945</td>
<td>878</td>
<td>356</td>
<td>40</td>
<td></td>
<td>3515</td>
</tr>
<tr>
<td>North Lanarkshire 1</td>
<td>11</td>
<td>23</td>
<td>31</td>
<td>82</td>
<td>164</td>
<td>225</td>
<td>183</td>
<td>63</td>
<td>3</td>
<td></td>
<td>785</td>
</tr>
<tr>
<td>South Lanarkshire 1</td>
<td>28</td>
<td>57</td>
<td>112</td>
<td>253</td>
<td>482</td>
<td>644</td>
<td>631</td>
<td>214</td>
<td>18</td>
<td></td>
<td>2439</td>
</tr>
<tr>
<td>Unassigned 2.3</td>
<td>15</td>
<td>121</td>
<td>121</td>
<td>196</td>
<td>292</td>
<td>351</td>
<td>342</td>
<td>287</td>
<td>98</td>
<td>5</td>
<td>1819</td>
</tr>
<tr>
<td><strong>NHS GGC Total</strong></td>
<td><strong>616</strong></td>
<td><strong>1343</strong></td>
<td><strong>2294</strong></td>
<td><strong>5715</strong></td>
<td><strong>10396</strong></td>
<td><strong>13345</strong></td>
<td><strong>12993</strong></td>
<td><strong>5391</strong></td>
<td><strong>593</strong></td>
<td><strong>9</strong></td>
<td><strong>52695</strong></td>
</tr>
</tbody>
</table>

Source: Sorian-SCI DC Comparision 6 May 2009

1 NHSGGC residents only

2 Unassigned due to no postcode available

3 Due to postcode not being available some patients may not be GGC Residents
Table 9.2 Total numbers and percentages of total eligible and diabetic populations split by deprivation categories resident in NHS Greater Glasgow and Clyde

<table>
<thead>
<tr>
<th>Deprivation category</th>
<th>Total Diabetic Population</th>
<th>% of Total Diabetic Population</th>
<th>NHS GGC Total Population</th>
<th>% Diabetics of Total Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most deprived 1</td>
<td>21614</td>
<td>41.1</td>
<td>444830</td>
<td>4.9</td>
</tr>
<tr>
<td>2</td>
<td>9735</td>
<td>18.5</td>
<td>206258</td>
<td>4.7</td>
</tr>
<tr>
<td>3</td>
<td>6409</td>
<td>12.2</td>
<td>157846</td>
<td>4.1</td>
</tr>
<tr>
<td>4</td>
<td>5883</td>
<td>11.2</td>
<td>164802</td>
<td>3.6</td>
</tr>
<tr>
<td>Least Deprived 5</td>
<td>7232</td>
<td>13.7</td>
<td>220736</td>
<td>3.3</td>
</tr>
<tr>
<td>Total 3</td>
<td>52624</td>
<td>100</td>
<td>1194472</td>
<td>4.4</td>
</tr>
</tbody>
</table>

1 Sorian-SCI DC Comparision 6 May 2009  
2 Small Area Population Estimates (SAPE) 2008  
3 1751 (3.3%) of Diabetic Population could not be assigned SIMD due to incomplete/missing postcode

Table 9.3 shows the eligible population with diabetes across deprivation categories. 21,614 (41%) of patients with diabetes are resident in the most deprived area compared to 7,233 (13.7%) who live in the least deprived area.
Table 9.3  NHS Greater Glasgow & Clyde eligible population for DRS screening split by deprivation category (SIMD 2006) and age group

