Public Health Screening Programmes

Annual Report

1 April 2012 to 31 March 2013

Version: 3.0
Published: 18 February 2014
Public Health – Health Services

CONTENTS

INTRODUCTION

This annual report presents information about the following screening programmes offered to residents across NHS Greater Glasgow and Clyde (NHSGGC) for the period 2012/13:

1. Cervical Screening

2. Breast Screening

3. Bowel Screening

4. Pregnancy Screening:
    - Communicable Diseases in Pregnancy
    - Haemoglobinopathies screening
    - Down's syndrome and other congenital anomalies

5. Newborn Screening:
    - Newborn Bloodspot
    - Universal Newborn Hearing

6. Diabetic Retinopathy Screening

7. Pre-School Vision Screening

8. Interim report on Aortic Abdominal Aneurysm Screening

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

In NHS Greater Glasgow and Clyde, the co-ordination of all screening programmes is the responsibility of the Public Health Screening Unit led by a Consultant in Public Health Medicine. Multidisciplinary Steering Groups for the programmes are in place and their remit is to monitor performance, uptake and quality assurance.

Reporting structures for Scottish public health screening programmes is currently under review. The proposed governance structure is illustrated in **Figure A.** Current governance arrangements for NHS Greater Glasgow and Clyde public health screening programmes is illustrated in **Figure B.**

Figure A: Proposed Scottish national reporting structures – National Public Health Screening Programmes

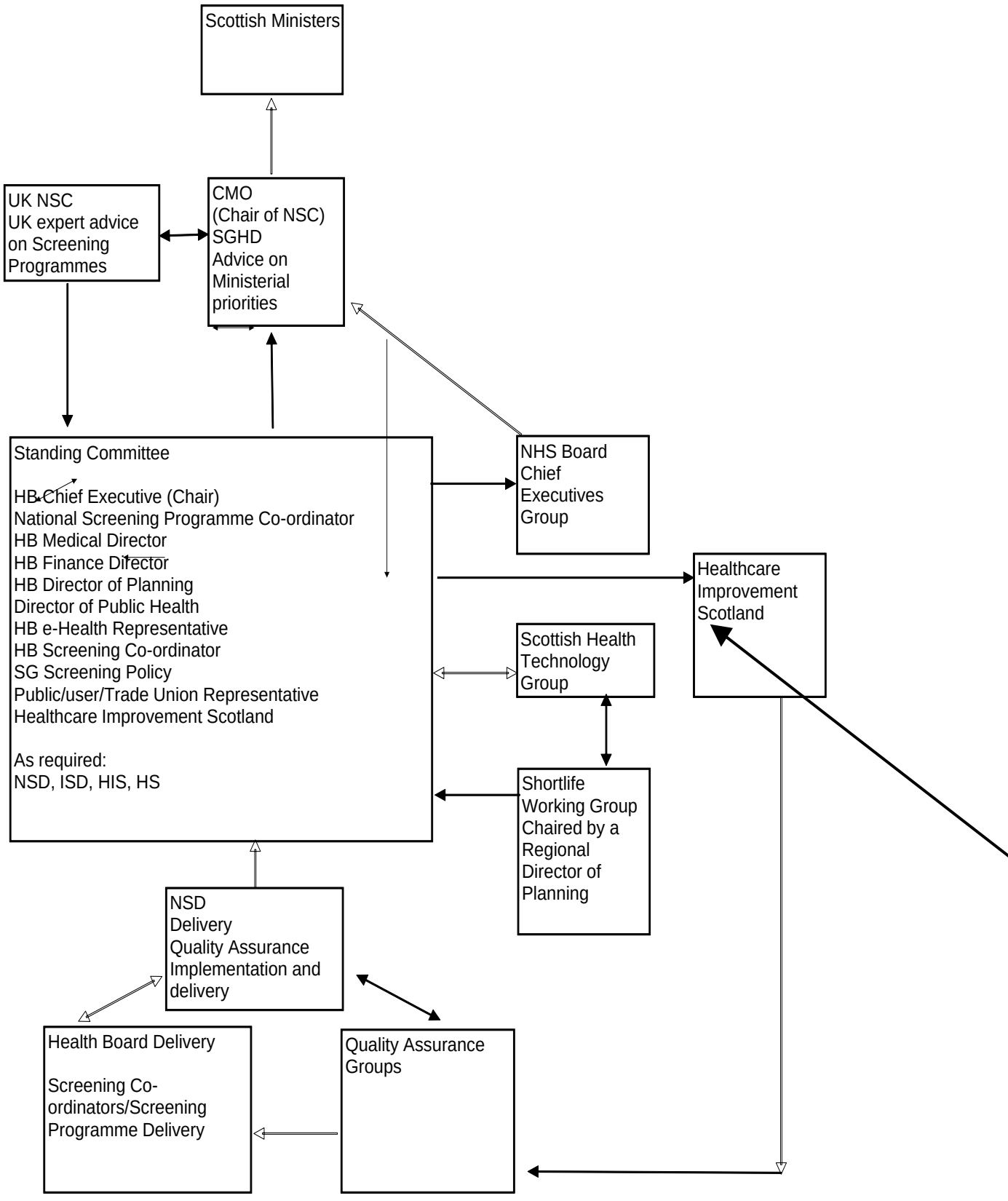
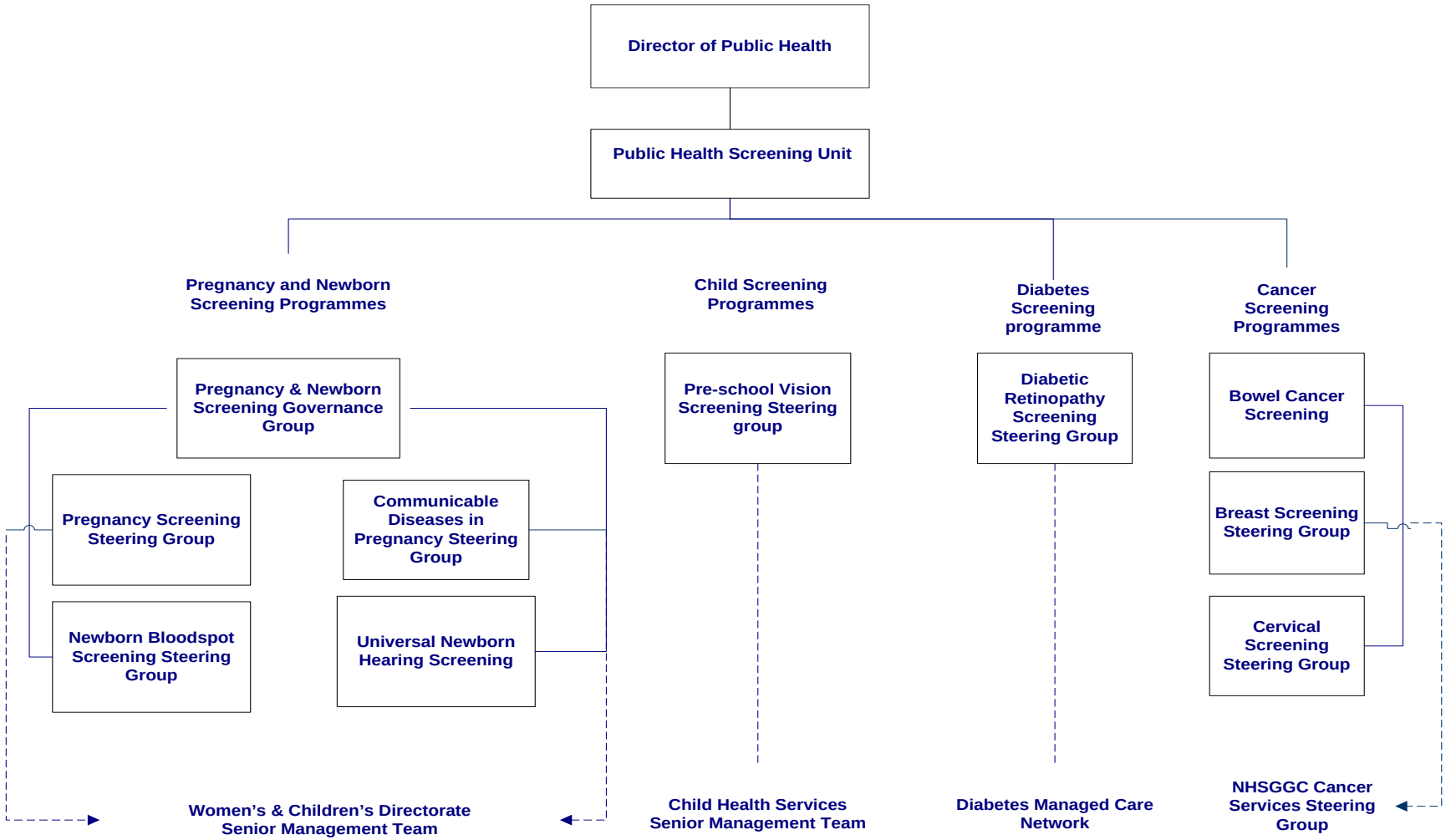


Figure A: Governance arrangements for the NHS Greater Glasgow and Clyde public health screening programmes



As the screening programmes stretch across the whole organisation, 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 Health Improvement Scotland which we strive to meet.

