Public Health Screening Programmes

Annual Report

1 APRIL 2007 TO 31 MARCH 2008

Public Health Screening Unit

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Introduction

This annual report presents information about the following screening programmes offered to residents across NHS Greater Glasgow and Clyde for the period 2007/08:

- Cervical 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

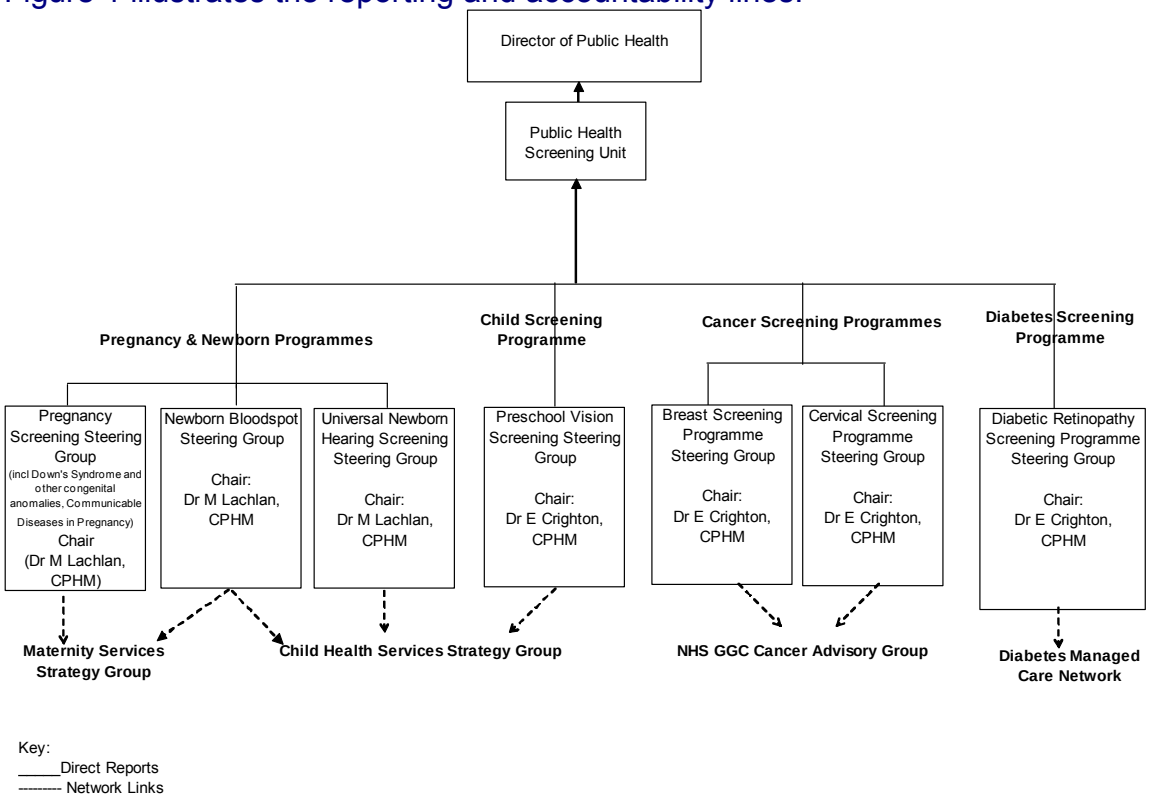
In addition, we have also highlighted plans for:

- bowel screening
- the replacement of the existing Pregnancy Screening Programme offered for Down's syndrome and other congenital anomalies
- 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 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 1 illustrates the reporting and accountability lines.



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

Table 1 Approximate Eligible Target Population

Screening Programme	Approximate Eligible Target Population GGC
Cervical Screening	113,000
Breast Screening	50,000
Communicable Diseases in Pregnancy*	15,500
Down's Syndrome and Neural Tube Defects*	15,500
Newborn Bloodspot Screening*	14,500
Universal Newborn Hearing Screening	10,500
Diabetic Retinopathy Screening	50,000
Pre-School Vision Screening	15,000

*Numbers include non NHS Greater Glasgow and Clyde residents attending NHS Greater Glasgow and Clyde sites. Some population subgroups are eligible for more than one programme.

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.

A series of meetings were held with colleagues from Mental Health Partnerships, local authority and voluntary addictions, substance misuse and alcohol services, Homeless Partnerships, Nursing Homes Practice 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.

SUMMARY

CHAPTER 1: CERVICAL SCREENING

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

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

- There are approximately 362,000 women aged 20 to 60 resident in NHS Greater Glasgow and Clyde in the target population. Following the exclusion of those with no cervix, approximately 344,000 women are eligible to be invited to participate in the programme over three years. Each year approximately 113,000 women are sent an invitation to attend.

- The cervical uptake rate, as defined by NHS Quality Improvement Scotland Standards, has been dropping: between 1999 - 2000 and 2006/07 the 5.5 year cervical screening uptake rate fell from 82.5% to 72.9% in Greater Glasgow, from 87% to 76.2% in Argyll and Clyde, and from 86.7% to 77.9% Scotland wide. Information Statistics Division (ISD) data continues to be reported based on the old NHS Board boundaries as the Community Health Index (CHI) continues to code patients according to those.

- We calculated the uptake rates for NHS Greater Glasgow and Clyde residents: the 5.5 year cervical screening uptake rate has dropped from 77.1% in 2006/07 to 71.9% in 2007/08 when only the no cervix exclusion has been applied. This is a significant drop compared to the estimated uptake rate of 81.5% for year 2001.

- When exception categories allowed under the General Medical Services (GMS) contract were included, the calculated 5.5 year uptake rate was 89.4% in 2006/07 and 82.7% in 2007/08.

- The uptake rates for the purpose of the General Medical Services target payments were between 9 and 12% higher than the Quality Improvement Scotland (QIS) standard uptake rate that allows only the “no cervix” exclusion. The downward trend in the cervical screening uptake has seen a drop following the implementation of the General Medical Services contract.

- On average across Greater Glasgow and Clyde 26% of women aged 20 to 60 have been excluded under one of the General Medical Services exclusions categories: 18.5% of women have been excluded as they defaulted following invitations to participate in screening and 5.11% 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 rate in 2007/08 was among the 20 to 24 year at 54% when only no cervix exclusion was applied. When calculations were made for the purpose of General Medical Services target payments the uptake rate was 68.9%. The highest uptake rate was among women aged 40 to 49, at 77.3% when only no cervix exclusion was applied (and 86.8% for purpose of GMS target payment calculations).

- The cervical screening uptake rate varied across deprivation categories. The lowest 5.5 year uptake rate in 2007/08 was seen among women resident in the most deprived neighbourhoods where the uptake rate was 68.4% while among the least deprived neighbourhoods the uptake rate was 78.3% when only the no cervix exclusion was applied. When calculations were made for the purpose of General Medical Services target payments the uptake among the most deprived neighbourhoods was 80.9% whereas among the least deprived was 86.6%.

- Approximately 94,000 smear tests were processed and reported in laboratories in NHS Glasgow and Clyde in 2007/08. These included repeat smears and smears taken at colposcopy as one woman can have more than one smear test in a year.

- The proportion of results reported as abnormal smears in 2007/08, after excluding the unsatisfactory tests, was 9.3%. Abnormal smear 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 diagnosed in 2007 were reviewed in 2007/08. Sixty seven women were diagnosed with invasive cancer in 2007. (Fifty patients were diagnosed with invasive cervical cancer in 2005 and 49 women were diagnosed with invasive cervical cancer in 2006). The largest number of cervical cancers occurred in women aged between 30 and 49 years.

- 33 of 50 invasive cervical cancers in 2005, 16 of 49 in 2006, and 25 of 67 in 2007 were detected at screening with the rest of the cases presenting to the service with symptoms.

- Only 25 women out of the 50 with invasive cervical cancer in 2005, 22 women of 49 with invasive cervical cancer in 2006 and 34 women of 67 with invasive cervical cancer in 2007 had a complete smear history. Over the three years audited, 26 women out of the 166 that developed cancer had never had a smear.

- There were 19 deaths from cervical cancer over the three years audited; 52 women were under follow up at colposcopy service and 85 were under follow up in the oncology service.

- The Scottish Cervical Call Recall System (SCCRS) was implemented in May 2007. The system provides women with a complete e-health record detailing their whole smear history which professionals involved with the screening programme have access to. Since the system was implemented, the turnaround time for smears reported has reduced. This is due to results being sent electronically to the smear takers and patients sent notification directly from SCCRS.

- As part of the initiatives aimed to improve uptake, we submitted comparative practice based uptake figures to all practices and to the Community Health (Care) Partnerships. In addition we submitted evidence to the Scottish Executive Health Department (now known as Scottish Government Health Directorates) to request changes to the General Medical Services contract to remove "defaulter" as an exclusion category.

- A subgroup of the NHS Greater Glasgow and Clyde Cervical Screening Steering Group has been set up to oversee the promotion of the cervical screening among hard to engage groups. Initiatives are aimed at women with learning difficulties, women in travelling communities, women in long term care and women abusing alcohol. Since the implementation of SCCRS all women attending the Sandyford Initiative have their smear history checked and are offered smears if overdue.

- From September 2008, a human papilloma virus (HPV) immunisation programme will routinely vaccinate girls aged 12 - 13 years of age against cervical cancer. A catch-up programme for girls under the age of 18 years will also be implemented. The cervical screening programme will continue after the HPV vaccine has been introduced. This is because the vaccine does not protect against all HPV types that may cause cervical cancer. The challenge will be to ensure that women understand the need for continuing cervical screening once the vaccination has been implemented.

- The cervical screening uptake has fallen throughout Scotland since 2004. Together with NHS Health Scotland and other NHS Boards we are currently commissioning research to explore women's attitudes leading to low uptake of cervical screening services. The research findings will inform the development of an up to date communication and engagement strategy.

CHAPTER 2: BREAST SCREENING

- This report represents interim data for the breast screening round 2006 – 2009 in NHS Greater Glasgow and Clyde for the period May 2006 to February 2008.
- The number of women eligible for breast screening across the area of Greater Glasgow and Clyde from May 2006 to February 2008 was 134,402.
- 50,000 women (37.2% of eligible women) have been invited for breast screening during May 2006 – February 2008.
- 34,659 women (69.3% of those invited) attended breast screening during the reported period.
- There were 248 women who were diagnosed with breast cancer following screening.
- NHS Greater Glasgow and Clyde will implement two view mammography from 2010.

CHAPTER 3: PLANNING FOR BOWEL SCREENING PROGRAMME

- Colorectal (Bowel) Cancer is the third most common cancer in Scotland. Every year over 3,400 people are diagnosed with the disease.
- 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 will implement the programme in April 2009.
- The programme will invite all men and women between the ages of 50 – 74 years registered with a General Practice. Other eligible individuals who are not registered with a General Practice will also be able to participate. Thereafter, all individuals will be routinely recalled every two years.
- It is estimated that 307,000 NHS Greater Glasgow and Clyde residents would be eligible to be invited to participate in the Bowel Screening programme every two years.
- The service is being redesigned and pathways have been agreed for patients referred to the Board with a positive guaiac Faecal Occult Blood test.
- All patients found to have a positive screening test will be offered either a face to face or telephone pre-assessment for colonoscopy.

- Patients will be offered a colonoscopy appointment date during the pre-assessment consultation.

- There will be an accreditation programme for screening colonoscopists.

- Patients whose colonoscopy could not be completed will have a same day radiological investigation.

- An information management and technology system for bowel screening is to be developed to record information on patients referred for Bowel Screening. The data collected will allow staff to monitor service performance and track patients through the process from point of referral to diagnosis and treatment for colorectal cancer.

- We have identified health improvement leads in Community Health (Care) Partnerships who will be responsible for the development and implementation of local action plans to engage with local communities and promote the uptake of bowel screening.

- A communications strategy to raise public awareness and maximise the uptake of bowel screening programme across NHS Greater Glasgow and Clyde is under development.

- A public launch is planned for March 2009.

CHAPTER 4: COMMUNICABLE DISEASES IN PREGNANCY

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

- Laboratory data indicates that the uptake of screening for communicable diseases in pregnancy is high for all four communicable diseases.

- Sixteen pregnant women were identified as having HIV by the screening programme, only one of whom was previously known to be HIV positive. Seventy-two women were detected as having hepatitis B virus and five women were detected to be positive for syphilis. The majority of these women were not previously known to be infected, therefore the detection of these women and the implications for their health and the health of their babies are immense and illustrates the success of the screening programme. All infected women and their babies were offered appropriate treatment and care.

CHAPTER 5: DOWN'S SYNDROME AND NEURAL TUBE DEFECTS

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

- In the year 2007/08, 15,656 women attended antenatal clinics across NHS Greater Glasgow and Clyde. Of that number, 13,956 women were NHS GGC residents and 1,700 women lived out with the Board area.

- There were three screening pathways in NHS Greater Glasgow and Clyde: first trimester combined ultrasound and biochemical testing for Down's syndrome and second trimester blood testing offered to women booking at the Queen Mother's Maternity Hospital until beginning of October 2007; 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 all other areas in NHS Greater Glasgow and Clyde, including those booking at Queen Mother's Maternity Hospital after October 2007.

- The overall percentage uptake for Down's syndrome and neural tube defect screening for women booking in NHS Greater Glasgow and Clyde was 66.1%. The uptake for Down's syndrome was 65% and uptake of biochemical screening for neural tube defect was 66.1%.

- The estimated overall percentage uptake for neural tube defects was 78.37%.

- Following screening, 8.4% of women were assigned to 'higher chance' groups: 5.9% of women overall were assigned to the 'higher chance' of Down's syndrome group, 0.3% of women assigned to the 'higher chance' of trisomy 18 group and 2.2% of women were assigned to a 'higher chance' of a neural tube defect.

- 496 amniocentesis tests were analysed by Cytogenetics Laboratory in 2007/08. 46 abnormalities were detected (9.3% of samples) and 29 of those (5.85% of total tests) had a diagnosis of trisomy (Down's syndrome/trisomy 18).

- 112 chorionic villus biopies (CVS) were analysed by Cytogentics Laboratory in 2007/08. 31 abnormalities were detected (27.7% of tests) and 18 of those (16.07% of tests) had a diagnosis of trisomy (Down's syndrome/trisomy 18).

- Outcome data for babies born to women screened in this year are not yet complete. To date, it is known that 8 cases of Down's syndrome, 4 cases of trisomy 18 and 13 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 6: 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 2007, 15,146 bloodspot samples were analysed by the National Newborn Screening Laboratory. 95% of samples arriving at the National Laboratory were reported within two working days as required by the clinical standards.

- In 2007/08, 14,194 babies of NHS Greater Glasgow and Clyde residents were screened which represents 97.5% of the total eligible population of 14,565.

- From 1 April 2007 to 31 March 2008, 9 cases of phenylketonuria, 6 cases of congenital hypothyroidism and 14 cases of cystic fibrosis were detected. All received appropriate management within the timescale set.

- In 2007, 81 bloodspot specimens could not be analysed and the tests had to be repeated due to insufficient amounts of blood on the bloodspot card.

- Following a review of the newborn bloodspot process in 2008, changes have been implemented to reduce the number of insufficient bloodspot tests; improve the process for requesting repeat bloodspot tests and the time taken to deliver the specimens to the laboratory, and increase the use of the Community Health Index.

CHAPTER 7: UNIVERSAL NEWBORN HEARING SCREENING

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

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

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

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

- From 1 April 2007 to 31 March 2008 95.8% (13849 babies) completed the screening programme. There were 172 referrals to audiology.

- 35 babies were confirmed to have a hearing loss following screening.

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

- Monitoring and evaluation of the programme confirms that the expected numbers of deaf children are being identified earlier than was possible before newborn screening was introduced. Lowering the age of diagnosis to less than 3 months allows intervention to take place before the critical age of 6 months.

CHAPTER 8: FUTURE DEVELOPMENTS - PREGNANCY AND NEWBORN BLOODSPOT SCREENING PROGRAMMES

- Screening for Medium Chain Acyl CoA Dehydro-genase Deficiency (MCADD) will be introduced in NHS Greater Glasgow and Clyde by March 2011 as an addition to the current newborn bloodspot screening tests.
- 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 March 2011.
- All pregnant women will be screened 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 will be developed to support the pregnancy and newborn bloodspot screening programmes. It is expected that this 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 9: 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.

- There are 48,360 people with diabetes in NHS Greater Glasgow and Clyde.

- As at May 2008, 35,118 (72.6%) people with diabetes were screened for diabetic retinopathy. At least 10.3% 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. 829 (1.7%) 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 to ophthalmology clinics. Following the review, the service has 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 has commenced to develop a single Greater Glasgow and Clyde service and to integrate the diabetes information management systems by April 2009.

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

CHAPTER 10: PRE-SCHOOL VISION SCREENING

- All children born between 1 March 2003 and 28 February 2004 were offered pre-school vision screening in 2007/08.

- 13,124 children aged between four to five years old were identified using the Community Health Index System as being eligible for pre-school vision screening in 2007/08.

- 9,662 children were screened out of 13,124 eligible children in 2007/08. This gave an uptake rate of 73.6%. The uptake rate varied across the geographical location from 34.3% in East Glasgow (due to lack of staff required to deliver the screening programme) to 81.8% in West Glasgow.

- 271 (2.1%) of eligible children were already attending an eye clinic.

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

- 7,574 children were screened in a nursery setting; that represents 78.3% of all screened children and 57.7% of all eligible children.

- Children who could not be screened in the programme at the end of the school year were invited to the hospital Orthoptic Department for screening. That represents 15.9% (2088) of the total eligible population (13,124) and includes children resident in East Glasgow where staff shortage has prevented the delivery of screening in nurseries.

- Following screening, 2,578 (26.7%) children were referred for further assessments. Of these, 371 (3.8%) were referred to an Optometrist for further assessment. This represents 2.83% of the total eligible population.

- 7,084 (73.3%) of children screened had a normal result following screening.

- The recruitment of staff to allow the delivery of screening in nurseries is a challenge and priority for the pre-school vision programme.

CHAPTER 1: CERVICAL SCREENING

Background

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

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

Aim of screening programme

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

Target population

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

Screening test

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

Liquid based cytology (LBC) is a 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.

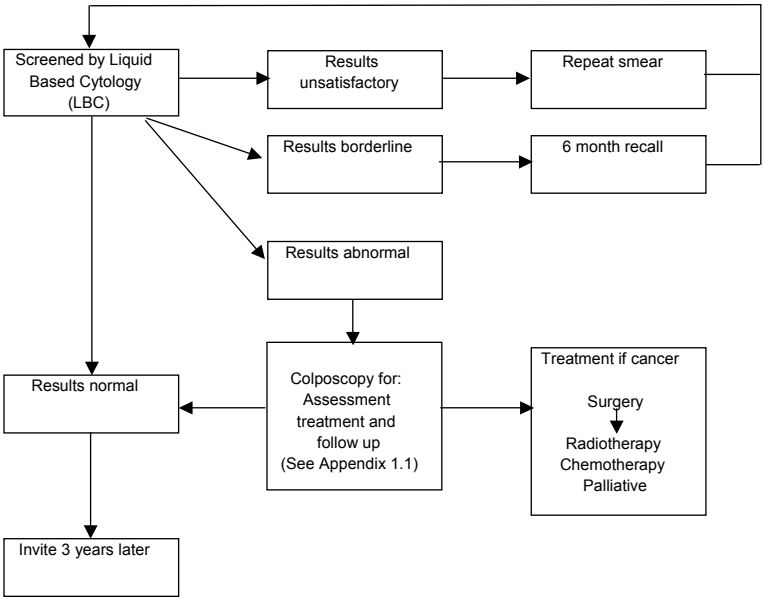
The sample is sent to the laboratory where it is spun and treated to remove obscuring material, for example mucus or pus, and a random sample of the remaining cells is taken. A thin layer of the cells is deposited onto a slide. The slide is examined in the usual way under a microscope by a cytologist.

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 identifies the numbers of women in the target and eligible populations for the cervical screening programme. There are approximately 362,800 women aged 20 to 60 resident in NHS Greater Glasgow and Clyde in the target population. Following the exclusion of those with no cervix, approximately 344,000 women are eligible to be invited to participate in the programme over three years. Each year approximately 113,000 women are sent an invitation to attend.

Table 1.1 NHS Greater Glasgow and Clyde Cervical Screening populations

		Eligible Population[2]	
Year	Target Population[1]	Women with no Cervix[3]	Target GMS Payments[4]
2000/01	360,361	338,068	
2001/02	360,170	337,919	
2002/03	360,069	338,184	
2003/04	360,644	339,460	292,652
2004/05	358,617	338,291	273,106
2005/06	364,919	345,408	272,447
2006/07	359,436	340,446	272,104
2007/08[5]	362,828	344,252	268,484

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

1 Women aged 20 to 60 years
2 Women aged 20 to 60 years except medically exempt women, as defined in 3 and 4
3 No Cervix excludes those women with the exclusion category "no Cervix"
4 Target Payments excludes those women with the exclusion categories as defined in the GP Contract, implemented in 2004
5 Based on GGC Resident Population and not Practice population

Table 1.1 also identifies the number of women that were considered to be eligible for cervical screening after the application of the exclusions allowed by the General Medial Services contract. Over 75,000 women who did not attend cervical screening after three invitations have been excluded from the eligible population under the 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.

The cervical uptake rate has been dropping in Greater Glasgow and Clyde and Scotland. Between 1999-2000 and 2007-2008, the 5.5 years cervical screening uptake rate fell from 87% to 76.2% in Argyll and Clyde, from 82.5 to 72.9% in Greater Glasgow and Clyde and from 86.7 to 77.9% Scotland wide.