<table>
<thead>
<tr>
<th>Agegrp</th>
<th>SIMD 2006</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Not Assigned</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Most Deprived</td>
<td>Least Deprived</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 to 19</td>
<td>212</td>
<td>89</td>
<td>85</td>
<td>89</td>
<td>126</td>
<td>15</td>
<td>616</td>
</tr>
<tr>
<td>20 to 29</td>
<td>500</td>
<td>233</td>
<td>177</td>
<td>153</td>
<td>168</td>
<td>112</td>
<td>1343</td>
</tr>
<tr>
<td>30 to 39</td>
<td>971</td>
<td>432</td>
<td>273</td>
<td>262</td>
<td>235</td>
<td>121</td>
<td>2294</td>
</tr>
<tr>
<td>40 to 49</td>
<td>2489</td>
<td>1071</td>
<td>687</td>
<td>605</td>
<td>667</td>
<td>196</td>
<td>5715</td>
</tr>
<tr>
<td>50 to 59</td>
<td>4329</td>
<td>1813</td>
<td>1268</td>
<td>1281</td>
<td>1413</td>
<td>292</td>
<td>10396</td>
</tr>
<tr>
<td>60 to 69</td>
<td>5493</td>
<td>2455</td>
<td>1633</td>
<td>1509</td>
<td>1905</td>
<td>350</td>
<td>13345</td>
</tr>
<tr>
<td>70 to 79</td>
<td>5403</td>
<td>2491</td>
<td>1579</td>
<td>1361</td>
<td>1817</td>
<td>342</td>
<td>12993</td>
</tr>
<tr>
<td>80 to 89</td>
<td>2041</td>
<td>1046</td>
<td>636</td>
<td>563</td>
<td>818</td>
<td>287</td>
<td>5391</td>
</tr>
<tr>
<td>90 to 99</td>
<td>175</td>
<td>105</td>
<td>70</td>
<td>59</td>
<td>82</td>
<td>35</td>
<td>526</td>
</tr>
<tr>
<td>100+</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>NHS GGC Total Diabetic</td>
<td>21614</td>
<td>9735</td>
<td>6409</td>
<td>5883</td>
<td>7232</td>
<td>1751</td>
<td>52624</td>
</tr>
</tbody>
</table>

Source: Sorian-SCI DC Comparison 6 May 2009
1 Unassigned due to no postcode available
2 Due to postcode not being available some patients may not be GGC Residents

At the time of writing the annual report, difficulties in extracting meaningful data from the information management system supporting the diabetic retinopathy screening service has led us to use a comparison of data between SCI-DC and Soarian taken at May 2009 (see Table 9.4).

Table 9.4  Number of eligible population screened and status of screening for DRS screening programme

<table>
<thead>
<tr>
<th>Status of Patient</th>
<th>Number</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Population</td>
<td>52624</td>
<td></td>
</tr>
<tr>
<td>Patients suspended permanently</td>
<td>2525</td>
<td>4.8%</td>
</tr>
<tr>
<td>Patients suspended temporarily</td>
<td>3939</td>
<td>7.5%</td>
</tr>
<tr>
<td>Did Not Attend (DNA)</td>
<td>4903</td>
<td>9.3%</td>
</tr>
<tr>
<td>Patients already Screened</td>
<td>37560</td>
<td>71.4%</td>
</tr>
<tr>
<td>Patients invited for a screen</td>
<td>3694</td>
<td>7.0%</td>
</tr>
</tbody>
</table>

Source: Sorian-SCI DC Comparison taken on 6 May 2009
As at May 2009, 37,560 (71.4%) patients were screened. 9.3% (4,906) people with diabetes were classified in Soarian as having not attended their appointment. (This could be an underestimate of the current situation as each week between 20% - 30% of invited patients do not attend, although some will attend later after receiving a reminder letter). 2,525 (4.8%) patients were suspended from the screening programme as they are already attending an ophthalmology clinic.

Service review

During early 2009 Greater Glasgow and Clyde Diabetic Retinal Screening services were brought into a single management structure with a single IT system to manage patient screening and onward referrals.

In 2008, a Critical Incident Review made a recommendation to implement the Diabetic Retinopathy Screening information management system in all ophthalmology clinics. Due to national work to upgrade Soarian and SCI DC systems, it has been necessary to delay implementation until Spring 2010.

In November 2008, the Clyde service began screening from a clinic room within Greenock Health Centre rather than having to use one of the mobile screening units.

Work has still to be undertaken to try and reduce the number of people who do not show up for appointments.