NHS Greater Glasgow and Clyde Public Health Screening Unit is committed to working in partnership with voluntary and statutory services to identify innovative ways to tackle inequalities in health and encourage uptake of screening programmes.

For the second year, this report will also include analysis on uptake among people with learning disabilities.

We cannot provide screening activity by ethnicity as the data is not available.

Table A shows the number of people eligible in NHS Greater Glasgow and Clyde in 2012/13 that were offered screening tests, the number of people who had taken up the offer of screening and the uptake rates for each of the screening programmes.

Table A: NHSGGC screening programmes uptake rates for the period 1 April 2012 to 31 March 2013

Screening programme	Total eligible population	Total number Screened	HIS Target	2012/13 % Uptake
Cervical screening[1]	347,841	261,243	80%	75.1%
Breast screening[2]	152,447	105,294	70%	69.1%
Bowel screening[3]	374,907	185,932	60%	49.6%
Pregnancy screening: • Communicable diseases in pregnancy [4]	14,074	13,384	No target	99.5%
• Down's syndrome	14,074	9,911	No target	70.4%
• Haemoglobinopathies	14,074	13,390	No target	95.1%
Newborn bloodspot Screening	13,915	13,086	No target	98.3%
Universal newborn hearing screening	14,903	14,475	No target	97.1%
Pre-school vision screening	13,795	12,010	No target	87.1%
Diabetic retinopathy Screening	53,502	46,988	80%	87.8%

Sources: NHSGGC bowel Screening IT system; West of Scotland Breast Screening; Scottish Cervical Call Recall System; PNBS; National Newborn Screening Laboratory; West of Scotland Prenatal Screening Laboratory; eSP; Visionworks, AAA

Notes:

1. Target population – number of women screened within 5.5 years
2. Target population – number of people screened within 3 years
3. Target population – number of people screened within 2 years
4. Percentage uptake of each of the tests has been calculated by dividing the number requesting tests by the total number of samples.
5. Screening activity covers the period 1 April 2012 to 31 March 2013

SUMMARY

CHAPTER 1: CERVICAL SCREENING

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

- 347,841 women were eligible to be invited to participate in the programme over three years.

- The 5.5 year uptake rate calculated for NHS Greater Glasgow and Clyde residents for 2012/13 was 75.1%**.** This was below the Scotland wide rate of 78.2% reported by ISD (2013) and the NHS HIS target of 80%.

- This represents an overall 0.9% decrease in uptake since 2011/2012. The lowest uptake of 65.7% was in Glasgow North West sector. East Dunbartonshire, East Renfrewshire, South Lanarkshire and North and South Lanarkshire exceeded the minimum standard of 80%.

- 64,414 (19.2%) did not take up the invite to have a smear despite a prompt letter and two reminders being sent and were classified as defaulters.

- The lowest 5.5 year uptake in 2012/13 was among the 21 to 24 year olds at 57% when only no cervix exclusion was applied. This represents a 2.8% decrease on previous year's uptake of 59.8%.

- The lowest 5.5 year uptake rate in 2012/13 was among women resident in the most deprived neighbourhoods at 73.6% when the no cervix exclusion was applied. Among women residents in the least deprived areas, uptake was higher at 79.6%.

- The uptake of cervical screening among women residents in the most deprived areas has decreased by 0.8% from 74.4% in 2011/12 to 73.6% in 2012/13. Uptake for women resident in the most affluent areas has decreased by 1.5% from 81.1% to 79.6% over the same period.

- 104,507 smear tests were processed and reported in laboratories in NHS Glasgow and Clyde. This represents an increase of 9.1% from the 95,874 smears processed in 2011/12.

- The overall percentage of unsatisfactory smears was 2.9% and above the Scottish average of 2.5%.

- 13.3% of smears were reported as abnormal after excluding unsatisfactory smears in 2012/13.

- 86.7% of smears processed were reported to be negative; 8.1% were borderline squamous; 3.4% mild dyskaryosis and 1.6% to have moderate to severe dyskaryosis

- Of the 6,408 patients referred to colposcopy for treatment, 4,728 (89.5%) were seen within 8 weeks.

- The performance of colposcopy units against benchmarking standards is now reviewed annually at the NHS Greater Glasgow & Clyde Colposcopy User Group. Where standards are not within the interquartile range, measures are identified and action plans introduced to improve performance.

- In 2012, we reviewed the case notes of all women who developed invasive cervical cancer.

- The largest number of cervical cancers occurred in women aged between 30 and 49 years.

- 39 cases of the 79 cases audited were screen detected.

- Over the five years audited, 51 (14.1%) women out of the 361 that developed cancer had never had a smear; 144 (39.8%) had complete smear histories and 161 (44.5%) of women had incomplete smear histories.

- In 2011, the most recent year for which completed data is available, the number of new cervical cancers registered among NHS Greater Glasgow and Clyde residents was 62. This gives a standardised incidence rate of 8.9 per 100,000 per population which is lower than that for Scotland at 10.7.

- In 2012, 32 women with a diagnosis of cervical cancer died in NHS Greater Glasgow and Clyde. This gives a standardised rate of 4.2 per 100,000 population compared to the Scotland rate of 4.1 per 100,000.

- Since 2008, all girls aged 12 to 13 years in their second year of secondary school are routinely offered vaccinations to protect them against the Human Papilloma Virus (HPV).

- Overall uptake across NHSGGC for the first dose of the HPV vaccination was 94.6% and 93.1% for the second dose. This was above the Scottish averages of 93.5% and 91.8% respectively. Uptake for the third dose was 78.8% which was below the Scottish average of 82%.

- Research was carried out in 2012 to identify the barriers to uptake in cervical screening among young women aged 21 - 35. Focus group findings were used to plan a social media campaign to address the three major issues that affect women taking up screening which are fear, pain and embarrassment. Three social media films will be developed and launched in early 2014.

- A training video for smear takers will be developed to improve and maintain professional skills as well as offering tips on addressing the barriers to low uptake in cervical screening. The video will be available for the Smear Taker training programme in May 2013.

CHAPTER 1: CERVICAL SCREENING

Background

Systematic cervical screening began in 1989 as part of the National Scottish Cervical Screening Programme (SCSP).

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

Aim of Screening Programme

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

Target Population

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

Screening Test

A “smear test” involves collecting cells from the surface of the cervix or ‘neck of womb’. The sample is then sent to a specialist laboratory. The cells are then examined under a microscope to see if any of them appear abnormal.

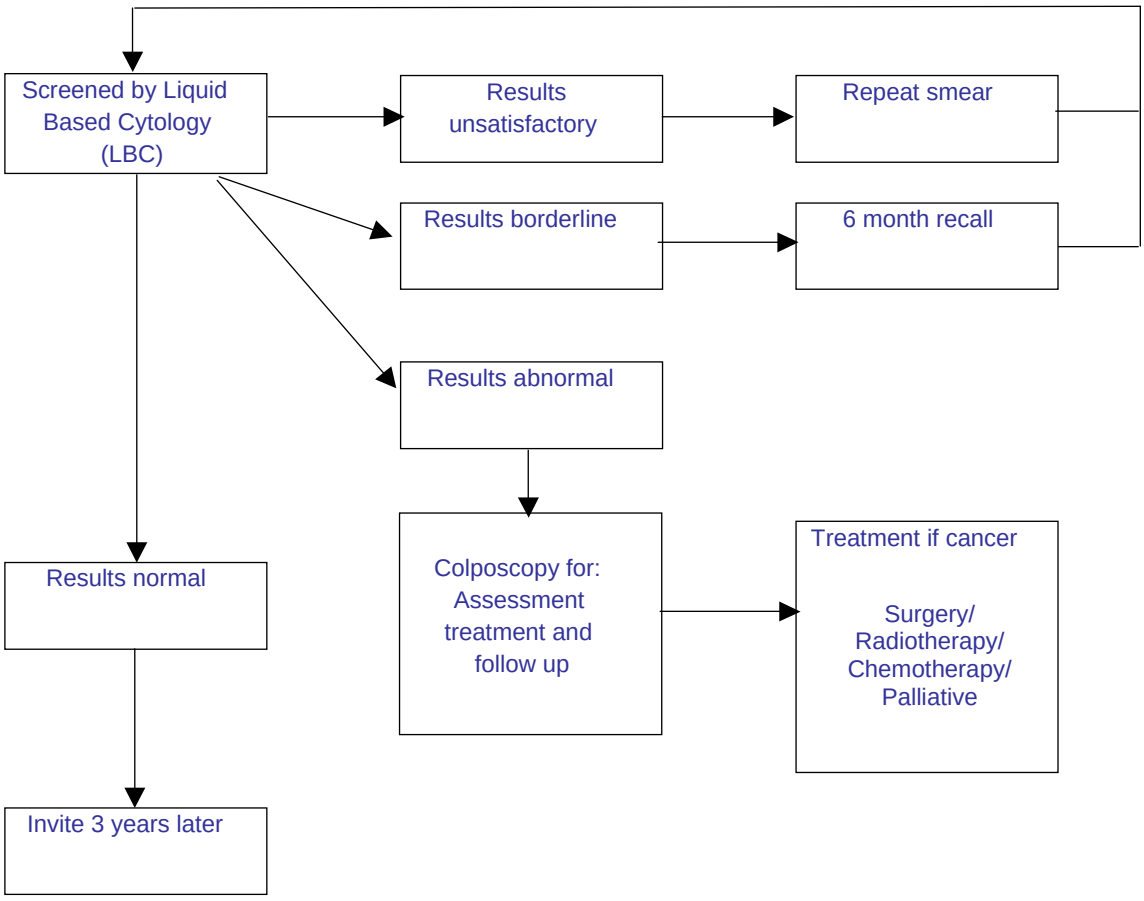
Liquid based cytology (LBC) is a way of preparing cervical samples for examination in the laboratory. The sample is collected using a special device which brushes cells from the neck of the womb. The head of the brush, where the cells are lodged, is broken off into a small glass vial containing preservative 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 then examined 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 (Appendix 1.1). Treatment of invasive cervical cancers follows agreed cancer treatment pathways.