Table 1.2 Uptake for Cervical Screening 1st January 1995 to 31st March 2008

Percentage uptake of females aged 20-60[1] who had a record of a previous smear taken within last 5.5 years

NHS Board of Residence	1999-2000	2001-02	2002-03	2003-04	2004-05	2005-06	2006-07	2007-08
Argyll & Clyde	87	85.8	85.2	84.3	83.3	82.2	81.1	76.2
Greater Glasgow	82.5	82.3	82.2	82.1	81.7	80.9	79.5	72.9
Scotland[2]	86.7	86.5	86	85.5	84.6	83.8	82.6	77.9

Source: ISD(D)4 Legacy applications for 1995 to 2006-07 data
Source: ISD(D)4 Scottish Cervical Call Recall System (SCCRS) for 2007-08 Data

1. Based on adjusted Community Health Index (CHI) population denominator (20-59 years, excluding medically ineligible women).

2. Exlcudes Lothian NHS Board (Data unavaliable/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.

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 numbers of and percentage uptake rates for NHS Greater Glasgow and Clyde residents screened by the programme in the last 5.5 years.

The 5.5 year cervical screening uptake rate, when only the no cervix exclusion has been applied, has dropped from 77.1% in 2006/07 to 71.9% in 2007/08. This is a significant drop compared to that of 81.5% in 2001. When exception categories allowed under the General Medical Services contract were included, the calculated 5.5 year uptake rate was 89.4% in 2006/07 and 82.7% in 2007/08.

On average, 26% of women aged 20 to 60 have been excluded under one of the categories: 18.5% of women have been excluded as they defaulted following invitations to participate in screening and 5.11% of women have been excluded as they have no cervix.

Table 1.3 Cervical Screening uptake for NHSGGC residents

	Number of Women Screened[1]		5.5 year[2] Percentage Uptake	
Year	Women with no Cervix[3]	GMS Target payments[4]	Women with no Cervix[3]	GMS Target payments[4]
2000/01	275,361		81.5%	
2001/02	276,239		81.7%	
2002/03	276,666		81.8%	
2003/04	271,419	260,863	80.0%	89.1%
2004/05	268,860	251,457	79.5%	92.1%
2005/06	267,931	246,570	77.6%	90.5%
2006/07	262,604	243,388	77.1%	89.4%
2007/08[5]	247,652	221,975	71.9%	82.7%

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

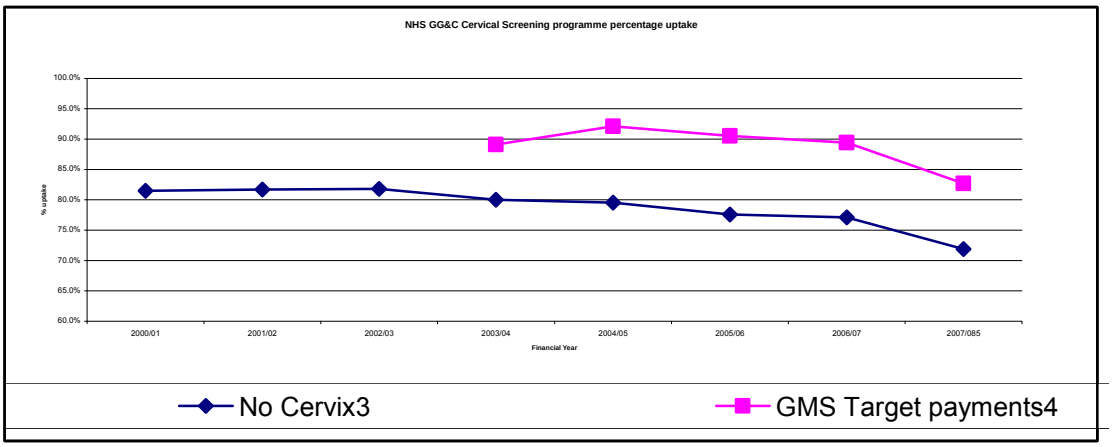
1 Women aged 20 to 60 years with an adequate smear within the last 5.5 years, except medically exempt women, as defined in 3 and 4
2 NHS Greater Glasgow and Clyde aims to identify, invite and encourage women to have a cervical smear at least once every 5.5 years

3 No Cervix excludes those women with the exclusion category "no Cervix"

4 Target Payments excludes those women with the exclusion categories as defined in the GP Contract, implemented in 2004
5 Based on GGC Resident Population and not Practice population

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 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



Source: CHI via Cervical Cytology System

Table 1.4 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 1.4 Cervical Screening Uptake Rates by CH(C)P

	Financial Year							*GMS Contract*
CHP/ CHCP[1]	**2007/08**	**2006/7**	**2005/6**	**2004/5**	**2003/4**	**2002/3**	**2001/2**	***2007/08***
East Glasgow	71.1%	75.0%	78.7%	78.1%	80.3%	80.4%	80.1%	*82.5%*
North Glasgow	68.3%	73.2%	77.0%	76.7%	79.0%	78.6%	78.6%	*80.7%*
South East Glasgow	70.2%	77.1%	79.6%	80.3%	81.0%	81.1%	80.5%	*80.6%*
South West Glasgow	70.3%	76.4%	79.2%	80.4%	82.5%	82.7%	82.3%	*81.1%*
West Glasgow	64.3%	73.1%	74.8%	75.8%	77.8%	76.7%	76.8%	*76.0%*
North Lanarkshire (part)	78.9%	82.7%	83.5%	83.7%	84.3%	83.0%	82.6%	*86.1%*
South Lanarkshire (part)	76.0%	80.1%	82.2%	82.3%	84.3%	84.4%	83.6%	*86.6%*
East Dunbartonshire	78.6%	83.3%	84.8%	85.2%	85.4%	85.6%	85.0%	*87.6%*
East Renfrewshire	77.5%	81.6%	83.8%	84.6%	85.7%	85.8%	85.0%	*85.9%*
Inverclyde	74.6%	77.2%	78.9%	79.7%	81.7%	82.2%	82.1%	*86.2%*
Renfrewshire	73.9%	77.8%	80.0%	80.6%	83.5%	83.8%	83.8%	*83.9%*
West Dunbartonshire	73.5%	78.9%	80.4%	80.6%	73.1%	83.3%	82.7%	*84.6%*
NHS GG&C[2]	**71.9%**	**77.1%**	**79.5%**	**80.0%**	**81.8%**	**81.7%**	**81.5%**	***82.7%***

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

1 2007/08 - 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 1.5 shows that the uptake of cervical screening varied across different age groups. The lowest 5.5 year uptake in 2007/08 was among the 20 to 24 year at 54% when only no cervix exclusion is applied. When calculations were made for the purpose of General Medical Services target payments the uptake was 68.9%.

Table 1.5 Cervical Screening Uptake rate by Age Group across NHS Greater Glasgow and Clyde fo

Age Group	No Cervix[1]					Target GMS Payments[2]				
	Eligible women	3.5 yrs uptake		5.5yrs uptake		Eligible women	3.5 yrs uptake		5.5yrs uptake	
		Total	%	Total	%		Total	%	Total	%
21-24	38824	19753	50.9	20963	54.0	26915	17621	65.5	18541	68.9
25-29	49167	28168	57.3	32857	66.8	36762	25578	69.6	28286	76.9
30-39	89027	57654	64.8	65971	74.1	69688	53428	76.7	58045	83.3
40-49	94759	65158	68.8	73243	77.3	76903	62294	81.0	66728	86.8
50-60	72475	48691	67.2	54618	75.4	58214	47165	81.0	50375	86.5
Total	**344252**	**219424**	**63.7**	**247652**	**71.9**	**268482**	**206086**	**76.8**	**221975**	**82.7**

Source:- Scottish Cervical Call Recall System

1 No Cervix excludes those women with the exclusion category "no Cervix"

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

Table 1.6 shows that the cervical screening uptake rate varied across deprivation categories. The lowest 5.5 year uptake rate in 2007/08 was seen among women resident in the most deprived neighbourhoods where the uptake rate was 68.4% while among the least deprived neighbourhoods the uptake rate was 78.3% when only the no cervix exclusion was applied. When calculations were made for the purpose of General Medical Services target payments the uptake among the most deprived neighbourhoods was 80.9% whereas among the least deprived was 86.6%.

Table 1.6 Cervical Screening Uptake rate by Deprivation Category for NHS Greater Glasgow and Clyde f

		No Cervix[1]					Target GMS Payments[2]				
SIMD[3]		Eligible	3.5 yr uptake		5.5 yrs uptake		Eligible	3.5 yr uptake		5.5 yrs uptake	
Most Deprived	1	128153	75901	59.2	87676	68.4	94916	70108	73.9	76381	80.5
	2	58735	36721	62.5	41548	70.7	45532	34461	75.7	37203	81.7
	3	46348	29932	64.6	33721	72.8	36616	28223	77.1	30398	83.0
	4	48102	32169	66.9	35775	74.4	38742	30513	78.8	32645	84.3
Least Deprived	5	60780	43544	71.6	47581	78.3	51027	41726	81.8	44182	86.6
New/Incomplete postcodes[4]		1926	1127	58.5	1313	68.2	1464	1027	70.2	1132	77.3
Missing postcodes		208	30	14.4	38	18.3	185	28	15.1	34	18.4
	Total	**344252**	**219424**	**63.7**	**247652**	**71.9**	**268482**	**206086**	**76.8**	**221975**	**82.7**

Notes

1 No Cervix excludes those women with the exclusion category "no Cervix"

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

3 - SIMD Quintles 2006

4 - Although incomplete these postcodes clearly fall within Greater Glasgow & Clyde boundaries

Cytopathology Laboratories Workload

Table 1.7 shows the number of tests performed in Cytopathology laboratories in the NHS Greater Glasgow and Clyde area. An essential criterion of the NHSQIS standards requires the laboratories to process a minimum of 15,000 smears annually and this has been achieved throughout the area. Approximately 94,000 smear tests were processed and reported in laboratories in NHS Glasgow and Clyde. These include repeat smears and smears taken at colposcopy as one woman can have more than one smear test.

Table 1.7 Number of smear tests performed in NHS GGC Laboratories

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

*IRH/VOL - includes smears tests 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); 2007/08 - Labs : Telepath & SCCRs

Scotland figures from ISD Website

Table 1.8 shows the proportion of unsatisfactory smears. Following the introduction of Liquid Based Cytology testing in 2003, there has been a marked decrease in the percentage of unsatisfactory smears with only 2.4% of smears required to be repeated due to an unsatisfactory result in 2007/08.

Table 1.8 Percentage of unsatisfactory smears reported in NHS GGC Laboratories

	Percentage of unsatisfactory smears of total number of smears							
Year	IRH*	VOL*	SGH	GRI	STOB	VIC	NHSGGC	Scotland
2000/01	6.0%	7.6%	9.1%	7.2%	7.6%	10.2%	**7.7%**	8.5%
2001/02	5.5%	6.3%	7.3%	10.5%	4.2%	8.5%	**8.1%**	8.8%
2002/03	5.9%	6.8%	5.9%	3.9%	n/a	n/a	**5.2%**	7.4%
2003/04	3.4%	4.6%	6.3%	3.9%	n/a	n/a	**4.4%**	3.9%
2004/05	2.7%	2.6%	2.2%	1.9%	n/a	n/a	**2.3%**	2.2%
2005/06	2.3%	n/a	2.9%	1.6%	n/a	n/a	**2.1%**	2.2%
2006/07	2.5%	n/a	3.0%	2.1%	n/a	n/a	**2.5%**	2.4%
2007/08	1.8%	n/a	2.7%	2.8%	n/a	n/a	**2.4%**	2.8%

*IRH/VOL - includes unsatisfactory smears repored 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); 2007/08 - Labs (SCCRs)

Scotland figures from ISD Website

Table 1.9 shows the proportion of results reported as abnormal smears in each of the cytopathology laboratories in NHSGGC, after excluding the unsatisfactory tests. Abnormal smears results include: borderline, mild, moderate and severe dyskaryosis, severe dyskaryosis/invasive, glandular abnormality and adenocarcinoma. 9.3% of smears were reported as abnormal in 2007/08.

Table 1.9 Percentage of unsatisfactory smears reported in NHS GGC Laboratories

	Percentage of Abnormal smear results of total satisfactory smears							
Year	IRH*	VOL*	SGH	GRI	STOB	VIC	NHSGGC	Scotland
2000/01	7.8%	8.6%	10.2%	11.2%	10.1%	8.5%	**9.4%**	8.0%
2001/02	7.2%	7.4%	7.8%	12.4%	16.5%	8.5%	**9.5%**	8.3%
2002/03	7.0%	8.3%	5.7%	10.0%	n/a	n/a	**8.1%**	7.3%
2003/04	7.6%	10.2%	5.2%	10.3%	n/a	n/a	**8.5%**	7.2%
2004/05	7.8%	7.4%	6.0%	9.8%	n/a	n/a	**8.2%**	7.2%
2005/06	7.6%	n/a	6.7%	10.7%	n/a	n/a	**8.7%**	7.4%
2006/07	8.2%	n/a	7.6%	10.2%	n/a	n/a	**8.9%**	7.6%
2007/08	8.5%	n/a	7.1%	11.1%	n/a	n/a	**9.3%**	7.7%

*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); 2007/08 - Labs (SCCRs)

Scotland figures from ISD Website

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

Table 1.10 shows the age distribution at the age of diagnosis for period 2007/08. The largest number of cervical cancers occur in women aged between 30 and 49 years.

Table 1.10 Number of NHSGGC residents with invasive cervical cancers by age and clinical stage of diagnosis

	Age Group							
Clinical stage of diagnosis	**20-29**	**30-39**	**40-49**	**50-59**	**60-69**	**70-79**	**80+**	**Total**
1a1 (less than 1b (confined to cervix)mm deep and >=7mm wide)	0	7	2	0	0	0	0	**9**
1a1 (less than 3mm deep and >=7mm wide)	4	4	1	0	0	0	0	**9**
1a2 (1b (confined to cervix)-Not known mm deep and <7mm wide)	1	1	0	0	0	0	0	**2**
1a2 (3-5mm deep and <7mm wide)	0	0	1	0	0	0	0	**1**
1b (confined to cervix)	0	11	3	1	3	0	0	**18**
2 or greater (spread outwith cervix)	2	5	13	2	2	2	1	**27**
No Details	0	1	0	0	0	0	0	**1**
Total	**7**	**29**	**20**	**3**	**5**	**2**	**1**	**67**

Source: NHSGGC Invasive Cancer Audit Database

Table 1.11 shows the distribution of diagnosis over a three year period from 2005 to 2007.

Table 1.11 Total number of women with invasive cervical cancers split by diagnosis and year

Clinical stage of diagnosis	**2005**	**2006**	**2007**	**Total**
1a1 (less than 1b (confined to cervix)mm deep and >=7mm wide)	13	15	9	37
1a1 (less than 3mm deep and >=7mm wide)	0	0	9	9
1a2 (1b (confined to cervix)-Not known mm deep and <7mm wide)	0	0	2	2
1a2 (3-5mm deep and <7mm wide)	0	0	1	1
1b (confined to cervix)	12	10	18	40
2 or greater (spread outwith cervix)	23	22	27	72
No Details	2	2	1	5
Total	**50**	**49**	**67**	**166**

Source: NHSGGC Invasive Cancer Audit Database

Table 1.12 shows that 33 of 50 invasive cervical cancers in 2005, 16 of 49 in 2006, and 25 of 67 in 2007 were detected at screening with the rest of the cases presenting to the service with symptoms.

Table 1.12

Modality of Presentation	Year of diagnosis		
	2005	2006	2007
Screen Detected	33	16	25
Symptomatic, last smear date <5 yrs	4	9	14
Symptomatic, last smear date >5 yrs	7	9	19
Symptomatic, No previous smear	6	14	9
No Details	0	1	0
Total	**50**	**49**	**67**

Source: NHSGGC Invasive Cancer Audit database

Some of the screen detected cancers might have had an opportunistic smear while presenting with genital tract complaints. Only 25 women out of the 50 with invasive cervical cancer in 2005, 22 women of 49 in 2006 and 34 women of 67 in 2007 had a complete smear history.

Over the three years audited, 26 women out of the 166 that developed cancer had never had a smear **(see Table 1.13).**

Table 1.13 Smear History of women with invasive cervical cancer

Smear History	Year of diagnosis		
	2005	2006	2007
Complete	25	22	34
Incomplete	20	13	24
No Previous Smear	4	13	9
Not Known	1	1	0
Total	**50**	**49**	**67**

Source: NHSGGC Invasive Cancer Audit database

* Apart from index smear ie the abnormal smear causing referral

Table 1.14 shows the status of the women included in the audit of invasive cancer at the time when the audit was carried out. There were 19 deaths over the three years audited; 52 women were under follow up at colposcopy service and 85 were under follow up in the oncology service. Following the implementation of the Scottish Call Recall Cervical System in May 2007, women that were previously lost to follow up would now be brought back into the call recall.

Table 1.14 Follow up status of the women with invasive cervical cancer

Status	Year diagnosis		
	2005	2006	2007
Lost to Colposcopy service	1	0	1
On Follow-up at Colposcopy	15	18	19
On Follow-up at Oncology/Beatson	23	21	41
Early Recall	1	0	0
Death	8	8	3
Unknown	2	1	1
No Details		1	2
Total	**50**	**49**	**67**

Source: NHSGGC Invasive Cancer Audit database

Information systems

Scottish Cervical Call Recall System (SCCRS)

The Scottish Cervical Call Recall System (SCCRS) was implemented in May 2007. The system 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 sent to the smear takers to view in SCCRS and patients are sent notification directly from Scottish Cervical Call Recall System.

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

As part of the initiative aimed to improve uptake, we submitted comparative practice-based uptake figures to all practices and to the Community Health Care Partnerships. In addition we submitted evidence to the Scottish Executive Health Department (now known as Scottish Government Health Directorates) to request changes to the General Medical Services contract to remove “defaulter” as an exclusion category.

A subgroup of the NHS Greater Glasgow and Clyde Cervical Screening Steering Group has been set up to oversee 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. Since the implementation of Scottish Cervical Call Recall System all women attending the Sandyford Initiative have their smear history checked and are offered smears if overdue.

Challenges and Future Priorities

From September 2008, a human papilloma virus (HPV) immunisation programme will routinely vaccinate girls aged 12 - 13 years of age against cervical cancer. A catch-up programme for girls under the age of 18 years will also be implemented. The cervical screening programme will continue after the HPV vaccine has been introduced. This is because the vaccine does not protect against all HPV types that may cause cervical cancer.

The challenge is to ensure that women understand the need for continuing cervical screening once the vaccination has been implemented. The information materials developed for the vaccination campaign include the message on the need to continue to attend cervical screening.

The cervical screening uptake has fallen Scotland wide since 2004. Together with NHS Health Scotland and other NHS Boards we are currently commissioning research to explore women's attitudes leading to low uptake of cervical screening services; the research findings will inform the development of an up to date communication and engagement strategy.

Appendix 1.1

Management And Follow-Up Advice For Cytology Results

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

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

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

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

Post Total Hysterectomy

No History of CIN/CGIN	No Recall
CIN or CGIN in history	No recall
CIN or CGIN within last 5 years in history - CIN/CGIN in specimen, completely excised	Smear at 12 months. If negative, no further recall.
CIN or CGIN in history - CIN/CGIN in specimen, incompletely excised	Smears at 6, 12 and 24 months. If negative, no further recall

CIN = cervical intraepithelial neoplasia
CGIN = cervical glandular intraepithelial neoplasia

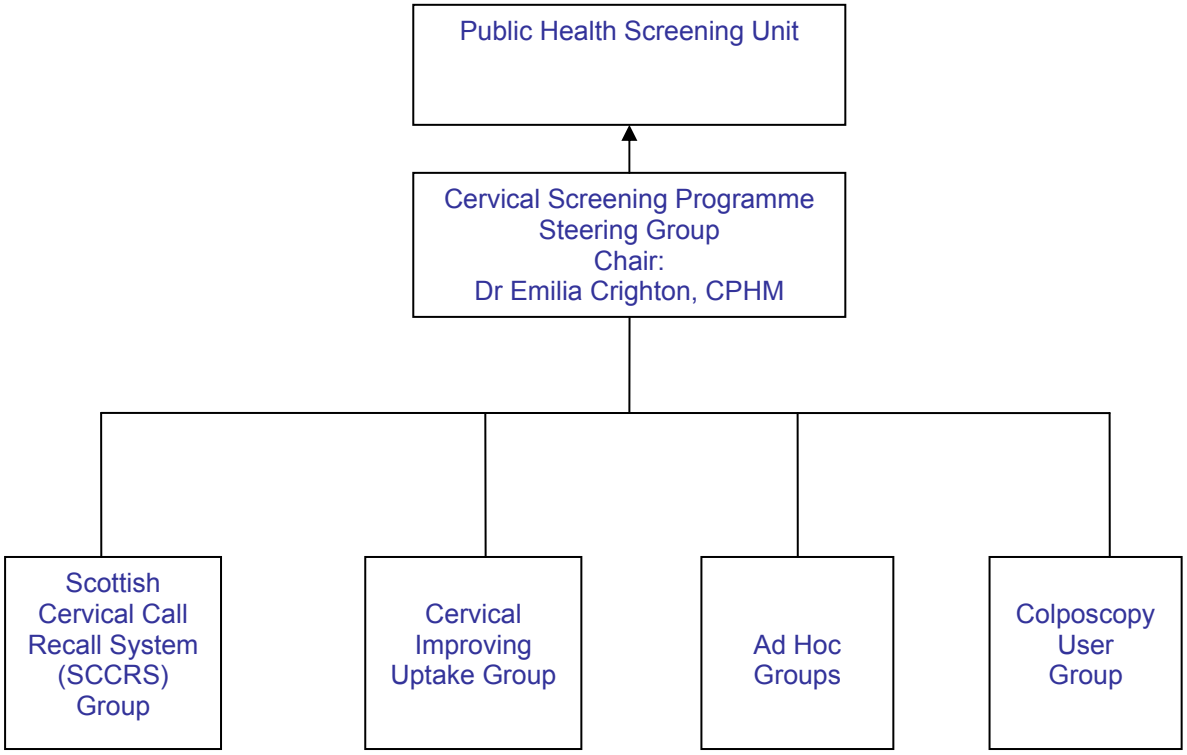
Appendix 1.2

Members of Cervical Screening Steering Group
(As at April 2008)

Dr Emilia Crighton	Consultant in Public Health Medicine (Chair)
Dr Urszula Bankowska	Associate Medical Director, Sandyford
Dr Margaret Burgoyne	Lead Clinician 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
Mrs Fiona Gilchrist	Screening Manager
Dr Mary Hepburn	Consultant Obstetrician/Gynaecologist
Dr James Kennedy	Consultant Gynaecologist – MCN Cancer Network representative
Dr Margaret Laing	Staff Grade
Mrs Annette Little	Information Analyst
Miss Denise Lyden	Project Officer
Ms Cynthia Mendelsohn	Lay Member
Ms Jane McNiven	Practice Manager
Dr Alan Mitchell	Clinical Director Renfrewshire CHP
Mrs Elizabeth Rennie	Screening Manager
Dr Mary Stephen	Consultant Pathologist
Dr Millicent Thomas	Consultant Pathologist
Ms Patricia Weir	Lay member
Dr Barbara West	General Practitioner
Ms Jackie Wright	Practice Nurse
Mrs Donna Athanasopolous	PERL Resources Co-ordinator

Appendix 1.3

Reporting Structure:
Cervical Screening Programme



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.