Integration of 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. It provides the diabetes population register for the call/recall for DRS and results of the Diabetic Retinopathy Screening which are available to clinical staff involved in the care of patients with diabetes.

Work was completed in June 2009 to integrate the NHS Greater Glasgow and Clyde diabetes information management systems across NHS Greater Glasgow and Clyde. However, technical issues have arisen and workarounds are in place to act as a failsafe to ensure all patients complete the screening episode and are referred appropriately.

Outstanding issues

To reduce the time currently taken to report results to patients and general practitioners in Greater Glasgow.
Challenges and future priorities

- It is anticipated that the number of people with diabetes will continue to increase that would require additional service capacity in the future. At present the current prevalence of diabetes for NHSGGC is 4%.

- Work will be undertaken to try and reduce the number of people who do not show up for appointments.

- The management team is exploring how the service capacity can be increased within the existing budget.
### Appendix 9.1

**Members of Diabetic Retinopathy Screening Steering Group (As at March 2009)**

<table>
<thead>
<tr>
<th>Name</th>
<th>Position/Department</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Emilia Crighton</td>
<td>Consultant in Public Health Medicine (chair)</td>
</tr>
<tr>
<td>Mrs Donna Athanasopolous</td>
<td>PERL Resources Co-ordinator</td>
</tr>
<tr>
<td>Mrs Jean Blackwood</td>
<td>Programme Director, Clyde Condition Management Programme</td>
</tr>
<tr>
<td>Mr Mark Darroch</td>
<td>HIT Joint Services Manager - Screening</td>
</tr>
<tr>
<td>Ms Janette Docherty</td>
<td>Medical Records Manager</td>
</tr>
<tr>
<td>Mrs Fiona Gilchrist</td>
<td>Assistant Programme Manager, Screening Dept</td>
</tr>
<tr>
<td>Mrs Annie Hair</td>
<td>Head of Children's Services</td>
</tr>
<tr>
<td>Ms Marianne Hayward</td>
<td>Co-ordinator for MCN for Diabetes</td>
</tr>
<tr>
<td>Mrs Fiona Heggie</td>
<td>Clinical Nurse Co-ordinator</td>
</tr>
<tr>
<td>Mrs Annette Little</td>
<td>Information Analyst</td>
</tr>
<tr>
<td>Miss Denise Lyden</td>
<td>Project Officer</td>
</tr>
<tr>
<td>Mrs Eleanor McColl</td>
<td>Screening Service Delivery Manager</td>
</tr>
<tr>
<td>Miss Chris McNeill</td>
<td>Head of Assessment and Care Services</td>
</tr>
<tr>
<td>Mr Eddie McVey</td>
<td>Optometric Advisor</td>
</tr>
<tr>
<td>Ms Patricia Morrison</td>
<td>DRS Manager</td>
</tr>
<tr>
<td>Dr Kirsty Proctor</td>
<td>Diabetes MCN Co-ordinator</td>
</tr>
<tr>
<td>Mr Keith Redpath</td>
<td>Director - West Dunbartonshire CHP</td>
</tr>
<tr>
<td>Mrs Elizabeth Rennie</td>
<td>Programme Manager, Screening Dept</td>
</tr>
<tr>
<td>Ms Karen Ross</td>
<td>MCN &amp; CDM Planning Manager</td>
</tr>
<tr>
<td>Mr David Sawers</td>
<td>DRS Service Manager</td>
</tr>
<tr>
<td>Dr William Wykes</td>
<td>Consultant Ophthalmologist</td>
</tr>
</tbody>
</table>
Appendix 9.2

Reporting Structure:
Diabetic Retinopathy Screening Steering Group

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

Diagram:
- Director of Public Health
- Public Health Screening Unit
- Diabetic Retinopathy Screening Programme Steering Group
  Chair: Dr E Crichton, CPHM
- Diabetic Managed Care Network
CHAPTER 10: PRE-SCHOOL VISION SCREENING

SUMMARY

- All children born between 1 March 2004 and 28 February 2005 were offered pre-school vision screening in 2008/09.