Figure 1.1 Cervical Screening Pathway



Colposcopy Referral Pathway

Referral to colposcopy services is principally via the direct referral route whereby women with abnormal smears are appointed to the closest colposcopy department according to postcode of residence. Patients with a suspicious cervix, suspicious symptoms or other clinical reasons are referred to colposcopy through standard referral routes from primary or secondary care.

Colposcopy

Colposcopy services in NHS Greater Glasgow and Clyde (NHSGGC) are provided over six sites: Stobhill ACH, Victoria ACH, Sandyford Initiative, Royal Alexandra Hospital, Inverclyde Royal Hospital and the Vale of Leven Hospital.

Colposcopy services on each site have a lead colposcopist and all sites participate in the NHS Greater Glasgow & Clyde Colposcopy User Group to address quality assurance issues within the Colposcopy service. The NHS Greater Glasgow & Clyde Colposcopy User Group is represented on the National Colposcopy Quality Assurance Group and the National Colposcopy Clinical Information and Audit System (NCCIAS) User Group. Scottish wide benchmarking standards are available having been developed from The British Society for Colposcopy and Cervical Pathology (BSCCP) standards.

Delivery of Cervical Screening programme

Table 1.1 shows the numbers of women in the target and eligible populations for the cervical screening programme. There were 363,101 women aged 21 to 60 resident in NHS Greater Glasgow and Clyde in the target population. Following the exclusion of those with no cervix, 347,841 women were eligible to be invited to participate in the programme over three years. Approximately 115,947 women were sent an invitation to attend.

Table 1.1 NHSGGC Cervical Screening population

Year[5]	Target Population[1]	Eligible Population[2]			
		All eligible women minus no cervix[3] (N)	Target population minus no cervix (%)	All eligible women based on GMS Payments[4]	All eligible women based on GMS Payments[4] (%)
2000/01	360,361	338068.0	6.2		
2001/02	360,170	337,919	*6.2*		
2002/03	360,069	338,184	*6.1*		
2003/04	360,644	339,460	*5.9*	292,652	*18.9*
2004/05	358,617	338,291	*5.7*	273,106	*23.8*
2005/06	364,919	345,408	*5.3*	272,447	*25.3*
2006/07	359,436	340,446	*5.3*	272,104	*24.3*
2007/08[5]	362,828	344,252	*5.1*	268,484	*26.0*
2008/09[5]	362,845	344,882	*5.0*	251,844	*30.6*
2009/10[5]	361,918	344,589	*4.8*	245,742	*32.1*
2010/11[5]	366,275	349,492	*4.6*	278,943	*23.8*
2011/12[5]	355,579	340,559	*4.2*	268,512	*24.5*
2012/13[5]	363,101	347,841	*4.2*	274,472	*24.4*

Sources: 2000/01-2006/07 - CHI via Cervical Cytology system

2007/08 - 2012/13 - Scottish Cervical Call Recall System

Notes:

1 Women aged 21 to 60 years

2 Women aged 21 to 60 years except medically exempt women, as defined in 3 and 4

3 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 NHSGGC resident population and not practice population

The table also shows the numbers of women that were considered as eligible for cervical screening after applying the exclusions allowed by the General Medical Services contract.

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 preceding 12 months" under the exception reporting.

The 5.5 year uptake rate calculated for NHS Greater Glasgow and Clyde residents for 2012/13 was 75.1% **(see Table 1.2)**. This was below the Scotland wide rate of 78.2% reported by ISD (2013) and the NHS HIS target of 80%.

This represents an overall 0.9% decrease in uptake since 2011/2012. The lowest uptake of 65.7% was in Glasgow North West sector. East Dunbartonshire, East Renfrewshire, and North and South Lanarkshire exceeded the minimum standard of 80%.

Table 1.2 NHSGGC Comparative uptake rates of cervical screening by CH(C)P

CHP/ CHCP[1]	% Uptake - All Eligible Women (excluding women with No Cervix)			% Uptake - All Eligible Women (based on Target GMS Payments[3])		
	2010/11	2011/12	2012/13	2010/11[3]	2011/12	2012/13
Glasgow North East	70.4%	72.3%	71.7%	78.2%	81.7%	81.4%
Glasgow North West	66.0%	67.5%	65.7%	74.0%	78.4%	76.2%
Glasgow South	73.6%	75.1%	74.6%	80.0%	83.8%	83.3%
North Lanarkshire[2]	83.4%	83.9%	83.3%	88.2%	90.7%	89.2%
South Lanarkshire[2]	80.5%	81.5%	81.6%	86.2%	88.1%	88.5%
East Dunbartonshire	81.9%	82.6%	82.2%	86.5%	89.4%	88.7%
East Renfrewshire	81.4%	82.2%	82.2%	86.4%	89.5%	89.2%
Inverclyde	77.2%	78.0%	78.0%	82.3%	85.7%	84.8%
Renfrewshire	78.5%	79.8%	79.5%	84.2%	87.1%	86.4%
West Dunbartonshire	77.7%	78.6%	78.3%	83.5%	86.4%	85.1%
NHS GGC[4]	**74.5%**	**76.0%**	**75.1%**	**81.1%**	**84.0%**	**83.6%**

Source: Scottish Cervical Call Recall System

Notes:

1 CHP/CH(C)P has been derived by NHSGGC Resident population

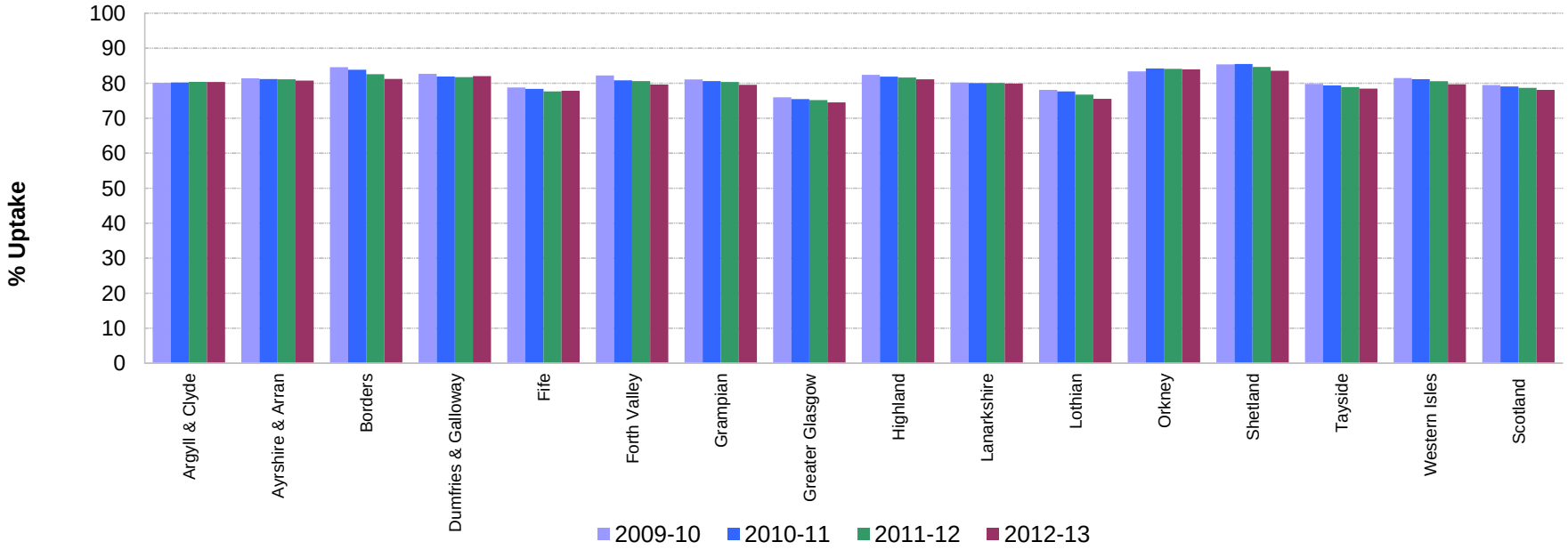
2 NHS GGC residents only

3 Uptake based on GMS target payments. Excludes women with exclusion categories as defined in the GP contract, implemented in 2004

4 Includes invalid and missing postcodes. Missing=not entered.Invalid=NHSGGC postcode but incorrect or new postcode and unable to derive CHP/CH(C)P

Figure 1.2 illustrates nationally published trends in cervical screening uptake for all Scottish Health Boards, based on the pre-2006 health boards configuration. There has been a slow decline in uptake for most health board areas, with the Scottish average for 2012/13 being 71.2%.