Target population

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

The screening test

The current screening method used consists of two mammographic views at first screen (called prevalent screen) and one view at subsequent screens (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 birthdays and then three yearly thereafter until her 70th birthday. The West of Scotland Breast Screening Centre also contacts all long-stay institutions to offer screening to eligible residents.

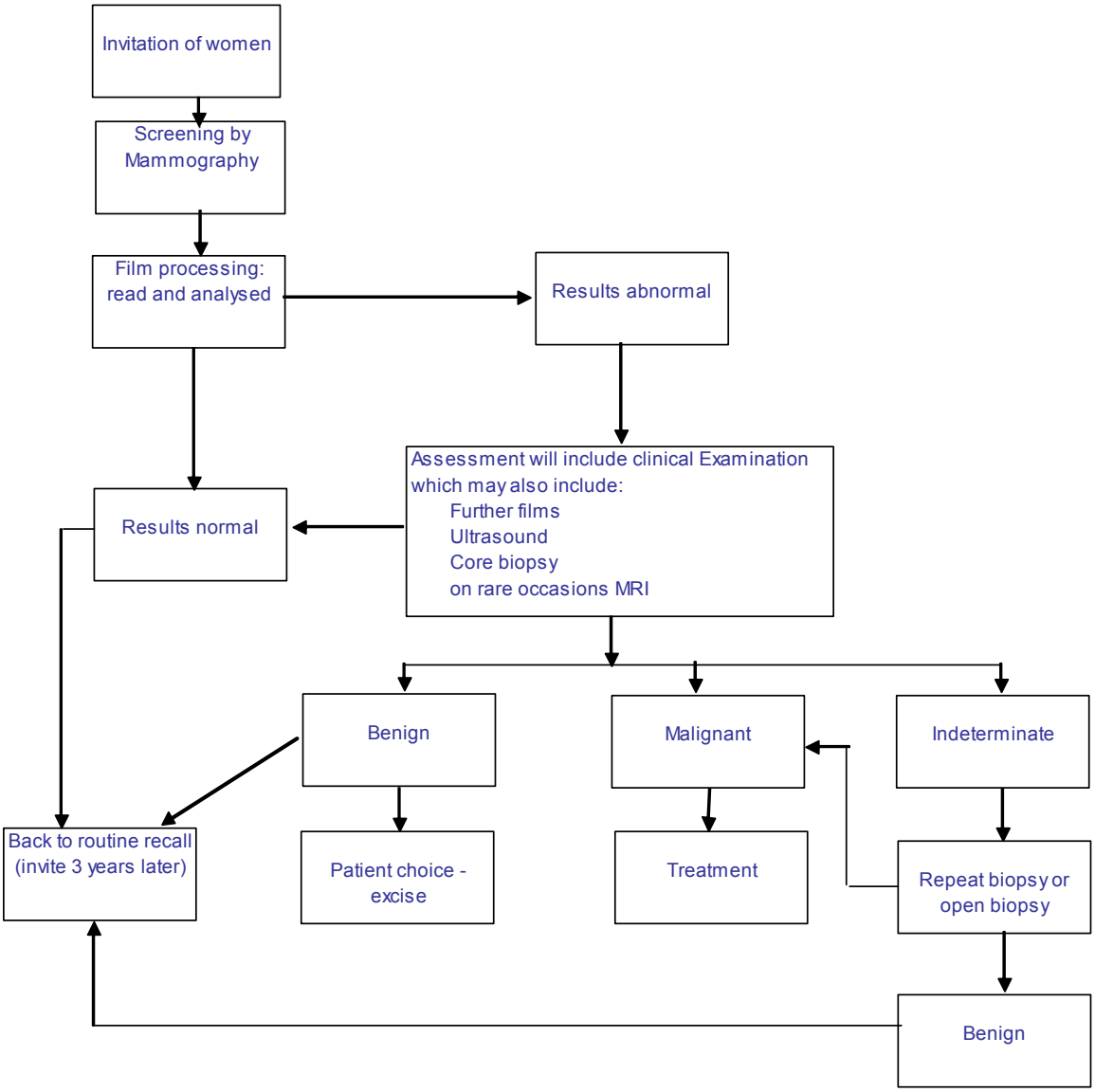
The mammograms taken during the screening visit are examined and the results sent to the woman and her GP. A proportion of women attending for screening will be recalled if the picture was not clear enough or asked to go to an assessment clinic for further tests if a potential abnormality has been detected.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



Uptake of breast screening in NHS Greater Glasgow and Clyde

Eligible population

The number of women eligible for breast screening across the area of Greater Glasgow and Clyde from May 2006 to February 2008 was 134,402 **(Table 2.1).** Eligible women were identified using the Community Health Index (CHI) system.

Table 2.1: Total number of women eligible for breast screening split by age bands and CH(C)P

CH(C)P	50 - 54	55 - 59	60 - 64	65 - 69	50-69
East Glasgow	3907	3582	3043	3079	13611
East Dunbartonshire	3897	3916	3280	2995	14088
East Renfrewshire	3160	3067	2490	2253	10970
Inverclyde	2752	2854	2410	2224	10240
North Glasgow	2818	2643	2251	2410	10122
North Lanarkshire	645	640	519	458	2262
Renfrewshire	5743	5970	4950	4521	21184
South East Glasgow	2963	2615	1983	2037	9598
South Lanarkshire	2077	1893	1517	1451	6938
South West Glasgow	3711	3059	2712	2679	12161
West Glasgow	3636	3124	2701	2603	12064
West Dunbartonshire	3217	3093	2577	2277	11164
Glasgow City	17035	15023	12690	12808	57556
NHSGGC Total	**38526**	**36456**	**30433**	**28987**	**134402**

Source: NHS GGC CHCP SAPE 01-06 by 5 yr age groups

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 February 2008. 50,001 (37.2%) women living in NHS Greater Glasgow and Clyde area were invited to attend breast screening.

34,659 women (69.3% of those invited) attended breast screening during the reported period. There were 248 women who were diagnosed with breast cancer following screening.

Table 2.2 : Interim progress report of breast screening from May 2006 to February 2008

	Female Population (Aged: 50-69)[1]	% Population of those invited	% Population of those attended	Number Invited[2]	Number Attended[2]	Number Cancers detected[2]	% Attend of those invited	% of Cancers of those attend	% of Cancers of those invited
East Dunbartonshire	14088	36.1	29.1	5080	4101	21	80.7	0.5	0.4
East Renfrewshire	10970	6.3	4.5	690	491	3	71.2	0.6	0.4
Glasgow East	13611	32.0	20.1	4356	2734	18	62.8	0.7	0.4
Glasgow North	10122	72.7	45.9	7362	4649	35	63.1	0.8	0.5
Glasgow South East	9598	86.5	61.2	8299	5872	54	70.8	0.9	0.7
Glasgow South West	12161	9.3	6.6	1127	797	6	70.7	0.8	0.5
Glasgow West	12064	25.3	16.2	3049	1950	16	64.0	0.8	0.5
North Lanarkshire[3]	2262	73.6	56.0	1665	1266	10	76.0	0.8	0.6
South Lanarkshire[3]	6938	13.2	9.5	919	662	6	72.0	0.9	0.7
Inverclyde[4]	10240	110.3	76.0	11296	7785	48	68.9	0.6	0.4
Renfrewshire[5]	21184	0.0	0.0	0	0	0	0.0	0.0	0.0
West Dunbartonshire	11164	55.2	39.0	6158	4352	31	70.7	0.7	0.5
GGC Total	**134402**	**37.2**	**25.8**	**50001**	**34659**	**248**	**69.3**	**0.7**	**0.5**
Argyll & Bute Total	12886	100	76.1	12881	9809	84	76.2	0.9	0.7
Total Screening	**147288**	**42.7**	**30.2**	**62882**	**44468**	**332**	**70.7**	**0.7**	**0.5**

Progress Details:

Greater Glasgow: Just over 1 year's worth of data. Rounds started - Mobile: Dec 06-Nov 07; Static: Nov 06 to Feb 08

Argyll & Bute, Inverclyde, Renfrewshire, West Dunbartonshire (formerly Argyll & Clyde):Just over 1 1/2 year's worth of data.

Round started May 06 and data collected up to Dec 07. No-one in Clyde screened as yet

Sources:

[1] NHS GG&C Populations CHCP SAPE 01-06 by 5 yr age groups with the exception of Argyll & Bute which is Population 2006 MYE - GRO

[2] West of Scoltand Breast Screening Service data

[3] NHS Greater Glasgow and Clyde residents

[4] Populations are based on resident populations. The number of invites,attends and Cancers are based on Practice population.

Some GGC residents living in Inverclyde attend a non GGC practice but have been included in the CHCP data.

[5]Renfrewshire screening round had not started by February 2008

Future developments

In Scotland women are offered two view mammography at their first screen and a single oblique view mammogram in subsequent screens. England and Wales have implemented two view mammography at every screen in 2003 and a business case to implement two view mammography in Scotland has been approved. Additional staff will be recruited and trained and equipment will be procured to allow for the increase in activity to be implemented in NHS Greater Glasgow and Clyde from 2010.

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 is underway to assess the requirements for the implementation of digital mammography in the near future.

Challenges and future priorities

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

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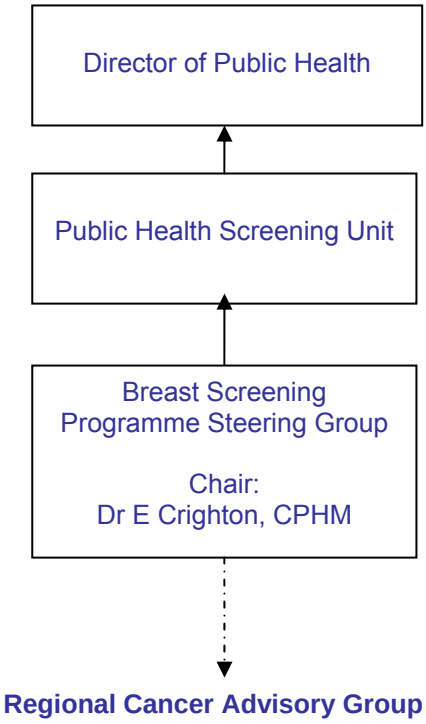
Appendix 2.1

Members of Breast Screening Steering Group (As at March 2008)

Dr Emilia Crighton	Consultant in Public Health Medicine (Chair)
Ms Anna Baxendale	Health Improvement & Equalities Manager
Ms Brenda Bellando	Business Manager
Prof Tim Cooke	Associate Medical Director
Dr Hilary Dobson	Clinical Director
Prof David George	Consultant Breast Surgeon
Mrs Fiona Gilchrist	Screening Manager
Dr Susan Langridge	General Practitioner
Mrs Annette Little	Information Analyst
Miss Denise Lyden	Project Officer
Ms Janet Mair	Regional Registration Manager
Ms Cynthia Mendelsohn	Lay Member
Dr Alan Mitchell	Clinical Director
Ms Ann Mumby	Superintendent Radiographer
Ms Elaine Murray	Community Liaison Officer
Mrs Elizabeth Rennie	Screening Manager
Dr Eilidh Renwick	General Practitioner
Ms Patricia Weir	Lay Member
Mr Nic Zappia	Head of Primary Care Support

Appendix 2.2

Reporting Structure:
Breast Screening Steering Group



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

CHAPTER 3: PLANNING FOR BOWEL SCREENING PROGRAMME

Background

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

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 will implement 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.

Eligible population

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

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

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

The screening test

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

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

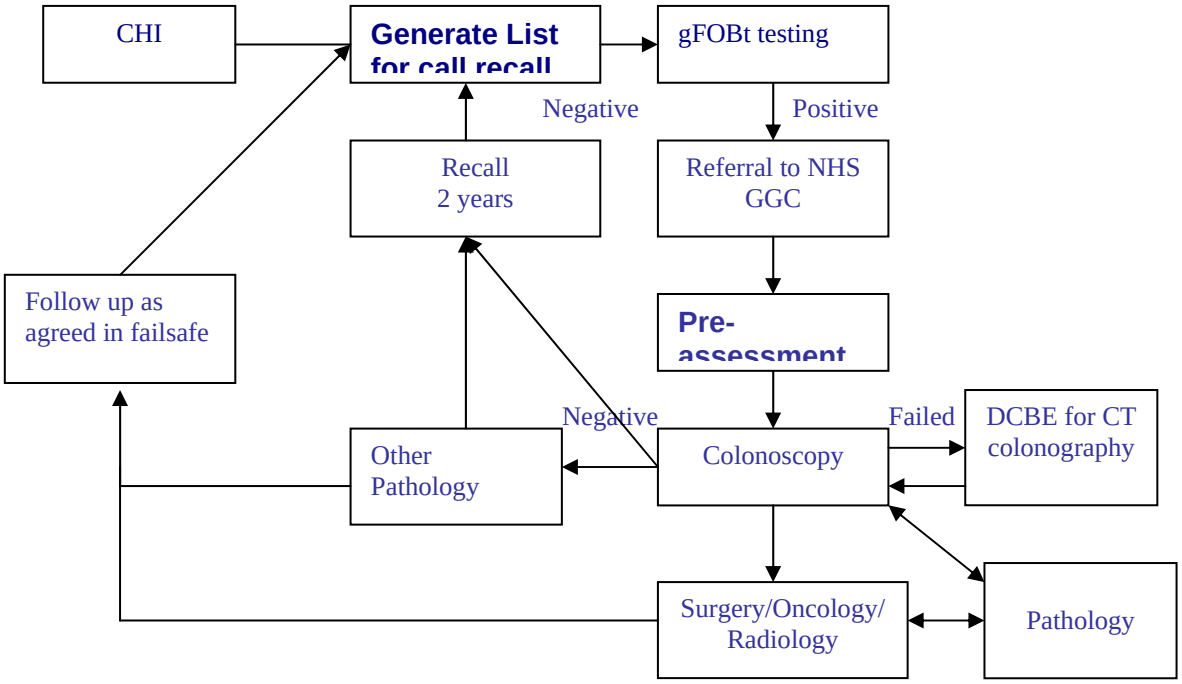
Screening setting

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

Screening pathway

Patients with positive screening results will receive diagnostic investigations and treatment that will be integrated within the existing NHS Greater Glasgow and Clyde colorectal service. **Figure 3.1** below gives an overview of the bowel screening pathway.

Figure 3.1 Overview of bowel screening pathway



If the overall result is positive the individual will be referred for assessment and offered a colonoscopy, if appropriate. Robust plans for referral and failsafe procedures have been agreed within NHS Greater Glasgow and Clyde.

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

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

The projected workload and outcomes for NHS Greater Glasgow and Clyde can be found in **Appendix 3.1.**

Implementation Plans

NHS Greater Glasgow and Clyde Bowel Screening Steering Group and implementation sub groups have been set up to co-ordinate the planning and implementation of the bowel screening programme. Plans are in place and on target to implement the programme by April 2009. Plans include:

1. the redesign of service and development of patient pathways for patients referred to the Board with a positive gFOBt screening test.

2. recruitment of pre-assessment nurses and administrative staff for the programme. All patients will be offered either a telephone or face to face pre-assessment. Pre-assessment staff will be able to offer patients a colonoscopy appointment over the telephone using the electronic outpatient scheduling system.

3. setting up an accreditation programme for screening colonoscopists. The accreditation will involve:

    - an audit of individual's recent practice, number of colonoscopies and rates of completions
    - a multiple choice exam and
    - direct observation of the colonoscopist undertaking two procedures by an independent assessor.

4. developing an information management and technology system for bowel screening to record information on patients referred for bowel screening. The data collected will allow staff to monitor service performance and track patients through the process from point of referral to diagnosis and treatment for colorectal cancer.

The system will be integrated with pathology, cancer MDT, SCI Gateway, SCI Store (for demographic details), and Clinical Portal. It will also be capable of producing local reports, alerts and letters with results and reports on progress against quality assurance standards and NHS Quality Improvement Scotland Standards.

5. We have identified health improvement leads in CH(C)Ps who will be responsible for the development and implementation of local actions plans to engage with local communities and promote the uptake of bowel screening.

6. A communications strategy to raise public awareness and maximise the uptake of bowel screening programme across NHS Greater Glasgow and Clyde is under development.

7. A public launch is planned for March 2009.

APPENDIX 3.1

Bowel Screening Programme: Projected Workload and Outcomes for NHS Greater Glasgow and Clyde

Projected Workload for Greater Glasgow and Clyde* in the Year 2006 based on 50% Uptake to FOB test in Males and 52% Uptake to FOB test in Females every 2 years

	Definition of process/outcome		Numbers of Males	Numbers of Females	Total Numbers Over 2 years	Total Numbers per annum
	Invited to participate		143,634	163,207	306,841	153,421
	Agreed to participate		72837	85809	158,645	79,323
	Completed FOB testing		71817	84868	156,685	78,343
Results of completed FOBts	Overall Negative FOB test		69784	83646	153,429	76,7145
	Overall Positive FOB test		2033	1222	3,255	1,628
Further investigation	Colonoscopy undertaken		1736	1047	2,782	1,391
	Incomplete colonoscopy		152	156	308	154
	Complete colonoscopy		1580	889	2,470	1,235
	Unknown if complete/incomplete		4	1	5	3
	DCBE undertaken		105	121	227	114
	Complete Investigation		1681	1008	2,689	1,345
	Incomplete Investigation		353	214	567	284

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	Definition of process/outcome		Numbers of Males	Numbers of Females	Total Numbers Over 2 years	Total Numbers per annum
Most severe	Invasive Cancer (including malignant adenomas)		185	89	274	137
	Polyp Cancer		41	19	59	30
	Other Pathology		424	286	710	355
	Normal Colon		340	339	679	190
	Adenoma (high, intermediate and low risk)		723	295	1,018	509
	No Further investigation conducted	i.e. refused further treatment, unfit, DNA, cancelled, gone private, deceased , interrupted investigation	309	185	494	247
	Unknown (includes non-diagnostic results)		11	9	21	11
Further Treatment	Surgery		187	88	275	138
	Oncological Referral	referred to oncology	103	48	152	76
	Oncological Treatment	i.e. chemotherapy/ radiotherapy	63	25	88	44
Adenoma Risk Classification$\Sigma\Sigma$	High risk adenoma		102	19	121	61
	intermediate risk adenoma		333	152	485	243
	low risk adenoma		250	118	368	184
	Unclassifiable risk adenomas		37	7	44	22

NOTE:

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

2. Population information is taken from the GRO Mid-Year health board estimates for 2000-2004 and the GRO health board population projections for 2005-2015

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

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

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

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

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

ΣΣ BSG Guidelines were used to assign risk categories to adenomas detected through the screening programme

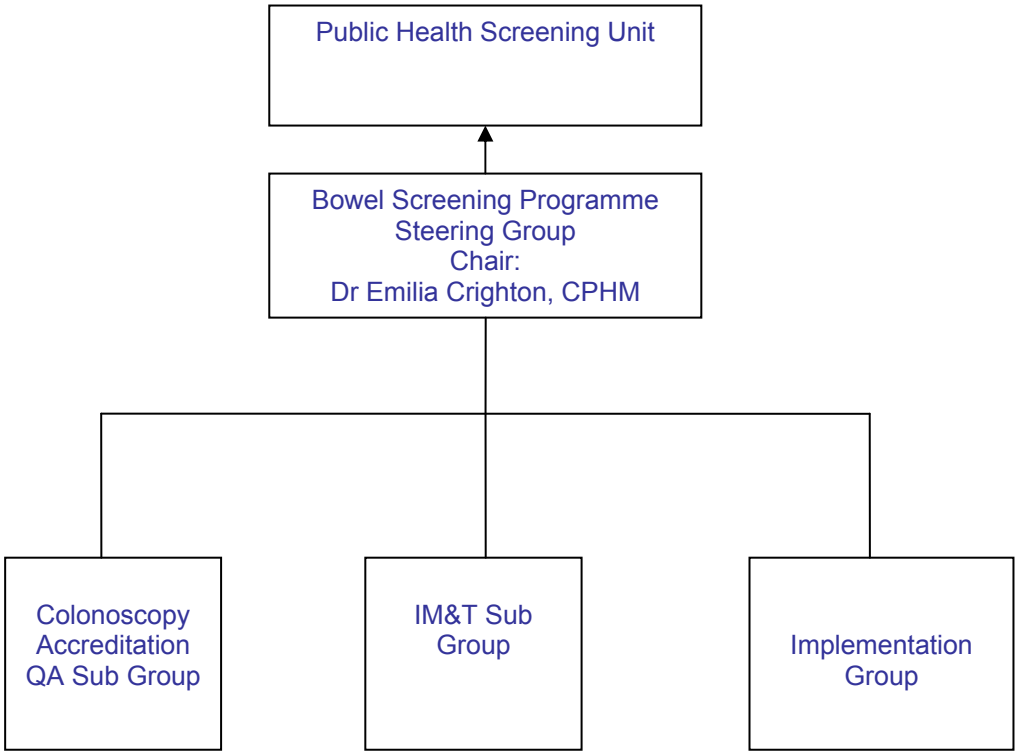
Appendix 3.2

Members of Bowel Screening Steering Group (As at March 2008)

Dr Emilia Crighton	Consultant in Public Health Medicine, Chair
Mr John Anderson	Consultant Surgeon
Mrs Donna Athanasopolous	PERL Resources Co-ordinator
Ms Jacqueline Carrigan	Clinical Directorate Finance Manager
Mr Andrew Daly	Head of Financial Planning and Allocations
Mr Patrick Finn	Consultant Colorectal and General Surgeon
Mrs Elizabeth Rennie	Screening Manager
Mrs Fiona Gilchrist	Screening Manager
Dr Derek Gillen	Lead Clinician for Endoscopy
Mr Alan Hunter	General Manager
Ms Heather Jarvie	Senior Health Promotion Officer
Mrs Maureen Kirkland	Lay Member
Mrs Annette Little	Information Analyst
Miss Denise Lyden	Project Officer
Ms Michelle McDermott	Programme Manager - Endoscopy
Ms Joyce McFadyen	Health Records Manager
Ms Cath McFarlane	General Manager
Ms Mary McGinley	General Manager (until 31 March 08)
Mrs Tricia McKenna	Colorectal Nurse
Dr John Morris	Consultant Gastroenterologist
Dr Kenneth O'Neill	Clinical Director, South West CHP
Mr Ian Pickford	Consultant Surgeon
Mrs Rebecca Reid	Clinical Service Manager
Dr Robin Reid	Associate Medical Director, Laboratories & Diagnostics
Dr Maureen Smith	General Practitioner
Mrs Claire Stewart	Clinical Service Manager

Appendix 3.3

Reporting Structure:
Bowel Screening Programme



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. (See Appendices 4.1 to 4.5)

- 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 Quality Improvement Scotland Standard 3a1.