- 13,235 children aged between four to five years old were identified using the Community Health Index System as being eligible for pre-school vision screening.

- 10,175 children were screened out of 13,235 eligible children in 2008/09. This gives an uptake rate of 76.9%. The uptake rate varies across the geographical location from 67.2% in East Glasgow to 81.1% in Clyde.

- 604 (4.6%) of eligible children were already attending an eye clinic.

- 63 (0.5%) parents refused consent for their children to be screened.

- 8,534 children were screened in a nursery setting; that represents 83.9% of all screened children and 64.5% of all eligible children.

- Children who could not be screened in the programme at the end of the school year were invited to a hospital Orthoptic Department for screening. This represents 14.2% (1,874) of the total eligible population (13,235). This includes children resident in East Glasgow where staff shortage has had an impact on the delivery of screening in nurseries.

- Following screening, 2,761 (27.1%) children were referred for further assessments. Of these, 301 (10.9%) were referred to a Community Optometrist for further assessment. This represents 2.27% of the total eligible population.

- 7,414 (72.9%) of children screened had a normal result following screening.

- The recruitment of Orthoptists to allow the delivery of screening in nurseries is a challenge and priority for the pre-school vision programme. In 2008, three Assistant Practitioners were appointed to the service to support Orthoptists with administrative duties.
CHAPTER 10 : PRE-SCHOOL VISION SCREENING

Background

Orthoptic, nursery based, Vision Screening is offered to pre school age children resident in NHS Greater Glasgow and Clyde area. UK National Screening Committee Child Health Sub-Group Report on Vision Screening (May 2005) 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 pre-school year, between the ages of four and five years”.

Amblyopia can be caused by either a squint (strabismus) or differences in the focussing power of each eye (refractive error) which results in the brain receiving different images from each eye. In an adult, receiving two images causes double vision, but a child compensates for the difficulty by suppressing one of the images. 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 co-operates 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.
Screening setting

The screening takes place in a child’s nursery setting as experience 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 2004 and 28 February 2005, were downloaded from CHI and matched against the lists received from nurseries.

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 a hospital Orthoptic Department to have their vision screened.

Following screening, a proportion of children required further testing. They were referred to secondary care for further assessment in the ophthalmology department to the shared care paediatric clinic 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 full General Ophthalmic Services (GOS) eye 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

All children resident in the NHS Greater Glasgow and Clyde are offered screening for visual impairment between four and five years of age in the pre-school year.

In 2008/09, 13,235 children aged between four to five years old were identified using the Community Health Index System as being eligible for pre-school vision screening (Table 10.1).

### Table 10.1 Eligible Population for Pre-School Vision by CHCP and deprivation category

<table>
<thead>
<tr>
<th>CHCP</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>East Glasgow</td>
<td>963</td>
<td>128</td>
<td>97</td>
<td>86</td>
<td>29</td>
<td>1303</td>
</tr>
<tr>
<td>East Dunbartonshire</td>
<td>55</td>
<td>141</td>
<td>105</td>
<td>191</td>
<td>547</td>
<td>1039</td>
</tr>
<tr>
<td>East Renfrewshire</td>
<td>84</td>
<td>84</td>
<td>96</td>
<td>135</td>
<td>719</td>
<td>1118</td>
</tr>
<tr>
<td>Inverclyde</td>
<td>382</td>
<td>121</td>
<td>90</td>
<td>142</td>
<td>120</td>
<td>855</td>
</tr>
<tr>
<td>North Lanarkshire¹</td>
<td>29</td>
<td>36</td>
<td>49</td>
<td>128</td>
<td>42</td>
<td>284</td>
</tr>
<tr>
<td>North Glasgow</td>
<td>845</td>
<td>55</td>
<td>51</td>
<td>89</td>
<td>95</td>
<td>1135</td>
</tr>
<tr>
<td>Renfrewshire</td>
<td>548</td>
<td>291</td>
<td>373</td>
<td>288</td>
<td>390</td>
<td>1890</td>
</tr>
<tr>
<td>South East Glasgow</td>
<td>465</td>
<td>297</td>
<td>150</td>
<td>191</td>
<td>77</td>
<td>1180</td>
</tr>
<tr>
<td>South Lanarkshire¹</td>
<td>212</td>
<td>111</td>
<td>55</td>
<td>196</td>
<td>70</td>
<td>644</td>
</tr>
<tr>
<td>South West Glasgow</td>
<td>787</td>
<td>290</td>
<td>186</td>
<td>80</td>
<td>85</td>
<td>1428</td>
</tr>
<tr>
<td>West Dunbartonshire</td>
<td>402</td>
<td>311</td>
<td>154</td>
<td>90</td>
<td>59</td>
<td>1016</td>
</tr>
<tr>
<td>West Glasgow</td>
<td>583</td>
<td>194</td>
<td>150</td>
<td>123</td>
<td>206</td>
<td>1256</td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td><strong>5355</strong></td>
<td><strong>2059</strong></td>
<td><strong>1556</strong></td>
<td><strong>1739</strong></td>
<td><strong>2439</strong></td>
<td><strong>13235</strong></td>
</tr>
</tbody>
</table>