Figure 1.2: Trends in the % uptake of females aged 20-60 with a record of a previous screening test taken within last 5.5 years by NHS Board of Residence from 2009/10 to 2012/13



Source: ISD (2013)

* IMPORTANT: These data are based on the pre-2006 Health Board configuration (former Argyll & Clyde). Figures for NHS Highland do not include the Argyll & Bute area and figures for NHS Greater Glasgow do not include the Clyde area.

1. Based on adjusted Community Health Index (CHI) population denominator: 20-59 years (excluding medically ineligible women) for years 1995 to 1996 and 20-60 years (excluding medically ineligible women) for years 1997-1998 to 2006-07. Based on SCCRS population denominator (excluding medically ineligible women) for 2007-08.
2. Excludes Lothian NHS Board for 2000-01 to 2006-07 (data calculated on a different basis - calendar year).
3. For 2000-01 to 2006-07 data for Lothian NHS Board are calculated on a different basis - calendar year.

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

Data Source: ISD(D)4 SCCRS for 2007-08 data onwards

In NHS Greater Glasgow and Clyde, 347,591 eligible women (excluding women with no cervix), 64,414 (19.2%) did not take up the invite to have a smear despite a prompt letter and two reminders being sent and were classified as defaulters **(see Table 1.3).**

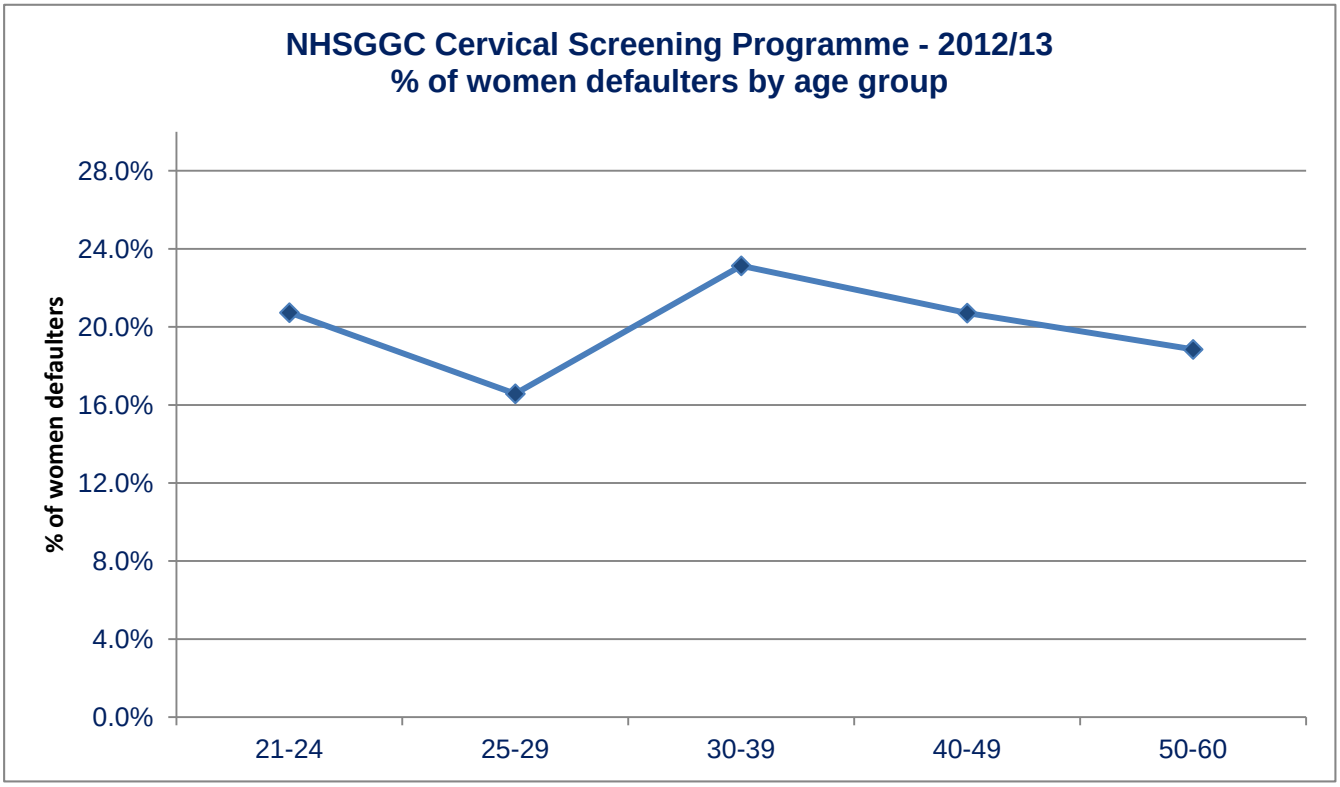
Table 1.3 shows the numbers and proportions of women excluded under the different exclusion categories. The highest proportion of women excluded under the GMS exception reporting as defaulted after three invites was among the 30 to 39 year olds (see **figure 1.3**).

Table 1.3 Number of women excluded from cervical screening programme by exclusion category

Reason for exclusion	No of Women Excluded	% of total eligible population
Pregnancy	992	0.3%
Co-Morbidity	21	0.0%
Opted Out	3,203	0.9%
Not Clinically Appropriate	2,116	0.6%
Terminally Ill	13	0.004%
Anatomically Impossible	56	0.0%
No Cervix	14,401	4.1%
No Further Recall	104	0.0%
Suspended	0	0.0%
Defaulter	68,414	19.2%
Transferred 0ut by SCCRs	0	0.0%
Total	**89,320**	**24.7%**

Source: 2012/13 - Scottish Cervical Call Recall System

Figure 1.3 Percentage of women excluded as defaulters by age



Source: 2011/12 – Scottish Cervical Call Recall System

Table 1.4 shows that the cervical screening uptake varied across different age groups. The lowest 5.5 year uptake in 2012/13 was among the 21 to 24 year olds at 57% when only no cervix exclusion was applied. This represents a 2.8% decrease on previous year's uptake of 59.8%. When exclusions allowed for the purpose of GMS target payments were made, uptake was 76.7% representing a decrease of 2.7% on previous year's uptake of 79.4%.

Table 1.4 NHSGGC Cervical screening uptake by age group

Age Group	All Eligible Women (excluding women with No Cervix[1)]					All Eligible Women (based on 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	40,393	22,043	54.6	23,021	57.0	25,385	19,146	75.4	19,458	76.7
25-29	49,501	30,746	62.1	34,941	70.6	37,333	27,935	74.8	29,661	79.4
30-39	85,581	59,087	69.0	66,795	78.0	68,662	54,745	79.7	57,907	84.3
40-49	90,517	65,691	72.6	73,227	80.9	75,514	62,460	82.7	65,414	86.6
50-60	81,849	55,955	68.4	63,259	77.3	67,578	53,937	79.8	56,926	84.2
Total	**347,841**	**233,522**	**67.1**	**261,243**	**75.1**	**274,472**	**218,223**	**79.5**	**229,366**	**83.6**

Source:- Scottish Cervical Call Recall System(2012/13)

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 1.5 shows that the cervical screening uptake rate varied across deprivation categories. The lowest 5.5 year uptake rate in 2012/13 was among women resident in the most deprived neighbourhoods at 73.6% when the no cervix exclusion was applied. Among women residents in the least deprived areas, uptake was higher at 79.6%.

The uptake of cervical screening among women residents in the most deprived areas has decreased by 0.8% from 74.4% in 2011/12 to 73.6% in 2012/13. Uptake for women resident in the most affluent areas has decreased by 1.5% from 81.1% to 79.6% over the same period.

Table 1.5 NHSGGC Cervical screening uptake by age and deprivation categories

SIMD[3]		Eligible Women	3.5 yr uptake Total	3.5 yr uptake %	5.5 yrs uptake Total	5.5 yrs uptake %	Eligible Women	3.5 yr uptake Total	3.5 yr uptake %	5.5 yrs uptake Total	5.5 yrs uptake %
Most Deprived	1	123,091	79,704	64.8	90,539	73.6	95,234	73,549	77.2	78,017	81.9
	2	60,253	39,795	66.0	44,766	74.3	47,225	37,141	78.6	39,106	82.8
	3	51,480	34,545	67.1	38,590	75.0	40,698	32,346	79.5	33,955	83.4
	4	49,478	33,410	67.5	36,941	74.7	39,063	31,494	80.6	32,865	84.1
Least Deprived	5	60,861	44,327	72.8	48,461	79.6	50,156	42,067	83.9	43,724	87.2
New/Incomplete postcodes[4]		2,678	1,741	65.0	1,946	72.7	2,096	1,626	77.6	1,699	81.1
Total		**347,841**	**233,522**	**67.1**	**261,243**	**75.1**	**274,472**	**218,223**	**79.5**	**229,366**	**83.6**

Source:- Scottish Cervical Call Recall System(2012/13)

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 2009

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

When calculations were made for the purpose of General Medical Services target payments, the uptake among women living in the most deprived neighbourhoods was 81.9% representing a decrease of 0.9% from 2011/12 uptake of 82.8%. Highest uptake of 87.2% was among residents living in least deprived areas and represents a decrease of 1.5% on 2011/12 uptake of 88.7%.