Delivery of screening programme 2007/08

15,656 pregnant women had a first booking visit at a Greater Glasgow and Clyde hospital during 2007/08. 12,141 took place at Greater Glasgow maternity units and 3,515 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 (16,023) is greater than the total number of booking visits (15,656). In addition in Greater Glasgow, the syphilis serology is sent to, tested at and reported from three local bacteriology laboratories and data transfer for reporting purposes is incomplete.

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

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

Table 4.1 Greater Glasgow laboratories

Samples 2007/08					Results					
	Total number of samples	Number requesting individual test	Number not requesting individual test	% uptake	Antibody detected		Antibody not detected		Insufficient[1] or not tested	
					No.	%	No.	%	No.	%
HIV	12189	11686	503	95.9	14[2]	0.1	11643	99.6	29	0.2
HBV	12189	11998	191	98.4	67[3]	0.6	11905	99.2	26	0.2
Rubella	12189	12178	11	99.9	11595[4]	95.2	566	4.6	17	0.1
Syphilis	12189	9996[5]	2193	82	5	0.1	9991	99.9	-	-

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] HIV – 1 previously known to be HIV positive

[3] One sample DNA negative - reported as not infectious risk

[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.

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

Table 4.2 Clyde laboratories

Samples 2007/08[1]					Results							
	Total number of samples	Number requesting individual test	Number not requesting individual test	% uptake	Antibody detected		Antibody not detected		Equiv		Insufficient[2] or not tested	
					No.	%	No.	%	No.	%	No.	%
HIV	3834	3669	165	95.7	2	0.05	3658	99.7	-	-	9	0.2
HBV	3834	3714	120	96.9	5	0.1	3703	99.7	-	-	6	0.2
Rubella	3834	3818	16	99.6	3492[3]	91.5	176	4.6	141[4]	3.7	9	0.2
Syphilis	3834	3713	121	96.8	-	-	3705	99.8	-	-	8	0.2

Notes
[1] Incomplete reporting of data from IRH lab from September and November 2007. 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.

Information systems

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

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

Future developments

From April 2008, all syphilis testing in Glasgow will be carried out at the West of Scotland Specialist Virology Centre rather than at the three local hospital labs.

A standard request form for communicable diseases screening in pregnancy currently used in Glasgow will be rolled out across the whole health board area.

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.

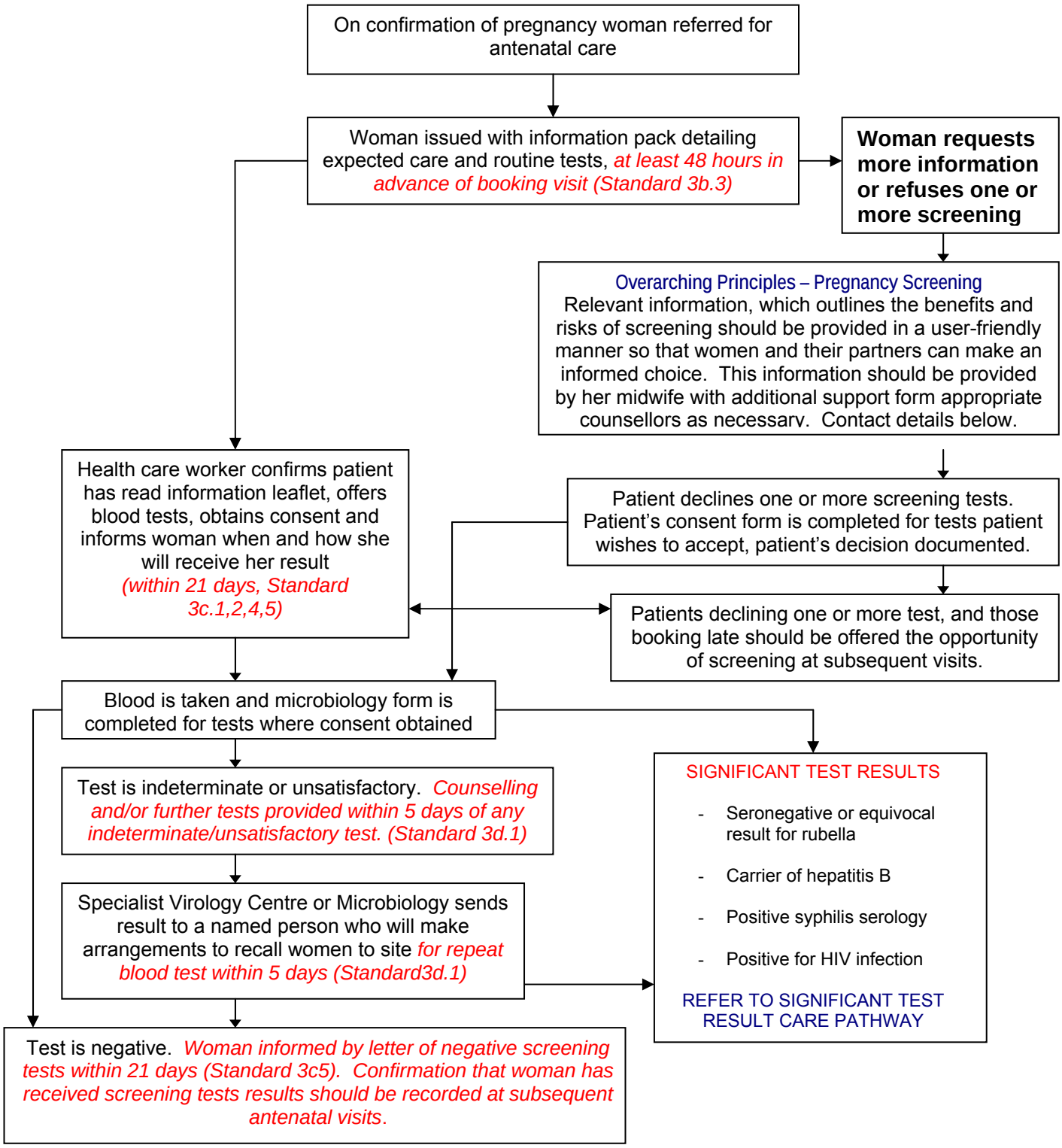
Although after-care of women and their children identified through screening is not strictly a screening function, the management, treatment and care of such individuals should be considered as a consequence of the screening programme. There are well-established follow-up protocols for babies born to 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, which reviews those HIV cases detected via the screening programme and examines where the protocol has been particularly successful or requires amendment.

Although uptake of screening is high for the Board as a whole, some areas have lower uptake than others. The Pregnancy Screening for Communicable Diseases subgroup will work with local units to try to identify reasons for such differences and will work towards improving uptake in these areas.

Differences in laboratory testing and reporting of rubella results across the labs have been noted. This has consequences for the proportion of women getting the MMR vaccine. The Pregnancy Screening for Communicable Diseases subgroup will work with the labs to standardise the reporting of results across the Board and reduce the number of tests reported as equivocal.

Appendix 4.1

Protocol for Offering Routine Antenatal Communicable Disease Test



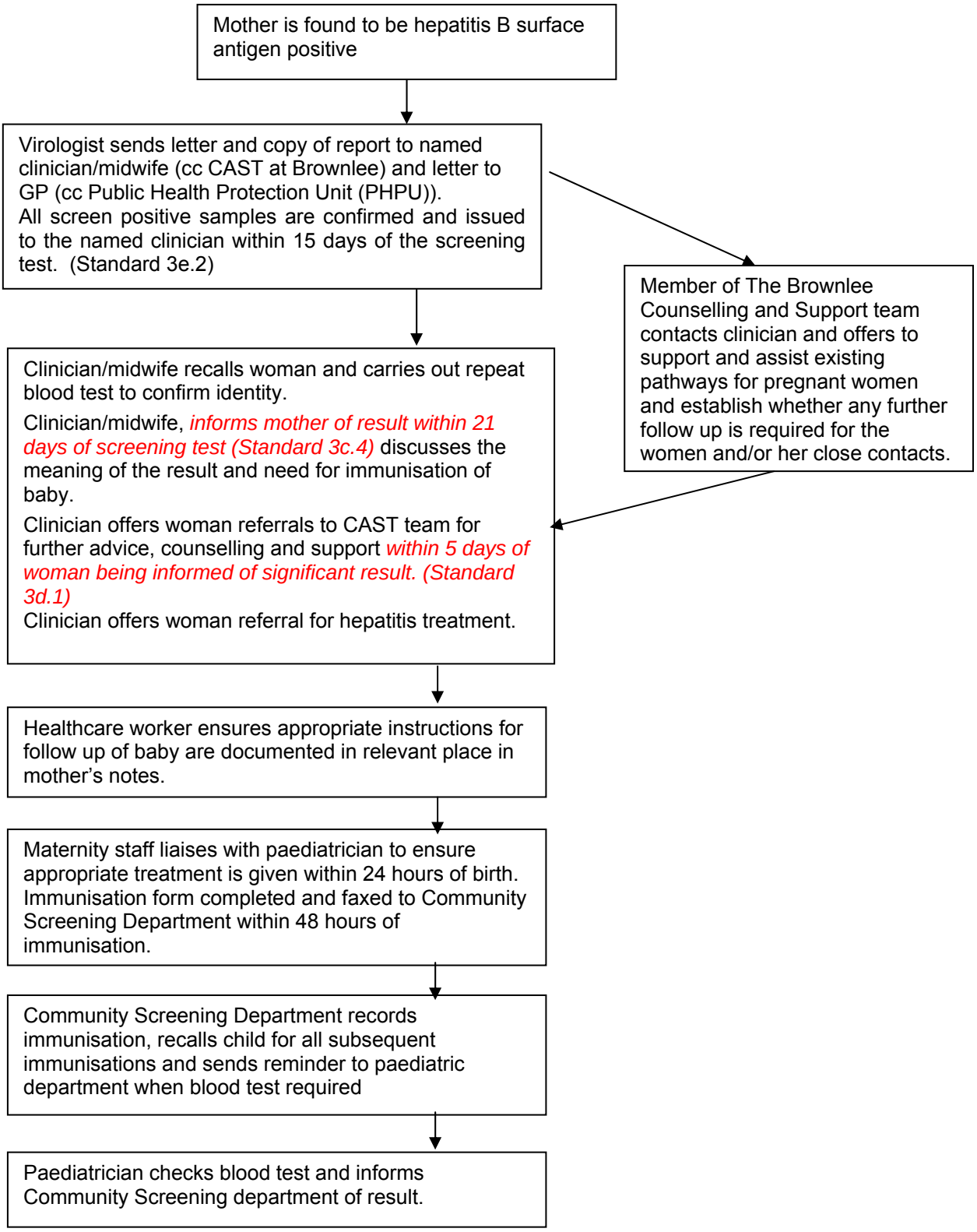
N.B. If a woman feels she has been/continues to be at risk of exposure to HIV, she should be offered re-testing 3 monthly in pregnancy. If a mother develops symptoms of hepatitis or a sexually transmitted infection she should be referred to SNIPs/or sexual health advisor.

Special Needs in Pregnancy (SNIPs) Midwife – Clyde Area
RAH – 0141 314 6199 or 0141 887 911 then page 56311
VOL – 01389 817 232 **IRH** – 01475 504 833
Women's Reproductive Health Service (WRHS) 0141 221 5267 or 0141 211 5337

Sexual Health Advisors, Sandyford Clinic – 0141 211 8634
Counselling and Support Team (CAST), Brownlee Unit 0141 211 1089

Appendix 4.2

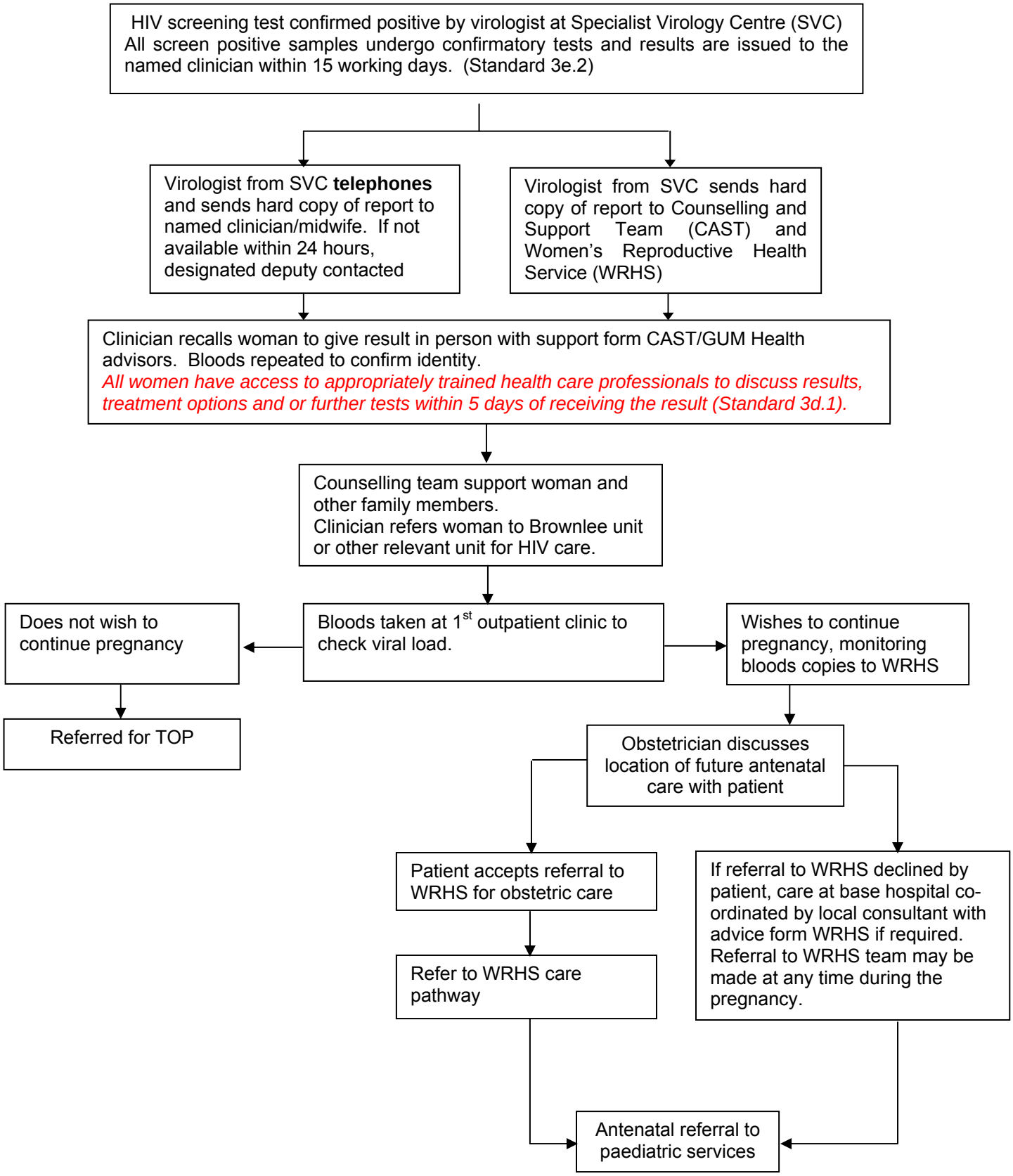
Protocol for Significant Laboratory Results: HEPATITIS B



Appendix 4.3

Protocol for Significant Laboratory Results

HIV



Appendix 4.4

Protocol for Significant Laboratory Results

Not Immune to Rubella Infection

Laboratory detects woman whose booking bloods indicate that she is not immune to rubella infection.

↓

Microbiologist/virologist notifies clinician/midwife responsible for woman's antenatal care.
All antibody negative rubella results are issued to obstetric team within 15 working days. (Standard 3e.4)
Microbiologist/virologist informs public health department for monitoring and audit purposes.

↓

Woman informed of result within 21 days of screening test. (Standard 3c.5)
Clinician/midwife discusses the need for MMR immunisation post delivery and documents woman's notes *within 5 days of woman receiving result. (Standard 3d.1)*

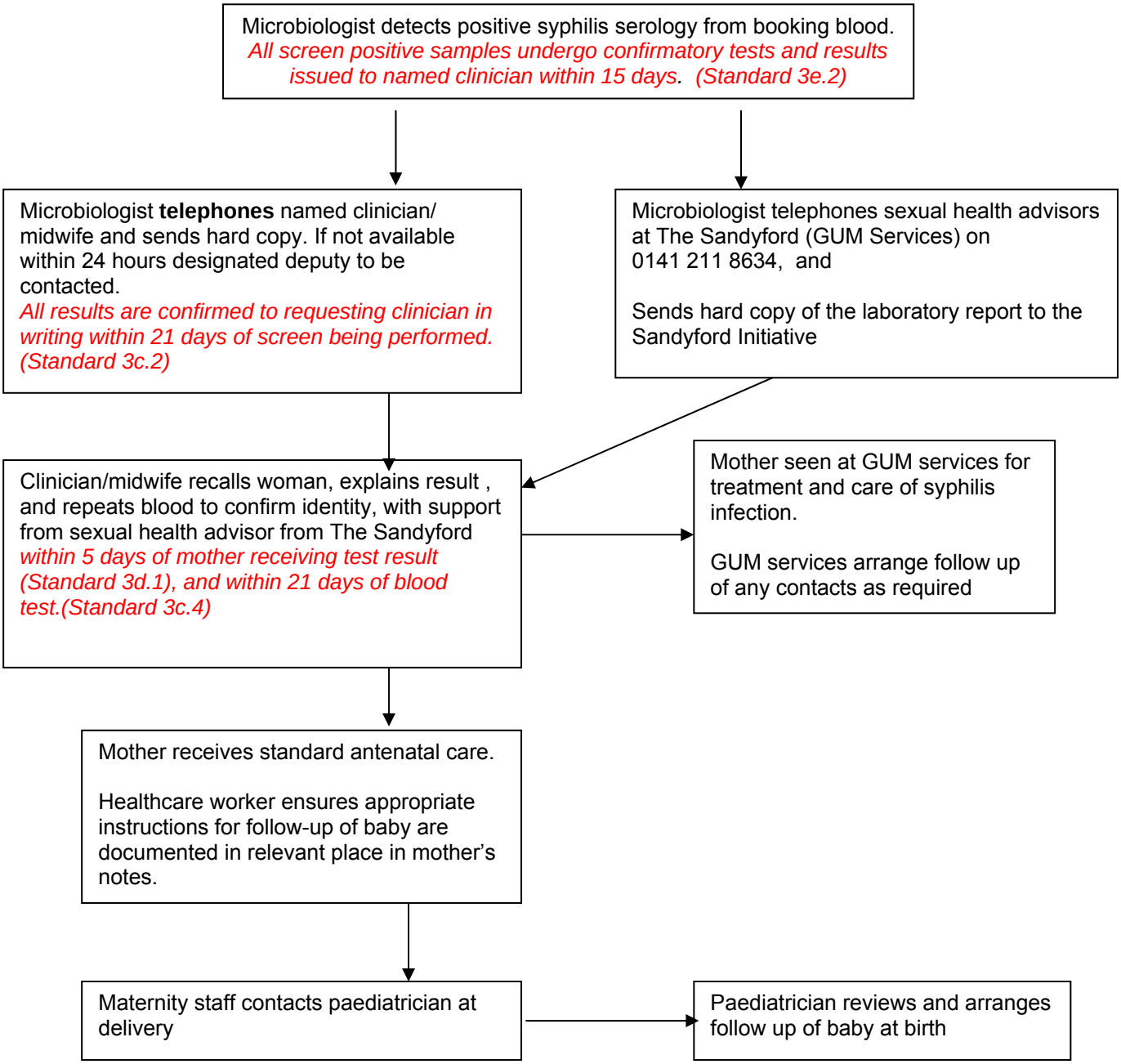
↓

Postnatal ward arranges consent, immunisation and contraception prior to patient's discharge from the ward.