Source: Vision Works - extract taken on 16 October 2009

¹ GG&C residents only

SIMD - Scottish Index for Multiple Deprivation 2006

Note: 87 patients unable to decipher CH(C)P or SIMD due to incomplete/incorrect postcode (inc in total)
Delivery of screening programme 2008/09

Table 10.2 shows the number of children eligible for screening for each geographical area; the number of children who were invited to be screened at a hospital Orthoptic Department; the number of children who moved out of the Board area; the number of children already attending an eye clinic, and the number of refused consent.

Table 10.2 Eligible Population for Pre-School Vision screening

<table>
<thead>
<tr>
<th>Argyll &amp; Bute</th>
<th>North</th>
<th>South</th>
<th>East</th>
<th>West</th>
<th>Clyde</th>
<th>Unknown</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>---</td>
<td>---------</td>
<td>---</td>
<td>---------</td>
<td>---</td>
<td>---------</td>
<td>---</td>
<td>---------</td>
</tr>
<tr>
<td>Total number of eligible children</td>
<td>189</td>
<td>100</td>
<td>2132</td>
<td>100</td>
<td>4170</td>
<td>100</td>
<td>1063</td>
</tr>
<tr>
<td>Number of children invited to be screened at hospital</td>
<td>60</td>
<td>31.7</td>
<td>674</td>
<td>31.6</td>
<td>1182</td>
<td>28.3</td>
<td>535</td>
</tr>
<tr>
<td>Number of children transferred out</td>
<td>10</td>
<td>5.3</td>
<td>40</td>
<td>1.9</td>
<td>105</td>
<td>2.5</td>
<td>21</td>
</tr>
<tr>
<td>Number of children already attending an eye clinic</td>
<td>7</td>
<td>3.7</td>
<td>111</td>
<td>5.2</td>
<td>171</td>
<td>4.1</td>
<td>48</td>
</tr>
<tr>
<td>Consent denied</td>
<td>0</td>
<td>0.0</td>
<td>30</td>
<td>1.4</td>
<td>44</td>
<td>1.1</td>
<td>11</td>
</tr>
</tbody>
</table>

Source: Vision Works - extract taken on 16 October 2009

1 Children aged 4 - 5 years old were identified from a download using the Community Health Index

2 Includes children absent from, or not registered with, a nursery

3 Optician screening

4,082 (30.8%) of the eligible children were invited to be seen by a hospital Orthoptics Department.

604 (4.6%) of eligible children were already attending an eye clinic.

125 (0.9%) parents refused consent for their children to be screened.