The comparative cervical screening uptake for women with learning disabilities by age group is shown in **Table 1.6.** The 5.5 years uptake for women with no cervix was 24.2% and represented a slight increase of 0.2% from 24% on previous year and is lower than the general population. The 5.5 years uptake based on the GMS contract decreased by 0.1% from 49.1% in 2011/2012 to 49% in 2012/13.

Table 1.6 NHSGGC Cervical Screening uptake of women with learning disability by age group

Age Group	All Eligible Women (excluding women with No Cervix[1)]					All Eligible Women (based on 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	118	17	14.4	18	15.3	34	15	44.1	16	47.1
25-29	227	50	22.0	57	25.1	113	48	42.5	55	48.7
30-39	362	85	23.5	97	26.8	170	79	46.5	82	48.2
40-49	511	115	22.5	134	26.2	236	113	47.9	122	51.7
50-60	491	93	18.9	108	22.0	206	91	44.2	97	47.1
Total	**1709**	**360**	**21.1**	**414**	**24.2**	**759**	**346**	**45.6**	**372**	**49.0**

Source: Scottish Call Recall System; NHS Greater Glasgow and Clyde Learning Disabilty LES extract Decemebr 2013

NHSGGC 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 NHS HIS standards requires the laboratories to process a minimum of 15,000 smears annually and this has been achieved.

These included repeat smears and smears taken at colposcopy as one woman can have more than one smear test. The total number of smear tests processed in 2012/13 was 104,507 and represents an increase of 8.3% from the 95,874 smears processed in 2011/12.

Table 1.7 Number of smear tests performed in NHS Greater Glasgow and Clyde laboratories

	Number of Smear Tests					
Year	**IRH***	**VOL***	**SGH**	**GRI**	**NHSGGC**	**Scotland**
2002/03	24,627	12,384	25,953	44,713	**107,677**	439,678
2003/04	23,607	12,052	25,824	44,422	**105,905**	429,522
2004/05	28,326	5,843	25,975	43,194	**103,338**	406,305
2005/06	36,166	n/a	23,160	44,035	**103,361**	410,241
2006/07	36,137	n/a	23,141	40,732	**100,010**	401,749
2007/08	30,955	n/a	23,742	39,684	**94,381**	373,340
2008/09	38,363	n/a	28,190	49,502	**116,055**	450,522
2009/10	34,166	n/a	25,138	46,025	**105,329**	415,497
2010/11	32,254	n/a	25,325	42,295	**99,874**	390,194
2011/12	31,120	n/a	23,460	41,199	**95,779**	408,838
2012/13	n/a	n/a	104,507	n/a	**104,507**	405,202

Sources: 2002-2007 Cervical Cytology System (CCS); 2007/13 - Labs : Telepath & SCCRs

Scotland figures from ISD Website

Notes:

GRI and IRH stopped reporting smears taken as at quarter ending 31st March 2012

VOL stopped reporting smears taken as at quarter ending 30th September 2004

Table 1.8 shows the proportion of the total cervical samples sent to each of the cytology laboratories that were reported as unsatisfactory smears in 2012/13. The overall percentage of unsatisfactory smears was 2.9% and above the Scottish average of 2.5%.

Table 1.8 Percentage of unsatisfactory smears reported in NHS Greater Glasgow and Clyde laboratories

Percentage of unsatisfactory smears of total number of smears						
Year	**IRH***	**VOL***	**SGH**	**GRI**	**NHSGGC**	**Scotland**
2002/03	5.9%	6.8%	5.9%	3.9%	**5.2%**	7.4%
2003/04	3.4%	4.6%	6.3%	3.9%	**4.4%**	3.9%
2004/05	2.7%	2.6%	2.2%	1.9%	**2.3%**	2.2%
2005/06	2.3%	n/a	2.9%	1.6%	**2.1%**	2.2%
2006/07	2.5%	n/a	3.0%	2.1%	**2.5%**	2.4%
2007/08	1.8%	n/a	2.7%	2.8%	**2.4%**	2.8%
2008/09	2.0%	n/a	2.7%	3.1%	**2.7%**	3.0%
2009/10	2.6%	n/a	2.9%	2.9%	**2.8%**	3.0%
2010/11	2.7%	n/a	2.6%	2.2%	**2.5%**	2.8%
2011/12	2.6%	n/a	2.9%	2.9%	**2.8%**	2.4%
2012/13	n/a	n/a	2.9%	n/a	**2.9%**	2.5%

Sources: 2002-2007 Cervical Cytology System (CCS); 2007/13 - Labs (SCCRs)

Scotland figures from ISD Website

Notes:

GRI and IRH stopped reporting smears taken as at quarter ending 31st March 2012

VOL stopped reporting smears taken as at quarter ending 30th September 2004

NHS Greater Glasgow and Clyde provided comparative performance feedback to individual smear takers based on the proportion of unsatisfactory smears reported.

To improve the skills of smear takers and reduce the number of unsatisfactory smears, NHS Greater Glasgow and Clyde introduced an in-house staff smear taker skills training programme in May 2010. A robust protocol to monitor smear takers' performance and support was implemented in 2012.

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 between 2002/03 and 2012/13. Abnormal smears results include: borderline, mild, moderate and severe dyskaryosis, severe dyskaryosis/invasive, glandular abnormality and adenocarcinoma. 13.3% of smears were reported as abnormal in 2012/13 representing an increase of 2.5% since 2011/12.

Table 1.9 Percentage of abnormal smears reported in NHS Greater Glasgow and Clyde laboratories

Percentage of Abnormal smear results of total satisfactory smears						
Year	**IRH***	**VOL***	**SGH**	**GRI**	**NHSGGC**	**Scotland**
2002/03	7.0%	8.3%	5.7%	10.0%	**8.1%**	7.3%
2003/04	7.6%	10.2%	5.2%	10.3%	**8.5%**	7.2%
2004/05	7.8%	7.4%	6.0%	9.8%	**8.2%**	7.2%
2005/06	7.6%	n/a	6.7%	10.7%	**8.7%**	7.4%
2006/07	8.2%	n/a	7.6%	10.2%	**8.9%**	7.6%
2007/08	8.5%	n/a	7.1%	11.1%	**9.3%**	7.7%
2008/09	9.6%	n/a	8.5%	10.9%	**9.9%**	8.4%
2009/10	8.9%	n/a	9.3%	11.8%	**10.3%**	8.7%
2010/11	9.8%	n/a	8.1%	13.2%	**10.8%**	9.4%
2011/12	8.8%	n/a	8.2%	13.8%	**10.8%**	9.1%
2012/13	n/a	n/a	13.3%	n/a	**13.3%**	9.7%

Source 2000-2007 Cervical Cytology System (CCS); 2007/13 - Labs (SCCRs)

Scotland figures from ISD Website

*IRH/VOL - includes unsatisfactory smears reported for Argyll and Bute area

GRI and IRH stopped reporting smears taken as at quarter ending 31st March 2012

VOL stopped reporting smears taken as at quarter ending 30th September 2004

Table 1.10 shows the detailed breakdown of smear results profile reported by NHSGGC laboratories.

Of the 104,507 smears tests received by the laboratories, 101,475 (97%) were processed. 86.7% of smears processed were reported to be negative; 8.1% were borderline squamous; 3.4% mild dyskaryosis and 1.6% to have moderate to severe dyskaryosis. Appendix 1.1 shows the management and follow up advice for cytology results.