Appendix 4.5

Protocol for Significant Laboratory Results

SYPHILLIS



Appendix 4.6

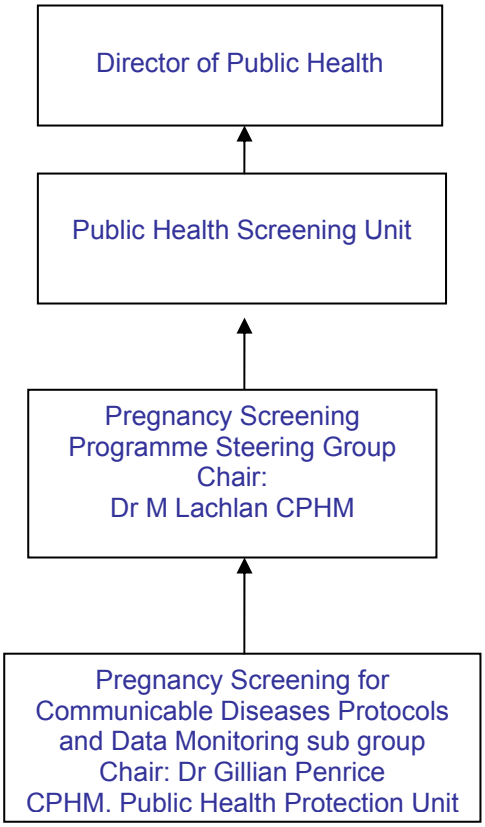
Members of Pregnancy Screening for Communicable Diseases Data and Monitoring Group

(As at March 2008)

Dr Gillian Penrice	Public Health Protection Unit (Chair)
Mrs Donna Athanasopolous	PERL Resources Co-ordinator
Ms Elizabeth Boyd	Clinical Effectiveness Facilitator
Dr Sheila Cameron	Consultant Clinical Scientist
Mrs Jacquie Campbell	General Manager
Mrs Louise Carroll	Programme Manager HIV/STIs
Ms Flora Dick	Special Needs (SNIPS) Midwife
Ms Catherine Frew	Data Analyst
Dr Michelle Gillies	Specialist Registrar
Mrs Annie Hair	Head of Children's Services
Dr Cathy Johnman	Specialist Registrar
Mrs Annette Little	Information Analyst
Miss Denise Lyden	Project Officer
Mrs Gwyneth MacDonald	Sexual Health Advisor
Dr Alan Mathers	Clinical Director Obstetrics and
Mrs Marie-Elaine McClair	Clinical Nurse Manager
Mrs Harriet O'Donnell	Health Protection Nurse Specialist
Mrs Diane Paterson	Lead Midwife
Ms Linda Rhodick	Medical Secretary/Data Co-ordinator
Dr James Robins	Consultant Obstetrician &
Dr Andrew Thomson	Consultant Obstetrician &
Mrs Janice Winter	Clinical Effectiveness Facilitator
Mr Roger Wong	Clinical Co-ordinator

Appendix 4.7

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



Key:
_____ Direct Reports

CHAPTER 5: DOWN'S SYNDROME AND NEURAL TUBE DEFECTS

Background

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

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

a) Down's syndrome

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

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

b) Neural Tube Defects

Neural tube defects (NTDs) are congenital malformations, which arise during the development of the brain and spinal cord. It can result in spina bifida (incomplete closure of the lower spine – this can be open or closed depending on whether or not there is tissue covering the lower spine), which causes walking difficulties as well as problems with bowel and bladder control; or anencephaly when the skull and brain are not properly formed.

Scottish Perinatal and Infant Mortality and Morbidity Report 2006 shows the rate of 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 7 hospitals and 10 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 2 different screening tests for Down's syndrome used in NHS Greater Glasgow and Clyde:

Blood testing in the second trimester (AFP and total beta HCG) and maternal age. It is carried out at 15-20 weeks.

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

b) Neural Tube Defects

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

- Blood testing in the second trimester (AFP and βHCG measured at around 16 weeks) and maternal age.
- 18-20 week foetal anomaly ultrasonography (which also assesses other foetal anomalies).

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

The diagnostic 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 foetal placenta. It is usually performed between 11 to 13 weeks and has a miscarriage rate of 2%.

Amniocentesis: This is an invasive procedure, where a needle is used to sample the fluid around the foetus. It is usually performed after 15 weeks gestation and has an 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 will include 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 counting all chromosomes and examining their structure and shape. The main disadvantage is the long wait for results.

Screening Pathway

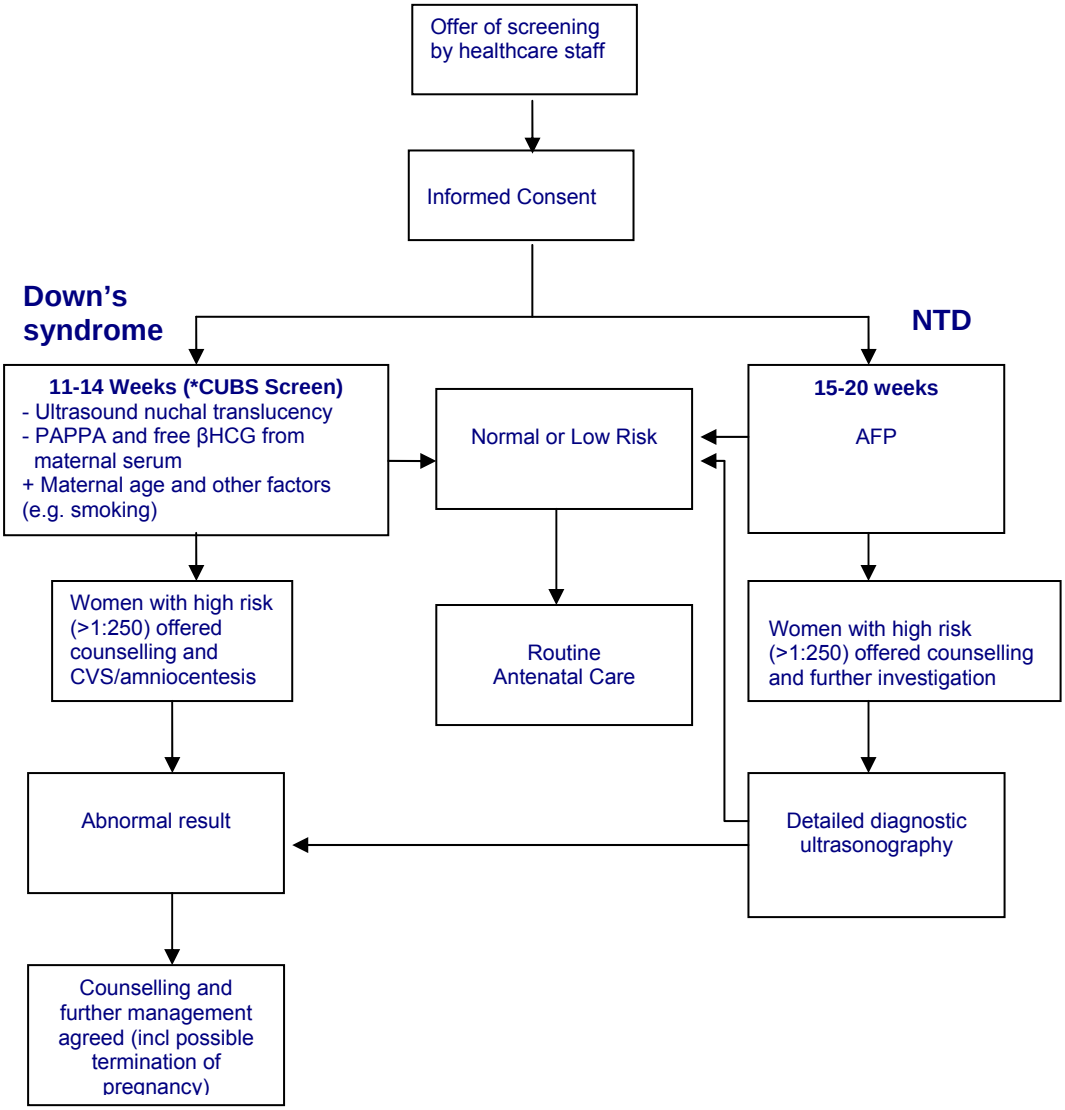
Throughout NHS Greater Glasgow and Clyde, there were three main screening pathways.

a) Queen Mother's Hospital (QMH)

Until the beginning of October 2007, Women booking at the Queen Mother's Hospital were offered combined ultrasound and biochemical screening (CUBS) for Down's syndrome in the first trimester, together with a second trimester AFP test for neural tube defects (see Figure 5.1). Subsequently, combined ultrasound and biochemical screening was withdrawn and women were offered combined second trimester screening (see Figure 5.3).

Figure 5.1

Queen Mother's Hospital:
Screening For Down's Syndrome and Neural Tube Defects



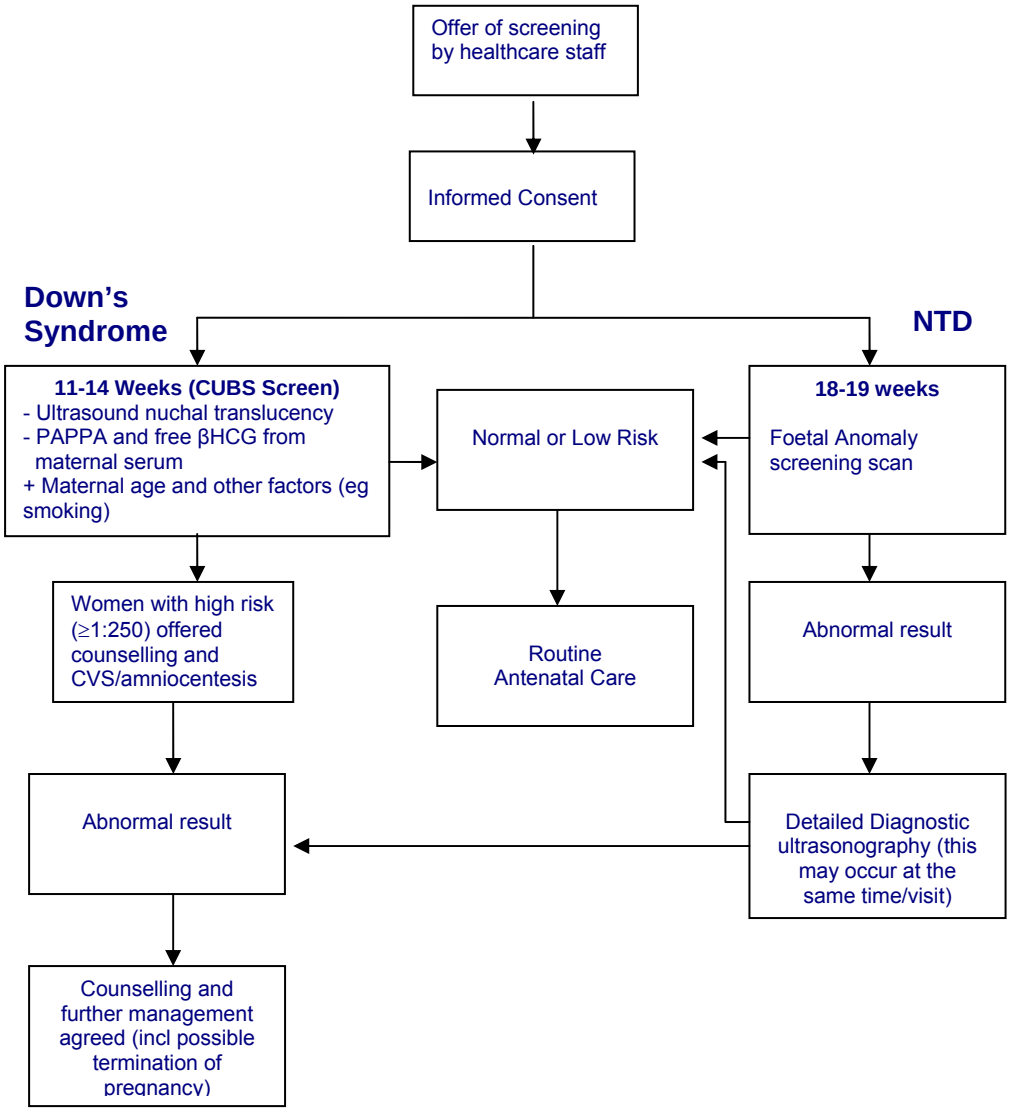
*CUBS screening was only offered until October 2007. Thereafter women were offered second trimester screen – see figure 5.3

b) Clyde area of NHS Greater Glasgow and Clyde

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

Figure 5.2

Clyde: Screening For Down's Syndrome and Neural Tube Defects

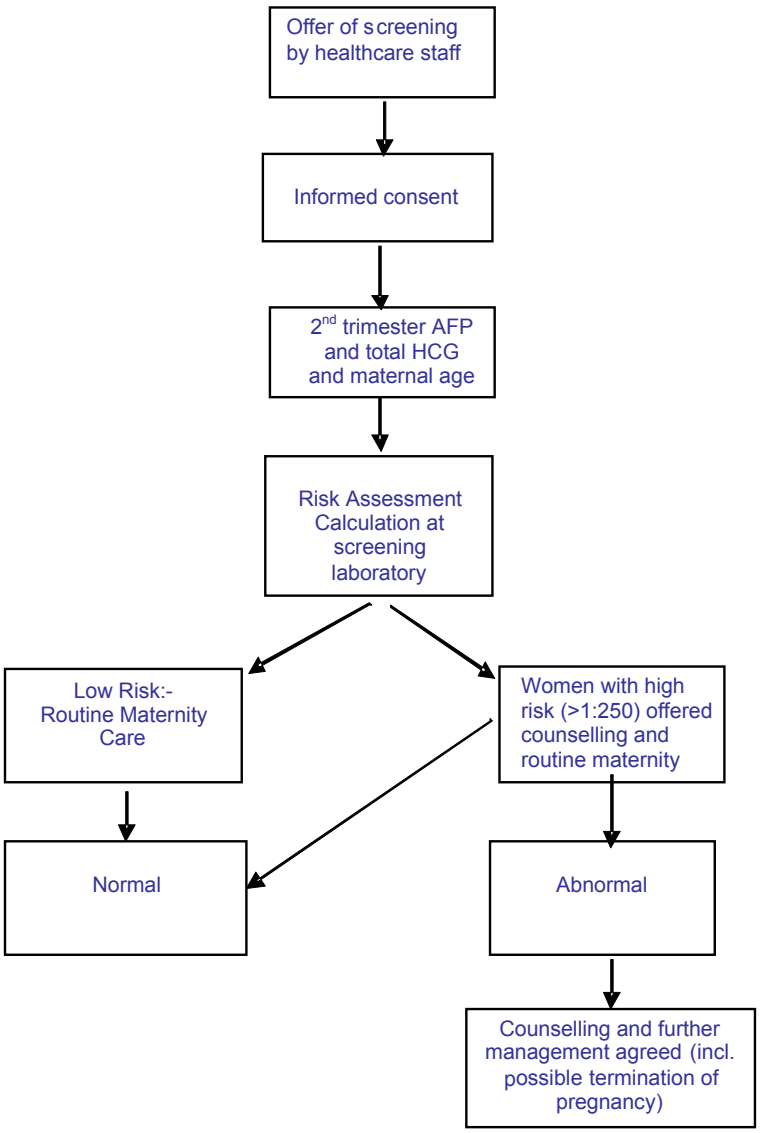


c) All others areas of NHS Greater Glasgow and Clyde (including Queen Mother's Maternity Hospital after October 2007) and women who book too late in their pregnancy to have first trimester screening)

These women are offered second trimester blood testing for Down's syndrome and neural tube defects (double test) (See Figure 5.3)

Figure 5.3

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



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 2007/08, 15,656 women attended antenatal clinics across NHS Greater Glasgow and Clyde. **Table 5.1** shows that 13,956 women were NHS Greater Glasgow and Clyde residents and 1,700 women lived outwith the Board area.

Table 5.1: Number of women booking antenatal clinics in NHS Greater Glasgow and Clyde

Clinic Name	NHS GGC residents	Non NHS GGC residents	Total
Greater Glasgow:			
Clarkston Clinic	31	3	34
Easterhouse Health Centre	119	2	121
Glasgow Princess Royal Maternity Hosp	4388	1004	5392
Kilsyth Health Centre	6	1	7
Possilpark Health Centre	41	0	41
Queen Mother's Hospital	3087	255	3342
Rutherglen Health Centre	173	17	190
Southern General Hospital	2544	107	2651
Springburn Health Centre	1	0	1
Victoria Infirmary	356	13	369
Sub total	**10746**	**1402**	**12148**
Clyde:			
Barrhead Health Centre	189	0	189
Vale of Leven Hospital	564	130	694
Erskine Health Centre	11	0	11
Renfrew Health Centre	57	0	57
Rankin Maternity Hospital	1006	86	1092
Johnston Health Centre	151	0	151
Royal Alexandra Hospital	1232	82	1314
Sub total	**3210**	**298**	**3508**
Total	**13956**	**1700**	**15656**

Source: SMR00

Delivery of Screening Programme 2007/08

Table 5.2 shows that 3,017 samples were received for first trimester combined ultrasound biochemical screening and 7,164 for second trimester Down's Syndrome and neural tube defects. 1,190 women chose to be tested for neural tube defects only.

Table 5.2 Number of women screened in 2007 by Division for type of screening test

Division	1st trimester CUBS		2nd trimester DS/NTD		2nd trimester NTD only (with no previous CUBS)		Overall %	Total number of women screened	Total Number of women bookers
Clyde	1946	58.6%	624	18.8%	16	0.5%	77.9%	2586	3319
Greater Glasgow	1071	8.7%	6540	53.0%	147	1.2%	62.9%	7758	12337
Total	**3017**	**19.3%**	**7164**	**45.8%**	**163**	**1.0%**	**66.1%**	**10344**	**15656**

Source: West of Scotland Regional Prenatal Screening Service

Note:

CUBS = combined ultrasound biochemical screening

DS = Down's Syndrome

NTD = neural tube defect

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 2007/08, the overall percentage uptake for Down's syndrome and neural tube defect screening for women booking in NHS Greater Glasgow and Clyde was 66.1%. The uptake for Down's syndrome was 65% and uptake of combined ultrasound and biochemical screening for neural tube defect was 66.1%. 1.0% of women chose to have only neural tube defect screening.

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

Fetal anomaly scanning is offered to all pregnant women in Clyde as part of a screening programme. In Greater Glasgow, a fetal anomaly scan is currently only offered to those women at risk. There are plans to offer this service to all pregnant women by 2011. (see Chapter 8, Future Developments for Pregnancy and Newborn Bloodspot Screening Programmes).

The estimated overall percentage uptake for neural tube defects was 78.37%. This has been calculated using the laboratory data (Table 5.2) and the number of women who had fetal anomaly scans in Clyde (Table 5.3).

Table 5.3: Total number of women who had a fetal anomaly scan

Clinic/Hospital	Total number of women who had a Fetal Anomaly Scan
Rankin Maternity Hospital	905
Royal Alexandra Hospital	2251
Vale of Leven Hospital	760
Clyde Subtotal	**3916**
Princess Royal Maternity Hospital	1682
Queen Mother's Hospital	1007
Southern General Hospital	868
Greater Glasgow Subtotal	**3557**
NHSGGC Total	**7473**

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, 4% 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, 6.8% of women were assigned to the 'higher chance' of Down's syndrome group, 0.4% 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.

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

CUB Screening	N	%
- Higher Chance' of Down's syndrome	120	4.0
- Higher Chance' of Trisomy 18	4	0.1
2nd Trimester Screening	N	%
- Higher Chance' of Down's syndrome	487	6.8
- Higher Chance' of Trisomy 18	28	0.4
- NTD risk (AFP≥ 2.0 MOM)	183	2.2

Source: West of Scotland Regional Prenatal Screening Service

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.

In 2007/08, **Table 5.5** shows that 496 amniocentesis tests were analysed by 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.

46 abnormalities were detected (9.3% of samples) and 29 of those (5.85% of total tests) had a diagnosis of trisomy (Down's syndrome/Trisomy 18).

Table 5.5 Amniocentesis Referrals 1st April 2007 - 31st March 2008

	Biochemical Screening	Maternal Age >35	Abnormalities on Scan	Other	Total
Number of women (= number of tests)	320	101	46	29	496
% total referral reasons	64.5%	20.4%	9.3%	5.8%	
Number with normal results	300	96	33	27	456
Number with diagnostic trisomy	15	4	9	1	29
% number with diagnostic trisomy	4.69%	3.96%	19.57%	3.45%	5.85%
Number of other non trisomy abnormalities	5	1	4	1	11
Total number of abnormalities	**20**	**5**	**13**	**2**	**40**
% total number of abnormalities	**6.25%**	**4.95%**	**28.26%**	**6.90%**	**8.06%**

source: Cytogenetics Laboratory

Notes:

1 Biochemical screening case with Trisomy also had a structural rearrangement (has only been included in trisomy figures)

2 Abnormal Scan cases with Trisomy also had a structural rearrangement which, if familial could increase risks in future pregnancies (have only been included in trisomy figures)

Table 5.6 shows that 112 chorionic villus biopies were analysed by Cytogenetics Laboratory in 2007/08. 31 abnormalities were detected (27.7% of tests) and 18 of those (16.07% of tests) had a diagnosis of trisomy (Down's syndrome/Trisomy 18).