Table 10.3 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 a community optometrist for further assessment; and the overall uptake rate.
Table 10.3 Uptake rates for pre-school vision screening

<table>
<thead>
<tr>
<th></th>
<th>Argyll and Bute¹</th>
<th>North</th>
<th>South</th>
<th>East</th>
<th>West</th>
<th>Clyde</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number screened in Nursery</td>
<td>121</td>
<td>1351</td>
<td>2801</td>
<td>486</td>
<td>1469</td>
<td>2306</td>
<td>8534</td>
</tr>
<tr>
<td>Number screened in Hospital¹</td>
<td>24</td>
<td>291</td>
<td>480</td>
<td>228</td>
<td>325</td>
<td>250</td>
<td>1598</td>
</tr>
<tr>
<td>Total Number Screened</td>
<td>145</td>
<td>1642</td>
<td>3281</td>
<td>714</td>
<td>1794</td>
<td>2556</td>
<td>10175</td>
</tr>
<tr>
<td>Did Not Attend Hospital Screening</td>
<td>22</td>
<td>332</td>
<td>578</td>
<td>262</td>
<td>340</td>
<td>340</td>
<td>1874</td>
</tr>
<tr>
<td>Number Eligible²</td>
<td>189</td>
<td>2132</td>
<td>4170</td>
<td>1063</td>
<td>2301</td>
<td>3151</td>
<td>13235</td>
</tr>
<tr>
<td>% Uptake</td>
<td>76.7</td>
<td>77.0</td>
<td>78.7</td>
<td>67.2</td>
<td>78.0</td>
<td>81.1</td>
<td>76.9</td>
</tr>
</tbody>
</table>

Source: Vision Works - extract taken on 16 October 2009

¹ NHS Greater Glasgow and Clyde children attending nursery in Argyll and Bute area
² Includes children absent from, or not registered with, a nursery and also children resident in East Glasgow
³ Children aged 4 - 5 years old were identified from a download using the Community Health Index
⁴ 43 Children were screened in NHS Lanarkshire
⁵ 229 Children were screening in community settings (Opticians)

10,175 children were screened out of 13,235 eligible children in 2008/09. This gives an uptake rate of 76.9%. The uptake rate varies across the geographical location from 67.2% in East Glasgow (due to staff shortage required to deliver the screening programme) to 81.1% in Clyde.

Children who could not be screened in the programme at the end of the school year were invited to a hospital Orthoptic Department for screening. This represents 14.2% (1,874) of the total eligible population (13,235). This includes children resident in East Glasgow where staff shortage has had an impact on the delivery of screening in nurseries.

8,534 children were screened in a nursery setting; that represents 83.9% of all screened children and 64.5% of all eligible children.
Table 10.4 shows the results of screening split by screening settings for which data is available and geographical area.

7,414 (72.9%) of children screened had a normal result following screening.

Following screening, 2,761 (27.1%) children were referred for further assessments. Of these, 301 (10.9%) were referred to an Optometrist for further assessment. This represents 2.27% of the total eligible population.

Table 10.3 Screening Outcomes

<table>
<thead>
<tr>
<th>Normal Result (NAD)</th>
<th>Nursery</th>
<th>%</th>
<th>Hospital</th>
<th>%</th>
<th>Total Normal Result</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursery</td>
<td>93</td>
<td>64.1</td>
<td>951</td>
<td>57.9</td>
<td>2187</td>
<td>66.7</td>
</tr>
<tr>
<td>Hospital</td>
<td>24</td>
<td>16.6</td>
<td>188</td>
<td>11.4</td>
<td>319</td>
<td>9.7</td>
</tr>
<tr>
<td>Total - Normal Result</td>
<td>117</td>
<td>80.7</td>
<td>1139</td>
<td>69.4</td>
<td>2506</td>
<td>76.4</td>
</tr>
</tbody>
</table>

| Referred for Assessment by Nursery | | | | | | |
| Referred for Assessment by Hospital | | | | | | |
| Total - Referred for Assessment | | | | | | |
| Total Number of Children Screened | | | | | | |

Sources: Vision Works - extract taken on 16 October 2009

1 NHS Greater Glasgow and Clyde children attending nursery in Argyll and Bute area
2 43 Children in total were screened in NHS Lanarkshire; 37 had an outcome of NAD; 6 had an outcome of Refer
3 Percentage is of number of children eligible

Note: Percentages are of total number of children screened

Workforce Issues

In 2008, three Assistant Practitioners were appointed to the service to support Orthoptists with administrative duties.