Table 1.10 Result profiles by age band: 1 April 2012 to 31 March 2013 (compiled from quarterly reports)
All NHS Greater Glasgow and Clyde Laboratories

	Under 20	20 - 24	25 - 29	30 - 34	35 - 39	40 - 44	45 - 49	50 - 54	55 - 59	60 - 64	65 and Over	Total All Ages	% Satisfactory	Cumulative %	Total Ages 20-59	% Satisfactory	Cumulative %
Unsatisfactory	22	320	385	357	282	366	371	407	418	101	3	3,032			2,976		
%Total	**2.9**	**2.0**	**2.5**	**2.6**	**2.4**	**2.8**	**2.8**	**3.8**	**5.1**	**5.5**	**2.0**	**2.9**			**2.9**		
Negative	548	11,415	12,043	11,638	10,038	11,632	11,642	9,804	7,400	1,661	120	87,941	86.7	86.7	86,817	86.7	86.7
Borderline change in squamous cells	136	2,459	1,578	1,063	757	800	703	426	204	44	4	8,174	8.1	94.7	8,005	8.0	94.7
Borderline change in endocervical cells	0	6	19	23	25	20	19	9	1	2	0	124	0.1	94.8	123	0.1	94.9
Low grade dyskaryosis	32	1,135	789	468	282	279	207	116	74	21	13	3,416	3.4	98.2	3,356	3.4	98.2
High grade dyskaryosis (moderate)	6	274	279	164	98	83	48	33	12	6	3	1,006	1.0	99.2	991	1.0	99.2
High grade dyskaryosis (severe)	5	119	198	119	109	59	61	29	10	3	4	716	0.7	99.9	705	0.7	99.9
High grade dyskaryosis ? invasive	0	0	4	3	4	3	2	1	3	2	1	23	0.0	99.9	21	0.0	99.9
Glandular Abnormality	0	5	15	20	9	6	6	2	0	0	0	63	0.1	100.0	63	0.1	100.0
Endocervical Adenocarcinoma	0	0	0	0	0	0	0	0	0	0	0	0	0.0	100.0	0	0.0	100.0
Endometrial or other malignancy	0	0	0	1	0	1	3	0	2	2	3	12	0.0	100.0	7	0.0	100.0
Total including unsatisfactory results	**749**	**15,733**	**15,310**	**13,856**	**11,604**	**13,249**	**13,062**	**10,827**	**8,124**	**1,842**	**151**	**104,507**			**103,064**		
Total excluding unsatisfactory results	**727**	**15,413**	**14,925**	**13,499**	**11,322**	**12,883**	**12,691**	**10,420**	**7,706**	**1,741**	**148**	**101,475**			**100,088**		

	All Ages	20-59
Abnormal	13,534	13,271
% abnormal	13.3	13.3

Source: Scottish Cervical Call Receall System (SCCRs)

Report Definitions:

1 Smears are those processed at a Lab, independent of a woman's area of residence or where smeared

Table 1.11 shows the activity data across NHSGGC colposcopy service. In 2012/13, there were 14,375 patient episodes. New outpatient episodes include all patients attending colposcopy services; return episodes will include treatment visits following the diagnosis of cervical intra-epithelial neoplasia (CIN) in addition to standard follow up visits for colposcopy based indications.

Table 1.11 NHSGGC Colposcopy Service workload 1 April 2012 to 31 March 2013

Attendance Status	Type of Episode			Total Episodes
	New Outpatients	Return/ Follow Up Outpatients	Inpatients	
Patient was Seen (Attended)	5,023	5,129	101	10,253
Cancelled by Patient	413	719	0	1,132
Cancelled by Clinic or Hospital	6	219	0	225
Patient attended but was not seen (CNW)	6	11	1	18
Patient Did Not Attend	960	1787	0	2,747
Total	6,408	7,865	102	14,375

Source: National Colposcopy Clinical Audit System (extracted October 2013)

British Society for Colposcopy and Cervical Pathology (BSCCP) standards suggest that all patients should be seen within 8 weeks of referrals and that high grade cases should be seen within 4 weeks of referral. In NHSGGC, colposcopy service aim to see all high grade cases within 2 weeks of referral and low grade cases within 8 weeks of referral.

Table 1.12 illustrates that 89.5% of patients were seen within 8 weeks. Delays in referral to first appointment may also include patient induced delays.

Table 1.12 NHSGGC waiting times from referral to colposcopy appointment

Type of Referral	Less than or equal to 4 weeks (a)		Greater than 4 weeks and <= 8 weeks (b)		Greater than 8 weeks (c)		Total New Referrals
Unsatisfactory	31	46.3%	33	49.3%	3	4.5%	67
Borderline / Low Grade	751	33.4%	1162	51.7%	334	14.9%	2247
High Grade	1054	87.9%	101	8.4%	44	3.7%	1199
Glandular Neoplasia / Adenocarcinoma	41	78.8%	10	19.2%	1	1.9%	52
Clinical Indication	90	59.2%	46	30.3%	16	10.5%	152
Other	542	53.6%	371	36.7%	98	9.7%	1011
Total	**2509**	**53.1%**	**1723**	**36.4%**	**496**	**10.5%**	**4728**

Source: National Colposcopy Clinical Audit System (extracted October 2013)

Notes

New Referrals by Time Waited from Referral to First Appointment

Benchmarking standards have been derived and are reviewed by the national colposcopy Quality Assurance group to allow comparison between colposcopists, colposcopy units, and health boards.

The benchmarking standards for NHSGGC colposcopy units are shown in **Table 1.13.** The performance of colposcopy units against benchmarking standards is reviewed annually at the NHSGGC Colposcopy User Group. Where standards are not within the interquartile range, measures are identified and action plans introduced to improve performance.

Table 1.13 NHSGGC Colposcopy benchmarking standards for 2012/2013

	Total New Outpatient Attendances	New Outpatient Attendances Abnormal Screening Smear	Cyto-reversion rates at 4 - 12 months after treatment if a smear is taken %	Confirmed histological treatment failures at 12 months %	Adequacy of cervix biopsy for histology %	Proportion of women, referred with abnormal cytology, where SCJ is visualised, treated at 1st visit with CIN on histology %	New referral for high grade dyskaryosis having biopsy %	Recommended for treatment as Inpatient %
TARGET	None	>= 50 (per annum)	> 90%	<= 5%	> 97%	>= 90%	> 90%	< 20%
SCOTLAND	13598	10534	91.1	3.1	98.5	83.5	92.6	7.7
Greater Glasgow & Clyde	**4714**	**3386**	**89.6**	**3.6**	**97.8**	**83.4**	**92.1**	**9.6**
Glasgow Royal Infirmary	2	1	62.5	10.0	100.0	0.0	0.0	0.0
Inverclyde Royal Hospital	239	162	87.5	0.0	100.0	93.1	78.4	30.5
New Victoria Hospital	1512	857	89.2	2.0	96.2	88.4	94.0	7.4
Royal Alexandra Hospital	414	370	89.1	1.7	99.3	85.7	93.7	9.6
Sandyford	334	179	84.9	2.8	98.6	87.1	94.6	5.0
StobhillHospital	2073	1698	91.2	2.1	97.9	79.8	92.7	9.3
Vale of Leven District General Hospital	140	119	92.5	43.1	99.5	0.0	81.8	6.5
Western Infirmary	0	0	0.0	0.0	0.0	0.0	0.0	0.0

Source: NCCIAS; Data extracted October 2013

Test of cure

In May 2012, NHSGGC implemented “test of cure” for women treated at Colposcopy for cervical disease (CIN 1, CIN2 and CIN 3). This involves testing follow up smear samples for HPV in addition to cytological examination. The combined algorithm allows the return to normal 3 yearly recall for approximately 1,300 women per annum whose HPV and ctytological result is normal.

Previously women with one mild dyskaryosis smear result were referred to colposcopy. Women are referred to colposcopy after two mild dyskaryosis smear results.

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 2012, we reviewed the notes of 79 women who developed invasive cervical cancer and had a pathology diagnosis made in NHS Greater Glasgow and Clyde laboratories.

Table 1.14 shows numbers and the distribution of women’s age at diagnosis for years 2008 to 2012. The largest number of cervical cancers occurred in women aged between 30 and 49 years.

Table 1.14 Number of NHSGGC residents with invasive cervical cancers by age at diagnosis and year of diagnosis

Age at Diagnosis	Year of Diagnosis				
	2008	2009	2010	2011	2012
20-29	8	7	10	7	12
30-39	19	15	26	17	29
40-49	11	23	27	11	18
50-59	10	8	8	11	7
60-69	3	8	5	8	7
70-79	2	6	11	8	5
80+	2	4	3	3	1
Unknown	0	1	0	0	0
Total	**55**	**72**	**90**	**65**	**79**

Source: NHSGGC Invasive Cancer Audit

Table 1.15 shows the distribution of clinical stage at diagnosis over a five year period from 2008 to 2012.

Table 1.15 Number of women with invasive cervical cancers by clinical stage and by year of diagnosis

Clinical stage of diagnosis	2008	2009	2010	2011	2012	Total
1a1, 1a2 or 1b	29	41	40	29	47	186
2 or greater (spread outwith cervix)	26	28	43	35	30	162
No Details		3	7	1	2	13
Total	**55**	**72**	**90**	**65**	**79**	**361**

Source: NHSGGC Invasive Cancer Audit Database

Table 1.16 shows that, in 2012, 39 of the 79 cases were screen detected. The rest of the cases presented to the service with symptoms. Some of the screen detected cancers might have had an opportunistic smear while presenting with genital tract complaints.

Table 1.16 Number of women with invasive cancers split by modality of presentation and year of diagnosis

Modality of Presentation	Year of diagnosis				
	2008	2009	2010	2011	2012
Screen Detected	26	25	27	19	39
Symptomatic	14	10	20	10	15
No Details	15	37	43	36	25
Total	**55**	**72**	**90**	**65**	**79**

Source: NHSGGC Invasive Cancer Audit Database

Table 1.17 shows that, in 2012, 34 women of 79 women had a complete smear history compared to 38 women who had incomplete smear histories.