Table 5.6 Chorionic Villus Biopsy Referrals 1st April 2007 - 31st March 2008

	Biochemical Screening	Maternal Age >35	Abnormalities on Scan	Other	Total
Number of women (= number of tests)	10	35	31	36	112
% total referral reasons	8.9%	31.3%	27.7%	32.1%	
Number with normal results	6	35	13	30	84
Number with diagnostic trisomy	4	0	14	0	18
% total with diagnostic trisomy	40.00%	0.00%	45.16%	0.00%	16.07%
Number of other non trisomy abnormalities	0	0	4	5	9
Total number of abnormalities	**4**	**0**	**18**	**5**	**27**
% total number of abnormalities	**40.00%**	**0.00%**	**58.06%**	**13.89%**	**24.11%**

source: Cytogenetics Laboratory

Table 5.7 shows data from the West of Scotland Regional Prenatal Screening Service for Down's syndrome and neural tube defects detected by screening in 2007/08. Outcome data for women screening in this year is not yet complete.

Table 5.7: Number of abnormalities detected by screening

Screening test	Condition	Number
second trimester double marker	Down's syndrome	7
	Trisomy 18	1
second trimester AFP	NTD	3
	Trisomy 18	1
	Triploidy	1
	Gastrochisis	1
first trimester Combined ultrasound and biochemical	Down's syndrome	1

.

Turnaround time for results to be available

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 2007-08 the average time taken from sample receipt until a report to be available was 1.3 working days. In 95% of cases a report was available by 2 working days after receipt and 98% of reports were 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 Priorities

Women booking in NHS Greater Glasgow and Clyde are offered different screening tests for Down's syndrome and neural tube defects. A simple pathway should be agreed and implemented subject to resources being available.

Current information systems do not allow the delivery of failsafe purposes across pregnancy screening programmes. An information management system should be developed to allow the delivery of the failsafe processes for all women working in NHS Greater Glasgow and Clyde.

CHAPTER 6: NEWBORN BLOODSPOT SCREENING

Background

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

Newborn Screening for phenylketonuria 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 every day foods including milk. Toxic levels of phenylalanine may build up causing irreversible brain damage unless the baby is urgently started on a special diet. With prompt treatment the baby is very likely to develop normally.

Recommended Age to Perform Screen

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

The screening test

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

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.

Figure 6.1 Newborn Screening Process – Phenylketonuria (PKU) & Congenital Hypothyroidism (CHT)

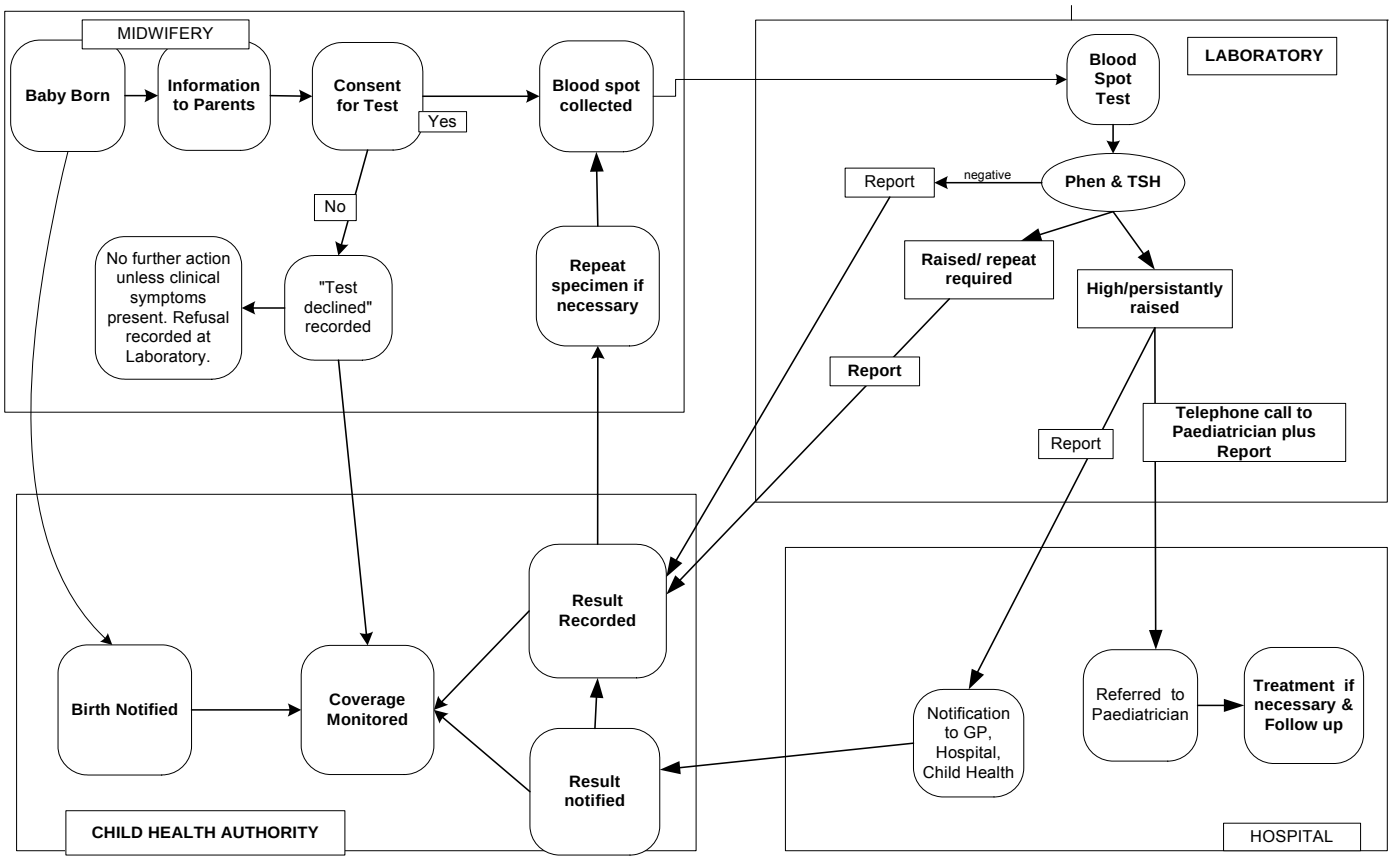
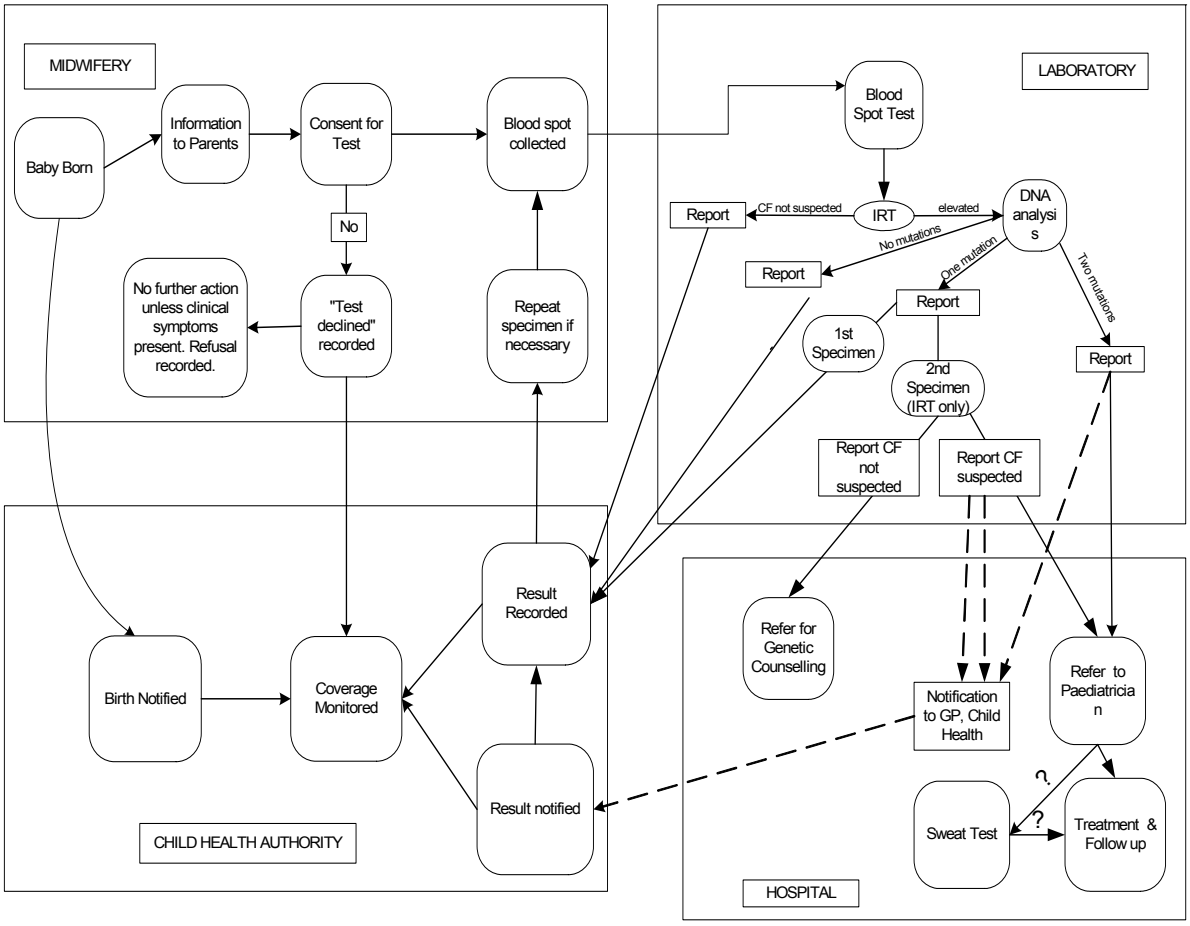


Figure 6.2 Newborn Screening Process: Cystic Fibrosis



Eligible Population

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

Delivery of screening programme 2007/08

Uptake of newborn bloodspot screening in NHS Greater Glasgow and Clyde

The number of babies of NHS Greater Glasgow and Clyde residents screened in 2007/08 was 14,194, 97.5% of the total eligible population of 14,565 (see **Table 6.3**.)

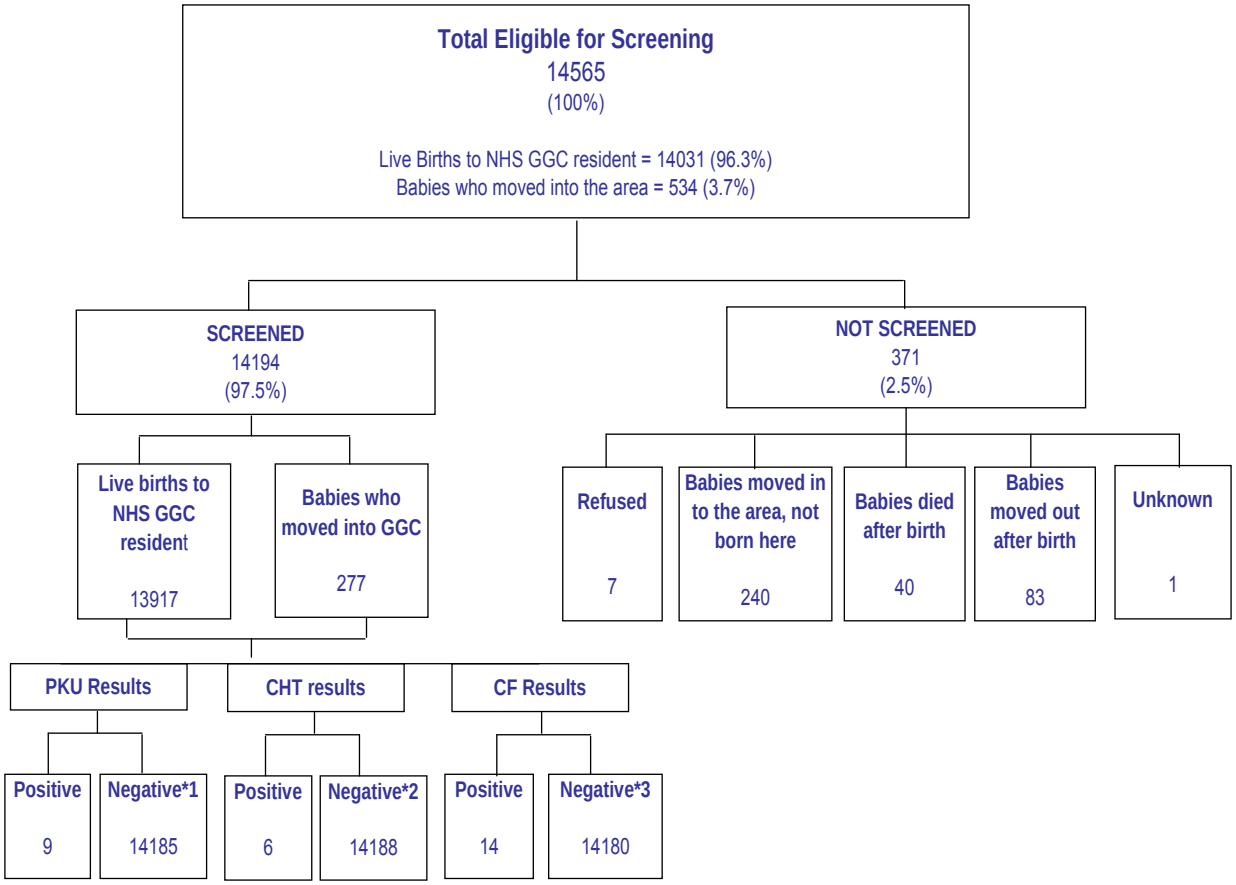
In 2007, 15,146 bloodspot samples were analysed by the National Newborn Screening Laboratory.

Figure 6.3 illustrates uptake rates and the results of the screening programme from 1 April 2007 to 31 March 2008.

Of the 371 (2.5%) not screened, only 7 refused screening, 232 moved in or out of the area and 40 babies died. There were 9 positive cases of phenylketonuria detected (an increase of 8 from previous year), 6 of congenital hypothyroidism and 14 of cystic fibrosis. All received appropriate management within the timescale of the standard.

Figure 6.3

NHS Greater Glasgow & Clyde
Summary of Bloodspot Screening Uptake & Results for babies born 1 April 2007 to 31 March 2008



*1 Total includes 1 results not in Child Health System; 4 verifications.
*2 total includes 3 verifications.
*3 Total includes 5 carriers; 13 late tests; 6 results not in Child Health System; 4 verifications.

PKU = phenylketonuria
CHT = congenital hypothyroidism
CF = cystic fibrosis

In 2007, 81 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.

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. In 2007, the Laboratory reported that of the 15,146 bloodspot samples received, 0.7% had taken more than 7 days to arrive at the laboratory. This was mainly due to the Royal Mail strike and Christmas and New Year period.

A review of the newborn bloodspot process was carried out in 2008 to identify ways to

- Reduce the number of insufficient bloodspot tests
- Speed up the process for requesting repeat bloodspot tests and
- Further reduce the time taken to deliver the specimens to the laboratory
- Increase the use of the patient identifier (Community Health Index) on the bloodspot request cards

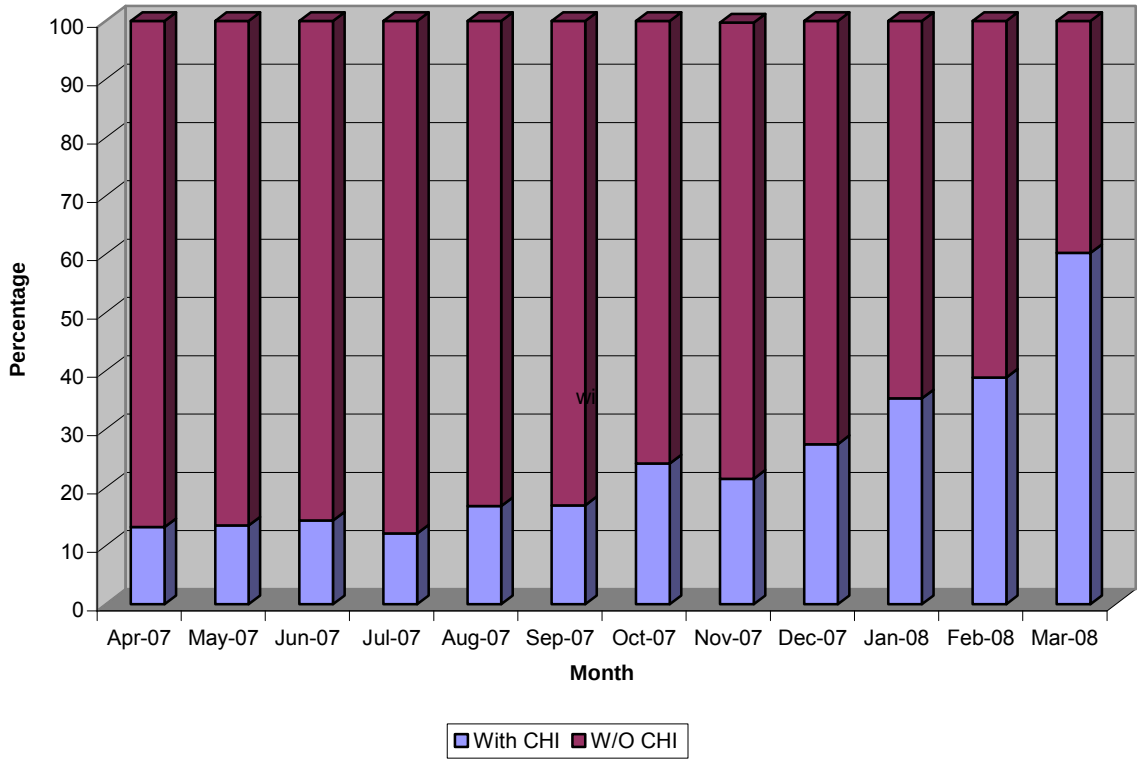
Following the review, the paper based process for requesting repeat bloodspot tests will be replaced by an electronic alert system which will be built within the newly IM&T system being developed for the pregnancy and newborn screening application. In the interim, Child Health Screening Department will be given electronic access to the National Newborn Screening Laboratory's network to check for repeat requests. The Child Health Screening Department will then arrange for a Community Midwife to arrange for a sample to be taken from the baby within two days.

The use of the patient identifier number (called the Community Health Index (CHI)) on bloodspot cards has increased dramatically following a series of changes to the administrative processes which included:

- Provision of feedback on CHI usage to individual maternity units
- Pre-printed labels with babies and mother's CHI details.
- Creation of a CHI register

Figure 6.4 shows that from April 2007 to March 2008, the use of the CHI number on bloodspot cards sent for analysis increased from 10% in April 2007 to almost 60% in March 2008.

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



Source: National Newborn Screening Laboratory

Information systems

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

Challenges and future priorities

The newborn bloodspot screening programme will see the addition of the haemoglobinopathy and MCCAD (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 2007, 60% of the bloodspot screening request cards had the Community Health Index recorded. Continuing feedback for units and support would be required to achieve a target of 97% CHI usage.

Appendix 6.1

Members of Newborn Bloodspot Screening Steering Group As at March 2008

Dr Margaret Lachlan	Consultant in Public Health Medicine (chair)
Mrs Donna Athanasopolous	PERL Resources Co-ordinator
Ms Dorothy Cafferty	Planning Manager
Mrs Jacquie Campbell	General Manager
Dr Anne Devenny	Consultant Paediatrician
Mrs Dorothy Finlay	Consultant Midwife
Mrs Fiona Gilchrist	Screening Manager
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 Marie-Elaine McClair	Lead Midwife PRM
Mrs Julie Mullin	Deputy Screening Manager
Mrs Diane Paterson	Lead Midwife
Dr Andrew Powls	Consultant Neonatologist
Mrs Janice Winter	Clinical Effectiveness Manager

CHAPTER 7: UNIVERSAL NEWBORN HEARING SCREENING

Background

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

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

One to two babies in every 1000 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 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 2007/08

Eligible population

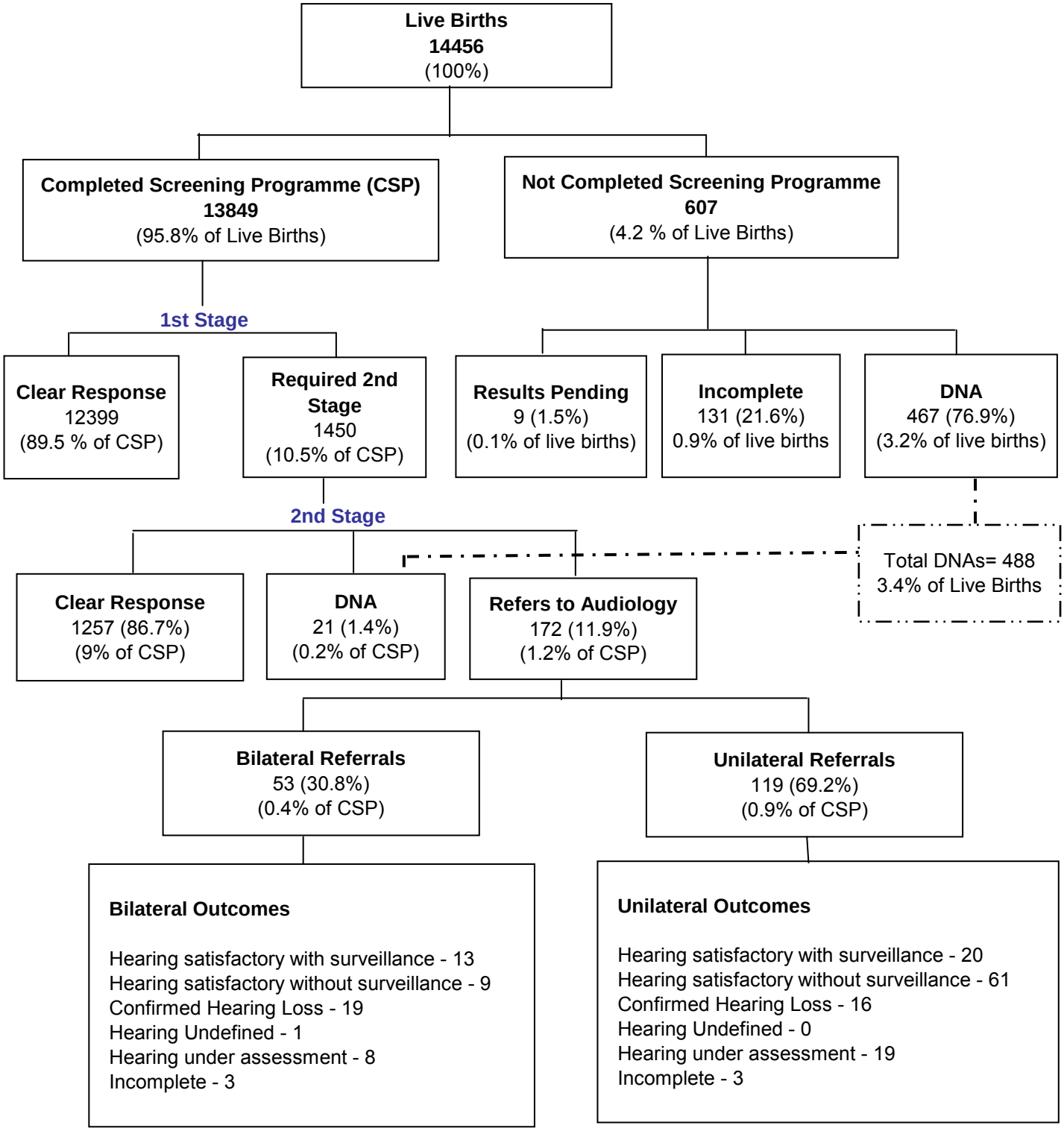
The screening programme covers all babies born to Greater Glasgow and Clyde residents and any babies moving into the area who are aged less than 6 months. Babies who are resident from other NHS Board areas but are born in NHS Greater Glasgow and Clyde are also screened by NHSGGC screeners.