Mop up clinics to screen children by North and South Glasgow Orthoptists were arranged to cope with the backlog of children to be screened in East Glasgow due to the staffing resources. In addition, an Orthoptist from the Southern General service agreed to screen nursery children in East Glasgow every Thursday during term time. As a result, uptake had improved from 34% from previous year to 67.2% in 2008/09 (Table 10.3).
Despite all efforts to recruit to the vacant Orthoptist post in East Glasgow, the post remains unfilled due to a national shortage of Orthoptists. Sessions are being covered by Orthoptists from other parts of the service.

Information systems

The VisualWorks system supports the delivery of the programme in the Greater Glasgow and Clyde. Work is progressing to develop a more robust reporting tool.

Challenges and future priorities

The recruitment of Orthoptists to deliver screening as agreed is a challenge and priority for the pre-school vision screening programme.
### Appendix 10.1

#### Members of Pre-school Vision Screening Steering Group
(As at March 2009)

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Emilia Crighton</td>
<td>Consultant in Public Health Medicine (Chair)</td>
</tr>
<tr>
<td>Mrs Donna Athanasopolous</td>
<td>PERL Resources Co-ordinator</td>
</tr>
<tr>
<td>Mrs Joan Ballantyne</td>
<td>Head Orthoptist</td>
</tr>
<tr>
<td>Mrs Angela Carson</td>
<td>Head of Optometry</td>
</tr>
<tr>
<td>Ms Mary Cunningham</td>
<td>Clinical Service Manager</td>
</tr>
<tr>
<td>Mrs Maggie Darroch</td>
<td>Optometrist</td>
</tr>
<tr>
<td>Ms Irene Forrest</td>
<td>Nursery Lead</td>
</tr>
<tr>
<td>Mrs Fiona Gilchrist</td>
<td>Assistant Programme Manager, Screening Dept</td>
</tr>
<tr>
<td>Ms Susan Groom</td>
<td>General Manager</td>
</tr>
<tr>
<td>Ms Shogufta Haq</td>
<td>Health Promotion Officer</td>
</tr>
<tr>
<td>Mrs Marian Hodgeson</td>
<td>Head of Pre-Five Children Strategy</td>
</tr>
<tr>
<td>Mrs Annette Little</td>
<td>Information Analyst</td>
</tr>
<tr>
<td>Miss Denise Lyden</td>
<td>Project Officer</td>
</tr>
<tr>
<td>Mrs Eleanor McColl</td>
<td>Screening Service Delivery Manager</td>
</tr>
<tr>
<td>Mr Stephen McLeod</td>
<td>General Manager -Specialist Children's Services</td>
</tr>
<tr>
<td>Ms Linda Morris</td>
<td>Senior Health Promotion Officer</td>
</tr>
<tr>
<td>Mrs Debbie Murray</td>
<td>Secretary/Senior Support Officer</td>
</tr>
<tr>
<td>Mrs Elizabeth Rennie</td>
<td>Programme Manager, Screening Dept</td>
</tr>
<tr>
<td>Mrs Diane Russell</td>
<td>Head Orthoptist</td>
</tr>
<tr>
<td>Mrs Elaine Salina</td>
<td>Principal Optometrist</td>
</tr>
</tbody>
</table>
Appendix 10.2

Reporting Structure:
Pre-School Vision Screening Steering Group

Key:
| Direct Reports | Network Links |

Diagram:
- Director of Public Health
- Public Health Screening Unit
- Preschool Vision Screening Steering Group
  - Chair: Dr E Crighton, CPHM
- Pre-school Vision Screening Operational Group
  - Chair: Mrs Elizabeth Rennie, Screening
- Child Health Surveillance Programme
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, Annette Little from Information Services, Stuart Imrie, Cytogenetics Laboratory, Joan Mackenzie, National Newborn Screening Laboratory and Jenny Crossley, Regional Pregnancy Screening Laboratory.

Many thanks go to all the healthcare professionals, support staff and Screening Department 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.