Over the five years audited, 51 (14.1%) women out of the 361 that developed cancer had never had a smear; 144 (39.8%) had complete smear histories and 161 (44.5%) of women had incomplete smear histories

Table 1.17 Smear histories of women with invasive cervical cancer

Smear History	Year of diagnosis					Total
	2008	2009	2010	2011	2012	
Complete	26	27	31	26	34	144
Incomplete	24	29	45	25	38	161
Not Applicable	5	16	12	12	6	51
Unknown			2	2	1	4
Total	**55**	**72**	**90**	**65**	**79**	**361**

Source: NHSGGC Invasive Cancer Audit Database

* Apart from index smear ie the abnormal smear causing referral

Table 1.18 shows the follow up status of the women included in the audit of invasive cancer at the time when the audit was carried out.

Table 1.18 Follow up status of the women with invasive cervical cancer

Status	Year diagnosis				
	2008	2009	2010	2011	2012
Death	2	0	6	8	5
Early recall	0	0	0	0	2
Lost to colposcopy service	1	0	1	0	1
On follow up at colposcopy	14	20	25	11	27
On follow up at oncology/Beatson	37	48	52	41	43
Unknown	1	4	6	5	1
Total	**55**	**72**	**90**	**65**	**79**

Source: NHSGGC Invasive Cancer Audit database

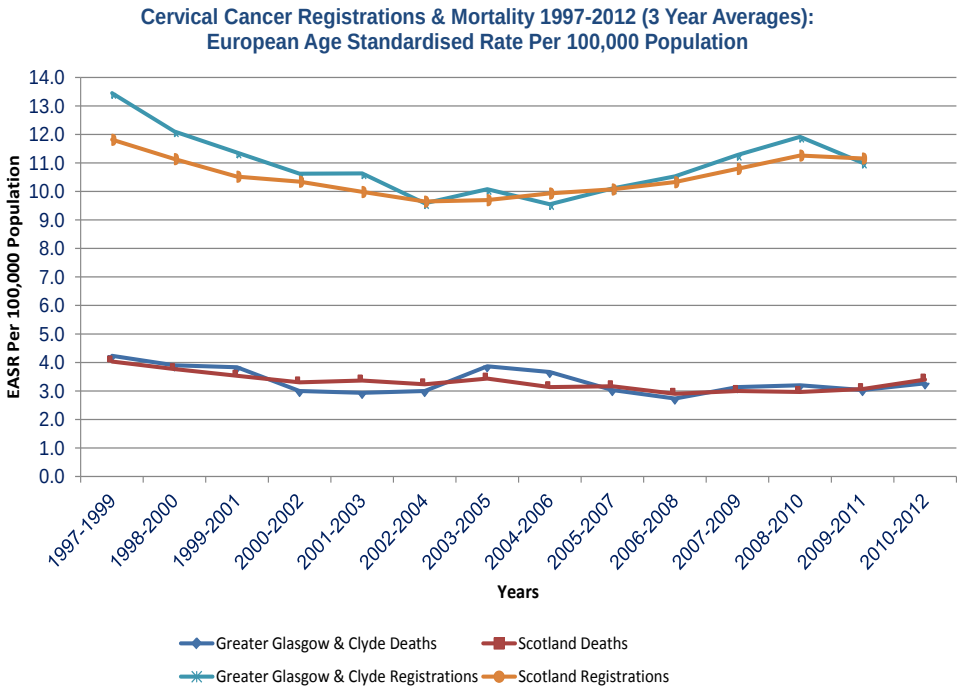
Morbidity and mortality from cervical cancer in NHS Greater Glasgow and Clyde and Scotland

In 2011, the most recent year for which completed data is available, the number of new cervical cancers registered among NHS Greater Glasgow and Clyde residents was 62 (see **table 1.19)**. This gives a standardised incidence rate of 8.9 per 100,000 per population which is lower than that for Scotland at 10.7.

Figure 1.4 illustrates that the standardised incidence and mortality rates for cervical cancer for NHS Greater Glasgow and Clyde and Scotland.

In 2012, 32 women with a diagnosis of cervical cancer died in NHS Greater Glasgow and Clyde. This gives a standardised rate of 4.2 per 100,000 population. The age standardised death rate for NHS Greater Glasgow and Clyde is slightly higher than the Scotland rate of 4.1 per 100,000.

Figure: 1.4 Cervical cancer registrations and deaths for NHS Greater Glasgow and Clyde and Scotland



Source: Scottish Cancer Registry, March 2013; National Records Scotland, September 2013

Table 1.19 Cervical Cancer Registrations and Deaths for the period 1997 - 2012

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
Greater Glasgow & Clyde																
Deaths																
Number	32	37	33	23	30	14	22	33	36	17	19	27	26	20	22	32
Standardised rate per 100,000 pop	4.1	4.4	4.2	3.1	4.2	1.7	2.9	4.4	4.3	2.3	2.5	3.4	3.5	2.7	2.9	4.2
Lower 95% Confidence Interval	2.7	3	2.8	1.9	2.8	x	1.8	2.9	3.0	x	x	2.2	2.2	1.6	1.8	2.8
Upper 95% Confidence Interval	5.8	6	5.9	4.5	5.9	x	4.3	6.1	5.9	x	x	4.9	5.0	4.0	4.3	5.9
Registrations																
Number	96	109	79	71	88	63	70	68	70	62	76	77	75	90	62	
Standardised rate per 100,000 pop	14.2	15.1	11.1	10.1	12.9	8.9	10.2	9.7	10.3	8.6	11.4	11.6	10.8	13.3	8.9	
Lower 95% Confidence Interval	11.4	12.3	8.7	7.9	10.3	6.8	7.9	7.5	8.0	6.5	8.9	9.1	8.5	10.6	6.8	
Upper 95% Confidence Interval	17.3	18.2	13.7	12.7	15.7	11.2	12.8	12.3	13.0	10.9	14.1	14.4	13.5	16.2	11.3	
Scotland																
Deaths																
Number	144	145	122	117	113	100	120	102	127	92	105	102	107	99	108	112
Standardised rate per 100,000 pop	4.3	4.1	3.7	3.5	3.4	3.0	3.7	3.0	3.6	2.8	3.1	2.8	3.1	3.0	3.1	4.1
Lower 95% Confidence Interval	*3.6*	*3.4*	*3.1*	*2.8*	*2.8*	*2.4*	*3.0*	*2.4*	*3.0*	*2.2*	*2.5*	*2.3*	*2.5*	*2.4*	*2.5*	3.4
Upper 95% Confidence Interval	*5.1*	*4.9*	*4.5*	*4.2*	*4.1*	*3.7*	*4.4*	*3.6*	*4.3*	*3.4*	*3.8*	*3.5*	*3.8*	*3.6*	*3.7*	4.9
Registrations																
Number	359	369	313	302	309	292	266	284	298	292	293	314	328	332	313	
Standardised rate per 100,000 pop	12.3	12.5	10.6	10.3	10.7	10.1	9.2	9.7	10.2	9.9	10.1	11.0	11.3	11.5	10.7	
Lower 95% Confidence Interval	11.0	11.3	9.4	9.1	9.5	8.9	8.1	8.6	9.1	8.7	8.9	9.8	10.1	10.3	9.5	
Upper 95% Confidence Interval	13.6	13.9	11.9	11.5	11.9	11.3	10.3	10.9	11.5	11.1	11.3	12.3	12.6	12.8	11.9	

Notes:

Cancer of the cervix uteri (ICD-10 C53)

Mortality Source: National Records of Scotland (NRS)
Data extracted: September 2012

Registrations
Source: Scottish Cancer Registry, ISD
Data extracted: March 2012

'-' = zero value.

'x' = not applicable.

Information systems

Scottish Cervical Call Recall System (SCCRS)

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

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.

HPV Vaccination

Since 2008, all girls aged 12 to 13 years in their second year of secondary school are routinely offered vaccinations to protect them against the Human Papilloma Virus (HPV). There are two types of HPV that cause 70% of cases of cervical cancers. The HPV vaccine does not protect against all cervical cancers so regular cervical screening is still important (ISD, 2011).

Table 1.20 shows the interim uptake rates for S2 routine cohort by the end of the school year by CHP for school year 2012/13.

Overall uptake across NHSGGC for the first dose of the HPV vaccination was 94.6%, and 93.1% for the second dose. This was above the Scottish averages of 93.5% and 91.8% respectively. Uptake for the third dose was 78.8% which was below the Scottish average of 82%.

Table 1.20: Interim annual HPV immunisation uptake rates for the S2 routine cohort by CHP for school year 2012/13[1];

Final uptake rates one year later for this S2 routine cohort of girls in 2012/13 will be published in September 2014.