Uptake of the screening programme

There were 14456 babies born in 2007/08 to residents of NHS Greater Glasgow and Clyde (Figure 8.1). 13849 were screened for hearing loss giving an overall uptake of 95.8%. 172 babies were referred to audiology and of those 35 were confirmed with a hearing loss. There were 2333 babies born from other NHS Board areas who were born in Greater Glasgow and Clyde and of those 1747 were screened by NHSGGC screeners.

Figure 7.1

Summary of Uptake and results of 1 April 2007 - 31 March 2008: 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

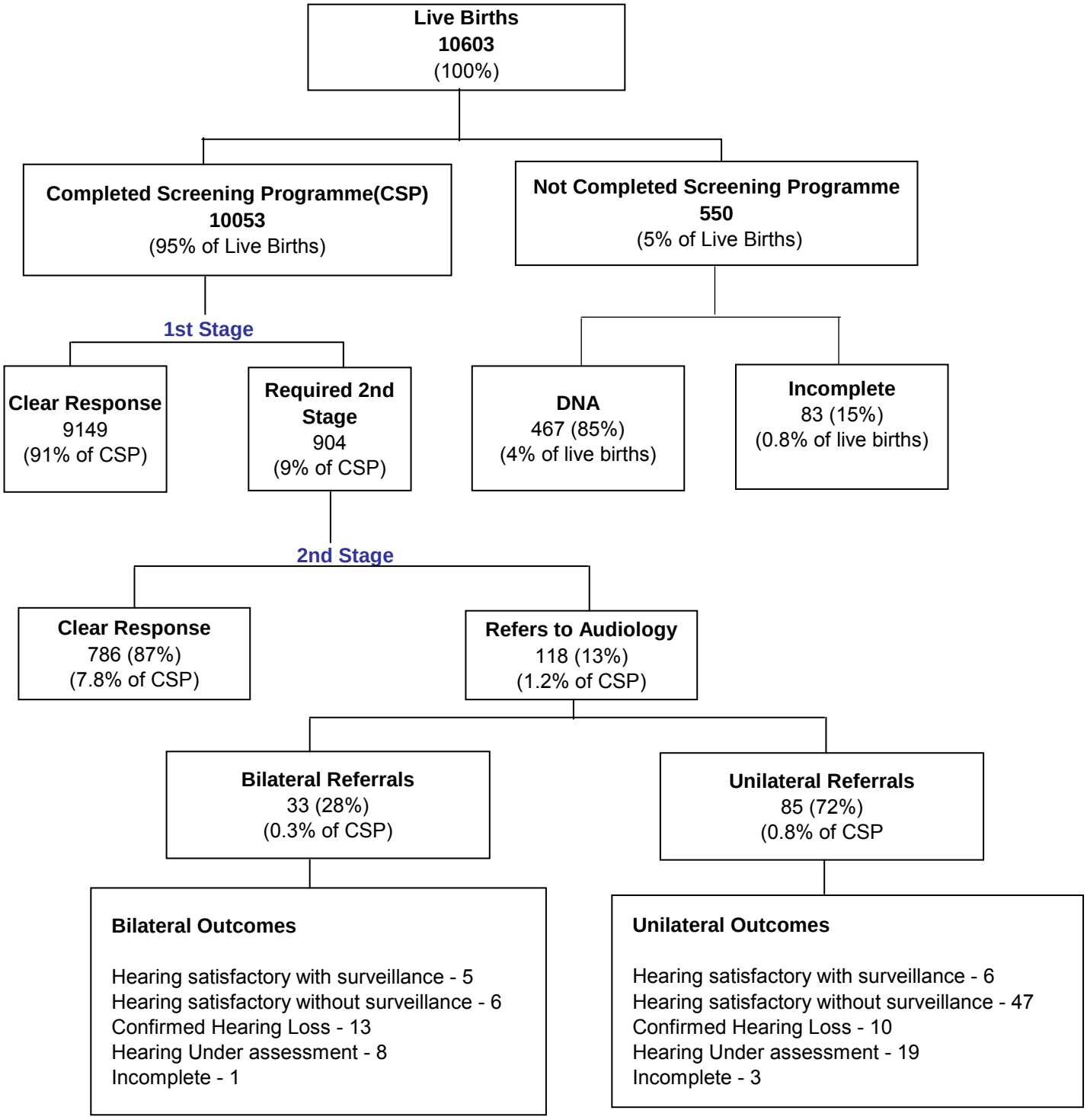
Results Pending - Includes all those babies who we are still trying to complete the screen

Incomplete/Not Completed - all 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 do not

Figure 7.2

Summary of Uptake and results of 1 April 2007 - 31 March 2008: Greater Glasgow



Definitions

1st Stage - is first AABR for Glasgow

2nd Stage - is the second AABR for Glasgow

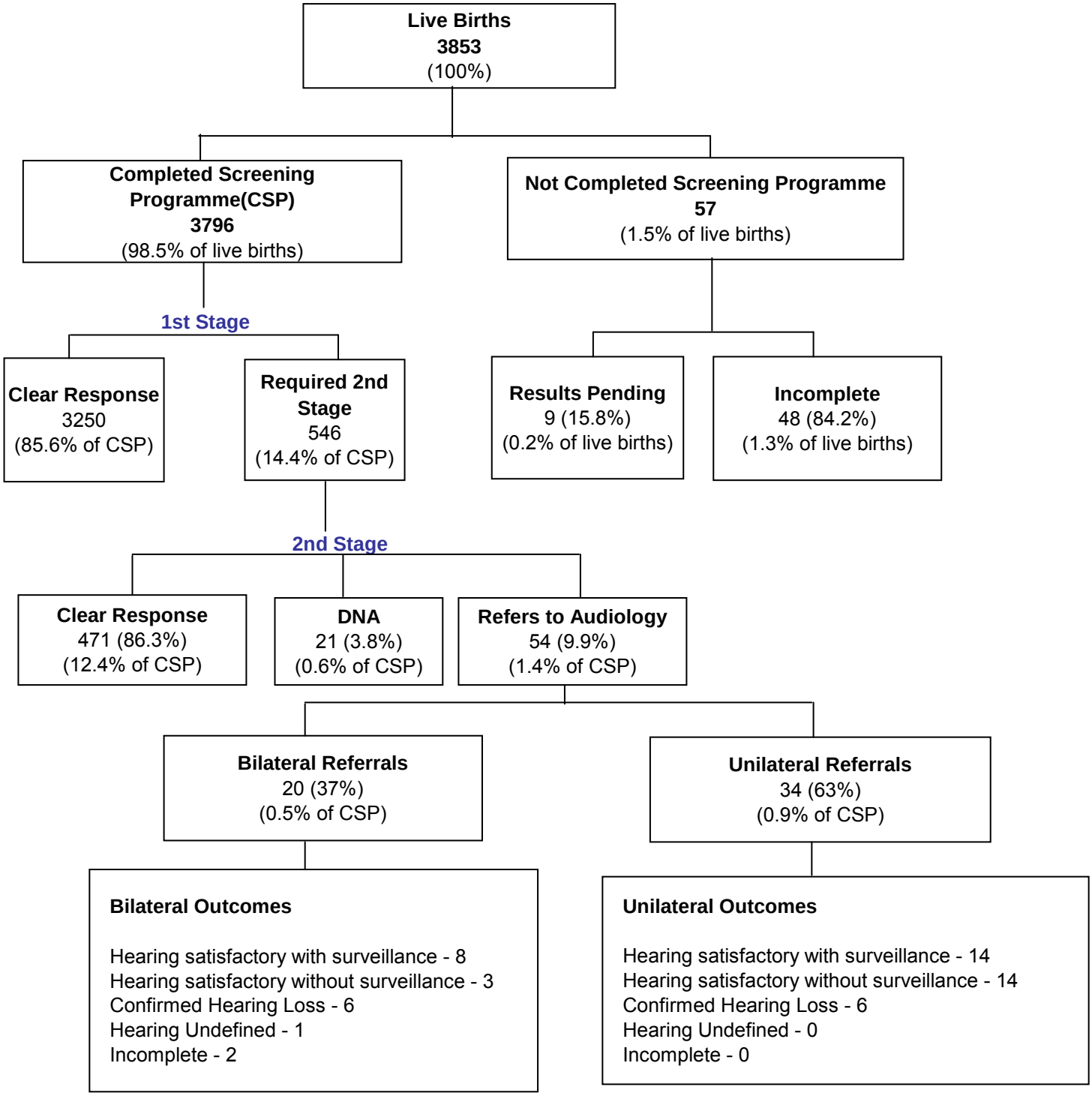
Results Pending - Includes all those babies who we are still trying to complete the screen

Incomplete/Not Completed - 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 do not

Figure 7.3

Summary of Uptake and results of 1 April 2007 - 31 March 2008: Clyde



Definitions

1st Stage - is the first OAE for Clyde

2nd Stage - is 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 do not

Audit of paediatric audiology services (including neonatal hearing screening)

In 2007, the Scottish Government commissioned an audit of paediatric audiology services and included neonatal hearing screening. The outcome of the report *Audit of Paediatric Audiology and associate Universal Neonatal Hearing Screening, Medical, Early Intervention and Family Support services*, August 2007 by MRC Hearing & Communication Group found that the NHS Greater Glasgow and Clyde Universal Neonatal Hearing Screening programme was meeting NHS Quality Improvement Scotland Standards, though they did make some recommendations to improve the service further. These recommendations have been taken forward for example:

- There is now continuous regular competency assessment of hospital screeners. Personal development plans for screeners and screening manager have now been completed.

- Contact has been established with other community based programme managers in the English newborn hearing screening programme to develop a system of competency assessment for health visitors in Clyde.

- A rolling replacement programme for screening equipment is now in place.

- NHS Greater Glasgow and Clyde is progressing work to scope the equipment and costs to allow Clyde screeners to transfer screening data electronically into national IT system (eScreener Plus).

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.

There is work at national level to seek a solution to develop an interface between the eSP, the Community Health Index (CHI) and Child Health information systems across Scotland. The link would remove the need for manual entry of data into eSP which would provide more screening time plus an important failsafe for notification of births ensuring no babies are missed.

As mentioned earlier, there are plans to allow Clyde screeners to upload screening data electronically into eSP.

Information to parents/carers

Maternity Services Strategy Group has developed pregnancy care schedules which now include at what stage and how information is given to parents/carers. This informs midwives what information is given to parents/carers at the appropriate time during the antenatal period.

Future challenges/developments

With the remarkably low number of babies in the Clyde area who fail to complete the screening programme, it is very beneficial to continue to provide the service in the community. However, the outcome of the Health Visitors' review may affect the way in which the screening programme is delivered in Clyde in the future.

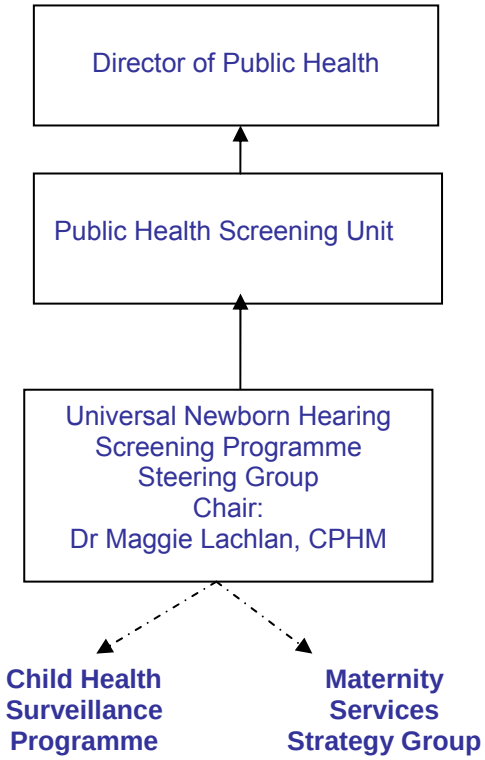
Appendix 7.1

Universal Newborn Hearing Screening Programme Steering Group
(as at March 2008)

Dr Margaret Lachlan	Consultant in Public Health Medicine (Chair)
Mrs Betty Adair	Lead Midwife
Ms Elizabeth Callander	Lead Midwife
Mrs Jacquie Campbell	General Manager
Mrs Patricia Carmichael	UNHS Programme Manager
Ms Gail Carroll	Assistant Technical Officer
Mrs Fiona Gilchrist	Screening Manager
Mrs Annie Hair	CHP Children's Services Lead
Mrs Leigh Hamilton	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
Ms Gillian McBride	Finance Manager
Dr Juan Mora	Consultant Audiological Physician
Mrs Julie Mullin	Deputy Screening Manager (Glasgow)
Miss Debbie Speers	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

Appendix 7.2

Reporting Structure:
Universal Newborn Hearing Screening Steering Group



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

CHAPTER 8 : FUTURE DEVELOPMENTS - PREGNANCY AND NEWBORN SCREENING PROGRAMMES

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

- to ensure all pregnant women are offered down's syndrome and other congenital amply 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.

Down's syndrome and other congenital anomaly screening

From 2010, all pregnant women will be offered Combined Ultrasound and Biochemical Screening in the first trimester of pregnancy in which measurement of biochemical markers in the mother's blood is combined with the ultrasound measurement of nuchal translucency in the fetus.

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

All women are also to receive a second trimester foetal anomaly ultrasound scan between 18 weeks, 0 days and 20 weeks, 6 days.

Newborn bloodspot screening for Medium Chain Acyl CoA Dehydrogenase Deficiency (MCADD).

Screening for MCADD will be introduced in NHS Greater Glasgow and Clyde by March 2011.

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
- **thalassaemias** 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

Sickle cell anaemia (Hb SS)
Hb SC disease
Hb S/ß-thalassaemia*
Hb S/DPunjab
Hb S/OArab
Hb S/HPFH

Notes:

1 *This is inclusive of Hb S/ß+, Hb S/ß0,Hb S/□ß and Hb S/Lepore.

2 It is not possible at birth to differentiate with certainty between sickle cell anaemia (Hb SS), Hb S/ß0-thalassaemia and Hb S with Hereditary Persistence of Fetal 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

ß-thalassaemia major
ß-thalassaemia intermedia
Hb H disease
Hb E/ß-thalassaemia
Hb SE

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 indentify 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 if either parent is 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 pregnancy 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 2 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

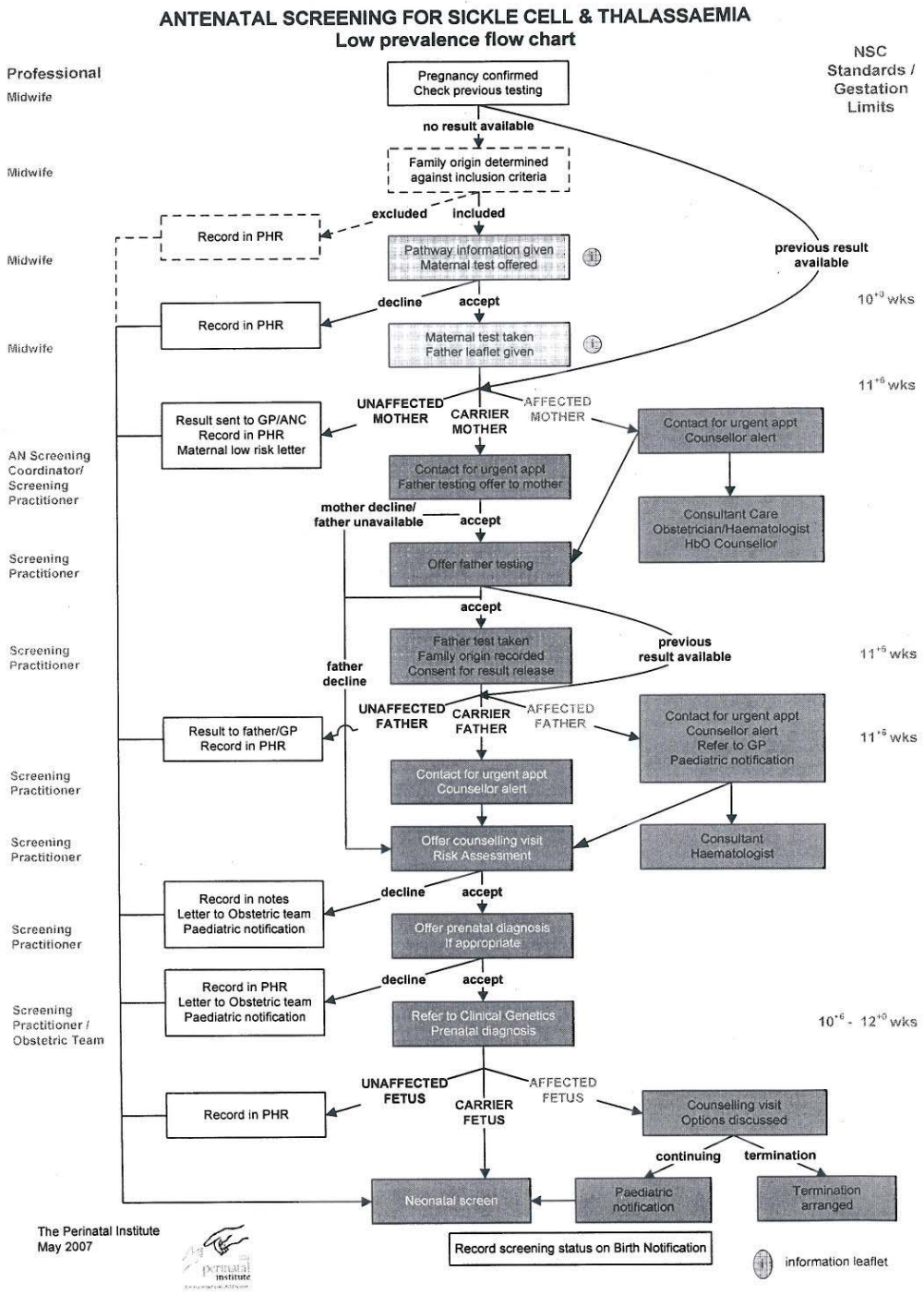
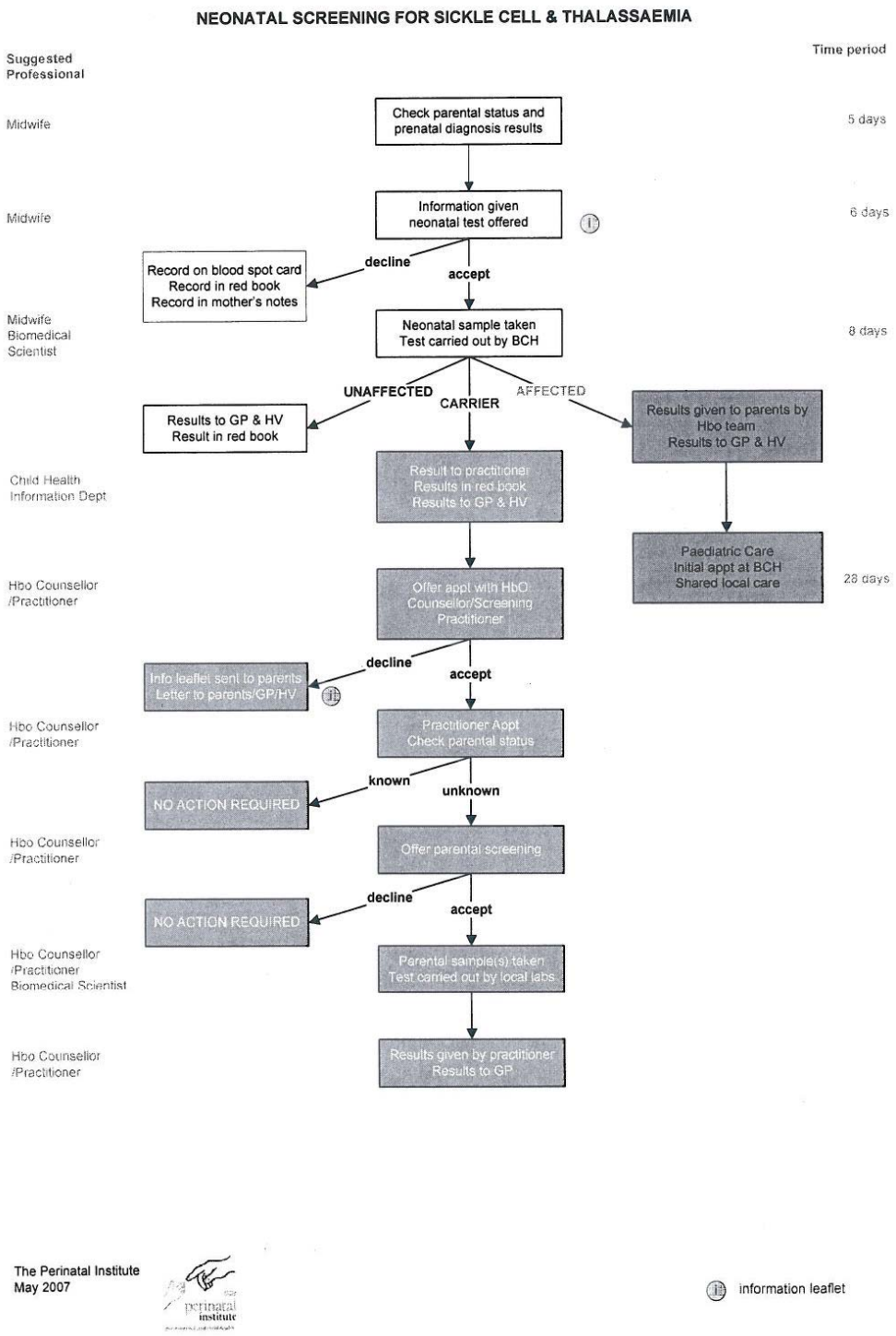


Fig. 8.2 Neonatal Screening



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

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.

Currently NHS Greater Glasgow and Clyde Diabetic Retinopathy Screening is 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.

A service level agreement is in place with NHS Highland for NHS Greater Glasgow and Clyde to offer the diabetic retinopathy screening programme to residents in Argyll and Bute.

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 and 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

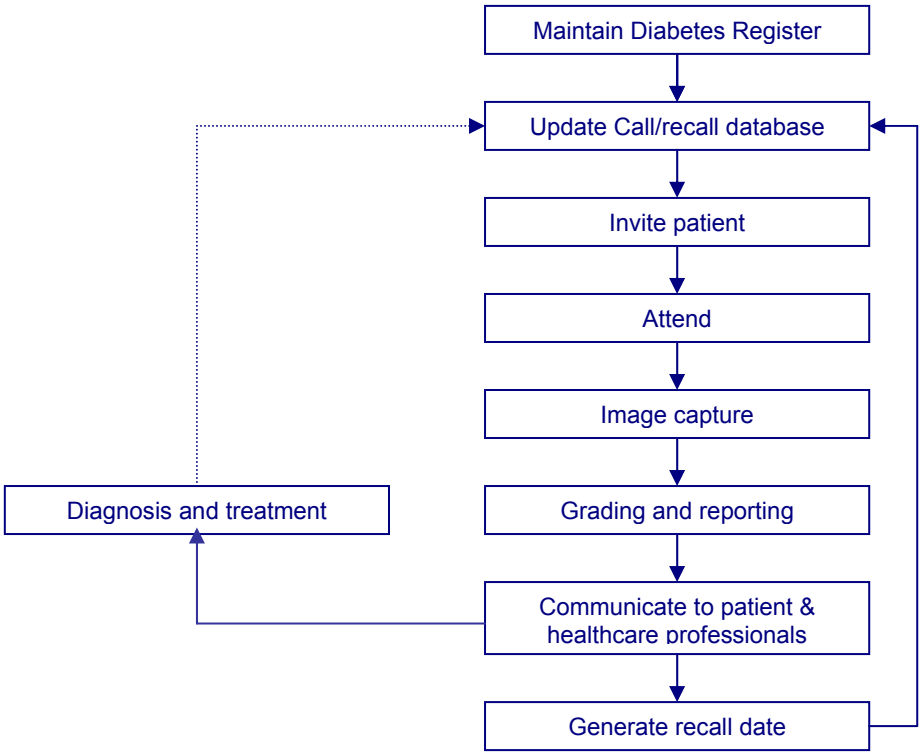
The screening programme takes place in a variety of settings. This can either be at a fixed site or within a mobile screening unit, which visits health centres and other locations around the area. Currently across Greater Glasgow and Clyde (including the Argyll and Bute area) there are ten fixed site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



Delivery of Screening Programme 2007/08

Table 9.1 shows that there are 48,360 people with diabetes in NHS Greater Glasgow and Clyde.

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

CH(C)P	12-19	20-29	30-39	40-49	50-59	60-69	70-79	80-89	90-99	100-110	Total
East Glasgow	66	155	204	660	1170	1499	1428	410	36	0	**5628**
North Glasgow	45	102	165	498	797	1088	1026	317	34	0	**4072**
South East Glasgow	44	111	249	578	966	1000	839	300	21	0	**4108**
South West Glasgow	58	120	211	649	1052	1291	1248	381	29	0	**5039**
West Glasgow	39	164	223	559	935	1175	1145	476	39	0	**4755**
East Dunbartonshire	56	84	134	367	715	1029	997	371	31	0	**3784**
West Dunbartonshire	49	98	181	433	803	1043	915	329	27	0	**3878**
East Renfrewshire	44	74	105	310	589	788	811	314	34	0	**3069**
Inverclyde	47	71	122	326	650	889	802	284	34	0	**3225**
Renfrewshire	83	133	287	713	1330	1787	1649	544	47	0	**6573**
North Lanarkshire[1]	11	24	32	82	146	221	161	44	2	0	**723**
South Lanarkshire[1]	24	62	99	245	451	608	565	156	12	0	**2222**
Unassigned[2]	5	39	66	125	199	264	346	204	33	3	**1284**
NHSGGC Total	**571**	**1237**	**2078**	**5545**	**9803**	**12682**	**11932**	**4130**	**379**	**3**	**48360**

Source: Soarian/SCI-DC Comparison taken on 13 May 2008

1. NHS Greater Glasgow and Clyde residents only
2. Unassigned due to no postcode available

20,151 (41.6%) of diabetics are resident in the most deprived area compared to 13.8% who reside the least deprived area. (**Table 9.2**)

Table 9.2: Eligible population for DRS Screening split by age group and deprivation category

	Most deprived			Least deprived			
Age Group	**1**	**2**	**3**	**4**	**5**	**Not Assigned[1]**	**Total**
12-19	206	75	75	87	123	5	**571**
20-29	465	220	181	154	175	42	**1237**
30-39	909	390	258	232	221	68	**2078**
40-49	2449	1059	661	596	655	125	**5545**
50-59	4130	1747	1176	1184	1362	204	**9803**
60-69	5343	2375	1538	1388	1771	267	**12682**
70-79	4977	2322	1432	1177	1676	348	**11932**
80-89	1562	884	461	407	612	204	**4130**
90-99	110	71	59	44	61	34	**379**
100-110	0	0	0	0	0	3	**3**
Total	**20151**	**9143**	**5841**	**5269**	**6656**	**1300**	**48360**

Source: Soarian/SCI-DC Comparison taken on May 2008

1. Unassigned due to no postcode available

Due to problems with extracting meaningful data from the information management supporting the diabetic retinopathy screening service, it was not possible to provide accurate data for a complete year. Therefore, a comparison of data between SCI-DC and Soarian was taken as at May 2008 (see Table 8.3).

As at May 2008, 35,118 (72.6%) patients were screened. 10.3% (4,998) people with diabetes were classified in Soarian as having not attended their appointment. This could be an underestimate of the current situation as approximately 20% of screening appointments are reported as "did not attend" by the service. 829 (1.7%) patients were suspended from the screening programme as they are already attending an ophthalmology clinic.

Table 9.3 Eligible population screened and status of screening

Status of Patient	Number	% of total
Total population	48360	100
Patients Suspended permanently	829	1.7
Patients suspended temporarily	3710	7.7
Did not attend (DNA)	4998	10.3
Patients already screened	35118	72.6
Patients invited for a screen	3705	7.7

Source: Soarian/SCI-DC comparaison

Service review

In February 2008, a full patient pathway review was undertaken to assess the effectiveness of the referral to ophthalmology process and the completeness of feedback received following attendance to ophthalmology clinics.

We carried out an indepth review of 682 patient case records. All patients who had been referred were attending ophthalmology clinics but the feedback following attendance to ophthalmology clinics was variable.

The service identified control measures that should be put in place that would allow the continuous monitoring of the delivery of the administrative tasks and the provision of feedback from ophthalmology clinics. This includes a "return receipt" for ophthalmology referrals.

An additional recommendation was made to allow direct access to the Diabetic Retinopathy Screening information management system in ophthalmology clinics. This is to be implemented by February 2009.

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 provide 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 patient with diabetes.

However, there are problems with the interface between SOARIAN and SCI-DC and work is progressing to integrate the diabetes information management systems across NHS Greater Glasgow and Clyde by April 2009. That will make possible the provision of combined reports on the NHS Greater Glasgow and Clyde Diabetic Retinopathy Screening programme.

Future developments

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

Outstanding issues

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

Challenges and future priorities

- Integration of the services It is now the intention of NHS Greater Glasgow and Clyde to bring the Greater Glasgow and Clyde services into a single management structure with a single IT system to manage patient screening and onward referrals. An organisational change process has been initiated to deliver a single management structure for the Diabetic Retinopathy Screening Service for NHS Greater Glasgow and Clyde. This process includes all of the current staff in both services who have been involved in agreeing future work processes for the integrated service.

- It is anticipated that the number of people with diabetes will increase that would require additional service capacity in the future.

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

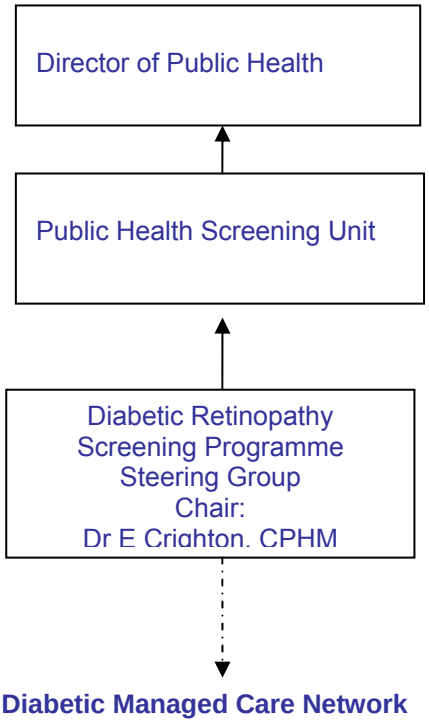
Appendix 9.1

Members of Diabetic Retinopathy Screening Steering Group
As at March 2008

Dr Emilia Crighton	Consultant in Public Health Medicine (chair)
Mrs Donna Athanasopolous	PERL Resources Co-ordinator
Mr Mark Darroch	HIT Joint Services Manager - Screening
Ms Janette Docherty	Medical Records Manager
Mrs Fiona Gilchrist	Screening Manager
Mrs Annie Hair	Head of Children's Services
Ms Marianne Hayward	Co-ordinator for MCN for Diabetes
Mrs Fiona Heggie	Clinical Nurse Co-ordinator
Mrs Annette Little	Information Analyst
Miss Denise Lyden	Project Officer
Miss Chris McNeill	Head of Assessment and Care Services
Mr Eddie McVey	Optometric Advisor
Ms Patricia Morrison	DRS Manager
Dr Alasdair Purdie	Consultant Ophthalmologist
Mr Keith Redpath	Director - West Dunbartonshire CHP
Mrs Elizabeth Rennie	Screening Manager
Ms Karen Ross	MCN & CDM Planning Manager
Mr David Sawers	DRS Service Manager
Dr William Wykes	Consultant Ophthalmologist

Appendix 9.2

Reporting Structure:
Diabetic Retinopathy Screening Steering Group



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CHAPTER 10 : PRE-SCHOOL VISION SCREENING

Background

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

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

Amblyopia and strabismus affects 3-6% of children, and although obvious squints are easily detected, refractive error and subtle squints often go undetected and thus amblyopia develops. Amblyopia can be treated using spectacle lenses to correct any refractive error and occlusion therapy - mainly eye patches. These treatments can be used alone or in combination. Treatment is most effective when the brain is still developing (in young children), and when the child 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 2003 and 28 February 2004, 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 the 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 Orthoptic Department that was in the same geographical sector as the nursery, unless the parent wished for the child to be seen in another Orthoptic Department that was closer to their home. A proportion of children requiring "further assessments" that comply with existing protocols were referred to the community optometrists. The assessment appointment involved a fuller vision examination. At that stage the examination determined if the screen was a false positive and no further action was required, or if the screen was positive and if so the specific disorder identified and treated.

Eligible population

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 2007/08, 13,124 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 9.1).

Table 10.1 shows the number of children eligible for screening for each geographical area; the number of children who were invited to be screened at the 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 10.1 Eligible Population for Pre-School Vision screening

	North		South		East		West		Clyde		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
Total number of eligible children[1]	**2149**	**100**	**4057**	**100**	**988**	**100**	**2435**	**100**	**3495**	**100**	**13124**	**100**
Number of children invited to be screened at hospital[2]	772	35.9	1588	39.1	866	87.7	704	28.9	859	24.6	**4789**	**36.5**
Number of children transferred out	58	2.7	104	2.6	33	3.3	64	2.6	43	1.2	**302**	**2.3**
Number of children already attending an eye clinic	19	0.9	26	0.6	4	0.4	27	1.1	195	5.6	**271**	**2.1**
Consent denied	19	0.9	28	0.7	1	0.1	12	0.5	3	0.1	**63**	**0.5**

Source: Screening Department

[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 and also children resident in East Glasgow

4,789 (36.5%) of the eligible children were invited to be seen by the hospital Orthoptics Department.

271 (2.1%) of eligible children were already attend an eye clinic.

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

Delivery of screening programme 2007/08

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Table 10.2 shows, by geographical sector, the total number of children screened and the split between nursery based screening and hospital based screening; the number and rate of children referred to an Optometrist for further assessment; and the overall uptake rate.

Table 10.2 Uptake rates for pre-school vision screening

	North	South	East	West	Clyde	Total
Number screened in Nursery	1234	2220	80	1562	2478	**7574**
Number screened in Hospital[1]	373	676	259	430	350	**2088**
Total Number Screened	1607	2896	339	1992	2828	**9662**
Did Not Attend Hospital Screening	399	912	607	274	397	**2562**
Number Eligible[2]	2149	4057	988	2435	3495	**13124**
% Uptake	**74.8**	**71.4**	**34.3**	**81.8**	**80.9**	**73.6**

Source: Screening Department

[1] Includes children absent from, or not registered with, a nursery and also children resident in East Glasgow

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

9,662 children were screened out of 13,124 eligible children in 2007/08. This gives an uptake rate of 73.6%%. The uptake rate varies across the geographical location from 34.3% in East Glasgow (due to lack of staff required to deliver the screening programme) to 81.8% in West Glasgow.

Children who could not be screened in the programme at the end of the school year were invited to the hospital Orthoptic Department for screening. This represents 15.9% (2088) of the total eligible population (13,124). This includes children resident in East Glasgow where staff shortage has prevented the delivery of screening in nurseries.

7,574 children were screened in a nursery setting; that represents 78.3% of all screened children and 57.7% of all eligible children.

Table 10.3 shows the results of screening split by screening settings for which data is available and geographical area.

7,084 (73.3%) of children screened had a normal result following screening.

Following screening, 2,578 (26.7%) children were referred for further assessments. Of these, 371 (3.8%) were referred to an Optometrist for further assessment. This represents 2.83% of the total eligible population. The data is incomplete for reporting purposes as the Clyde information cannot be easily collected.

Table 10.3 Screening Outcomes[1]

	North		South		East		West		Clyde		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
Normal Result (NAD) Nursery	863	69.9	1687	76.0	50	62.5	936	59.9	2002	80.8	5538	57.3
Normal Result (NAD) Hospital	259	69.4	571	84.5	167	64.5	250	58.1	299	85.4	1546	16.0
Total - Normal Result	**1122**	**69.8**	**2258**	**78.0**	**217**	**64.0**	**1186**	**59.5**	**2301**	**81.4**	**7084**	**73.3**
Referred for Assessment by Nursery	371	30.1	533	24.0	30	37.5	626	40.1	476	19.2	2036	21.1
Referred for Assessment by Hospital	114	30.6	105	15.5	92	35.5	180	41.9	51	14.6	542	5.6
Total - Referred for Assessment	**485**	**30.2**	**638**	**22.0**	**122**	**36.0**	**806**	**40.5**	**527**	**18.6**	**2578**	**26.7**
Total Number of Children Screened	**1607**		**2896**		**339**		**1992**		**2828**		**9662**	
Total number of children referred to an Optometrist [1]	**142**	**6.6**	**66**	**1.6**	**32**	**3.2**	**131**	**5.4**	**n/a**	**n/a**	**371**	**3.8**

Sources: Screening Department [1]; Orthoptic Department [2]

n/a = data is not available

Orthoptic Resource

Due to a national shortage of Orthoptists, one Orthoptist post in Glasgow Royal Infirmary remains unfilled despite earnest efforts to recruit to this post. Unfortunately the vacancy has impacted on the service being provided in parts of East Glasgow and north of the Clyde.

Orthoptic Sessions

The number of sessions devoted to screening for the pre-school intake in 2007/08 can be seen in **Table 10.4**. Clyde sessions could not be collected easily for reporting purposes and therefore the data in Table 9.4 is incomplete.

"Hospital" sessions refer to children called for screening to the local hospital because they were absent from nursery when the orthoptist was present and also those children not attached to a nursery, and also children from East Glasgow. This does not include referrals from the screening service to either the Hospital Eye Service HES or to the child's own optometrist.

Table 10.4 Orthoptic Sessions

Orthoptic Sessions	North	West	South	East	Clyde
Nursery	124	151	194	9	n/a
Hospital	30.5	42	64	18	n/a
Total Sessions	**154.5**	**193**	**258**	**27**	**n/a**

Source: Orthoptic Department
n/a = data not available

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

Information systems

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

The VisualWorks system supports the delivery of the programme in the Greater Glasgow area and plans are underway to implement the system in Clyde during 2008. Work is also planned to develop a more robust reporting tool.

Outstanding issues

Workforce for delivery of the screening sessions and implementing skill-mix in working practices.

Challenges and future priorities

The recruitment of staff to allow the delivery screening as agreed is a challenge and priority for the pre-school vision programme.

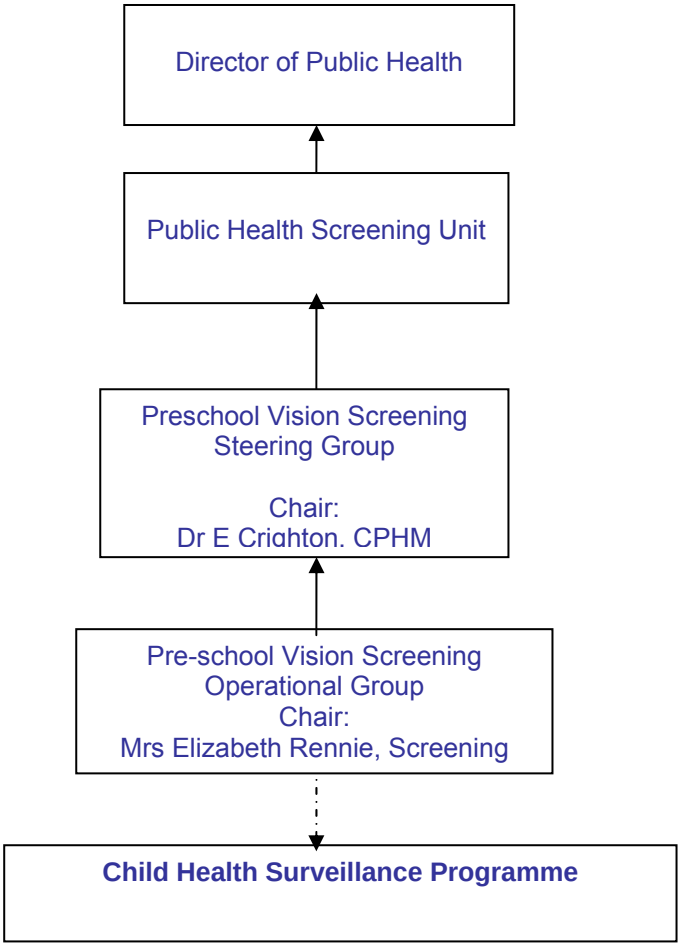
Appendix 10.1

Members of Pre-school Vision Screening Steering Group (as at March 2008)

Dr Emilia Crighton	Consultant in Public Health Medicine (chair)
Mrs Donna Athanasopolous	PERL Resources Co-ordinator
Mrs Joan Ballantyne	Head Orthoptist
Mrs Angela Carson	Head of Optometry
Ms Mary Cunningham	Clinical Service Manager
Ms Maggie Darroch	Optometrist
Ms Irene Forrest	Nursery Lead
Mrs Fiona Gilchrist	Screening Manager
Ms Susan Groom	General Manager
Ms Shogufta Haq	Health Promotion Officer
Mrs Marian Hodgeson	Head of Pre-Five Children Strategy
Mrs Annette Little	Information Analyst
Miss Denise Lyden	Project Officer
Mr Stephen McLeod	Planning Manager - Specialist Children's Services
Ms Linda Morris	Senior Health Promotion Officer
Mrs Elizabeth Rennie	Screening Manager
Mrs Elaine Salina	Principal Optometrist
Miss Debbie Speers	Secretary/Senior Support Officer

Appendix 10.2

Reporting Structure:
Pre-School Vision Screening Steering Group



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Acknowledgments

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