Community Health Partnership[3]	Number of girls in cohort[2]	Number 1st dose	% uptake of 1st dose	Number 2nd dose	% uptake of 2nd dose	Number 3rd dose	% uptake of 3rd dose
East Dunbartonshire CHP	572	548	95.8	539	94.2	476	83.2
East Renfrewshire CH&CP	556	525	94.4	523	94.1	468	84.2
Glasgow City CHP[4]	2,828	2,643	93.5	2,585	91.4	2,077	73.4
Inverclyde CHP	398	382	96.0	382	96.0	374	94.0
Renfrewshire CHP	977	940	96.2	927	94.9	805	82.4
West Dunbartonshire CHP	504	484	96.0	476	94.4	397	78.8
NHSGG Total	**5,835**	**5,522**	**94.6**	**5,432**	**93.1**	**4,597**	**78.8**
Scotland[3]	**27,195**	**25,424**	**93.5**	**24,957**	**91.8**	**22,302**	**82.0**
Glasgow City CHP sectors[5]:							
Glasgow North East	880	831	94.4	812	92.3	641	72.8
Glasgow North West	786	742	94.4	727	92.5	594	75.6
Glasgow South	1,162	1,070	92.1	1,046	90.0	842	72.5

Source: CHSP School (May 2013)/SIRS (August 2013)

1. Uptake rates are based on immunisations recorded on the CHSP School system and SIRS as at 14 August 2013. Final uptake rates for these girls one year later will be published in September 2014.

Health Improvement

Research was carried out in 2012 to identify the barriers to uptake in cervical screening among young women aged 21 - 35. Focus Group findings were used to plan a social media campaign to address the three major issues that affect women taking up screening which are fear, pain, and embarrassment. Three social media films will be developed and launched in early 2014. The films will be available on NHSGGC website and Youtube. Health Improvement teams and health professionals can use the films to aid discussion with women on the benefits of cervical screening.

In addition, a training video for smear takers will be developed to improve and maintain professional skill as well as offering tips on addressing the barriers to low uptake in cervical screening. The video will be available for the Smear Taker training programme in May 2013.

Challenges and future priorities

- To continue efforts to target the most deprived and vulnerable population groups to improve uptake of cervical screening and attendance at colposcopy clinics through social marketing and health improvement teams engaging with community groups.

- Continue providing smear taker skills update training programme to further reduce the number of unsatisfactory smears.

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.
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)

Appendix 1.2

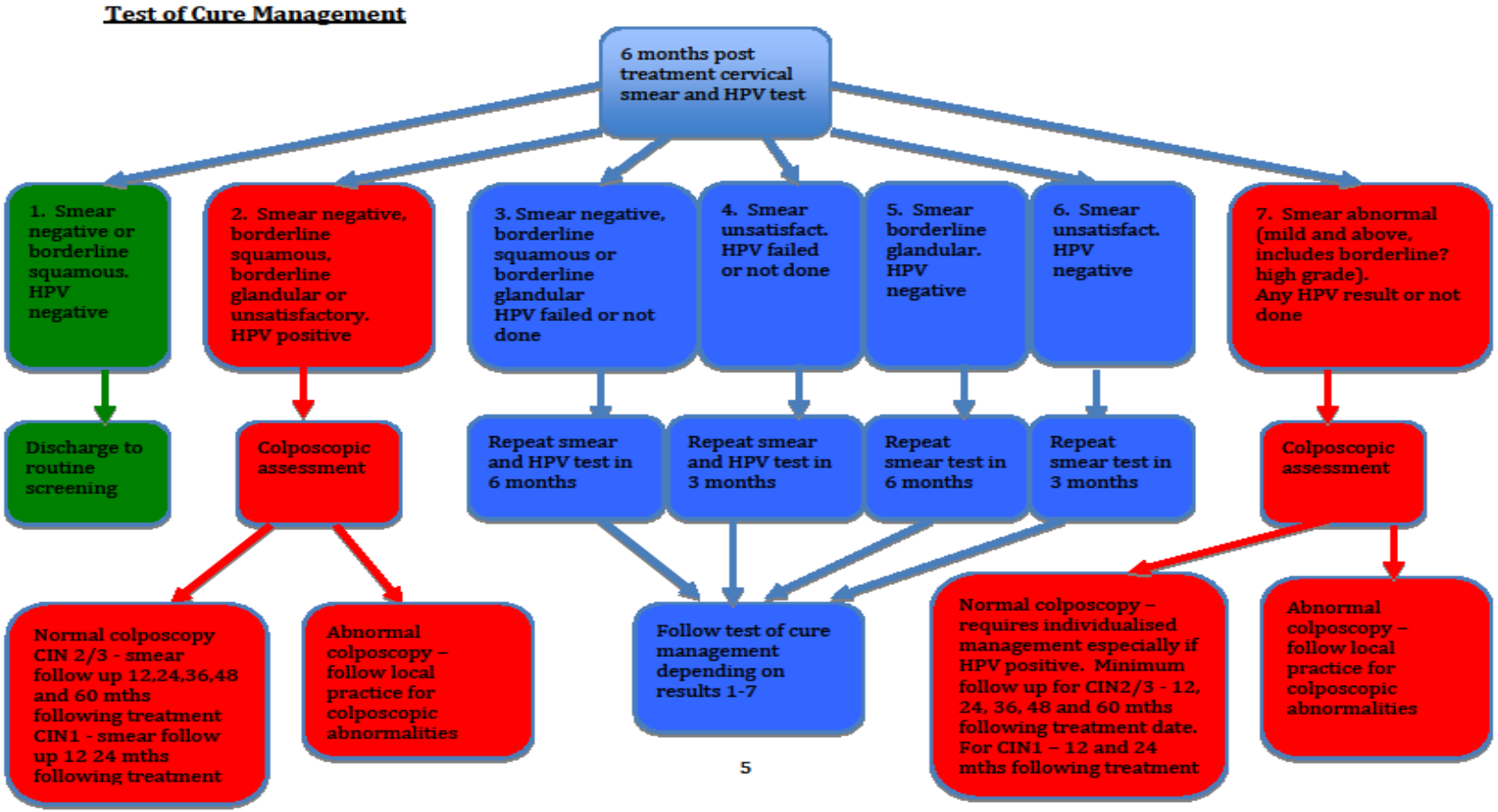
Management and follow up for cytology results: Post Total Hysterectomy

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 1.3

Management and follow up for cytology post treatment cervical smear and HPV test (Test of Cure)



Appendix 1.4

Members of Cervical Screening Steering Group (As at March 2013)

Dr Emilia Crighton	Consultant in Public Health Medicine (Chair)
Dr Margaret Burgoyne	Head of Service, Pathology
Dr Kevin Burton	Consultant Gynaecologist
Mrs Elaine Garman	Public Health Specialist, NHS Highland
Mrs Fiona Gilchrist	Assistant Programme Manager, Screening Dept
Dr Tamsin Groom	Consultant in Sexual and Reproductive Health Medicine
Mrs Gillian Halyburton	Primary Care Nurse Advisor
Mrs Kathy Kenmuir	Primary Care Support Nurse
Dr Margaret Laing	Staff Grade in Cytology/Colposcopy
Mrs Annette Little	Information Analyst
Miss Denise Lyden	Project Officer
Mrs Lin Calderwood	HI&T Service Delivery Manager
Ms Jane McNiven	Practice Manager
Dr Alan Mitchell	Clinical Director Renfrewshire CHP
Mrs Elidhi O'Neill	Health Visitor, West Dunbartonshire CHP
Mrs Christine Paterson	Primary Care Support Nurse
Mrs Elizabeth Rennie	Programme Manager, Screening Dept
Ms Claire Donaghy	Health Improvement Senior (Cancer)
Ms Jackie Wright	Practice Nurse

SUMMARY

CHAPTER 2: BREAST SCREENING

- This report represents interim screening round data from 1 April 2012 to 31 March 2013.

- 152,447 women registered with a practice in NHS Greater Glasgow and Clyde area were invited to attend breast screening. These included women living in other NHS board areas as data cannot be excluded from analysis.

- 105,294 (69.1%) women attended breast screening during the previous three years. This represents a decrease of 0.7% since 2011/12 when uptake was 69.8%. The minimum standard is 70%.

- There were 737 (0.7%) women who were diagnosed with breast cancer following screening.

- In 2011, the number of new breast cancers registered in NHS Greater Glasgow and Clyde was 974. This gives a standardised incidence rate of 126.7 per 100,000 per population which is lower than that for Scotland (130.1).

- In 2012, there were 237 deaths from breast cancer, giving a standardised rate of 26.6 per 100,000 population. This is slightly higher than that for Scotland (25.8).

- For the period 2009 to 2012, a total number of 4,145 breast cancers were detected. 507 (12.2%) were potential interval cancers; 1,250 (30.2%) were screen detected and 2,388 (57.6%) were symptomatic (Table 2.4). There has been a year on year increase in the number of cancers detected since 2009 to 2012.

- To capitalise on the planned national Detect Cancer Early social marketing campaign of 2013, NHS Greater Glasgow & Clyde has developed a local social marketing campaign to reinforce the DCE breast cancer messages and encourage women to take up breast screening. This will include direct marketing, public relations and health improvement initiatives.

CHAPTER 2: BREAST SCREENING

Background

Breast cancer is the most common cancer in women in Scotland. Incidence rates continue to rise with a 10% increase over the last decade. This is partly due to increased detection by the Scottish Breast Screening Programme and to changes in the prevalence of known risk factors, such as “age at birth of first child, decreases in family size, increases in post menopausal obesity and alcohol consumption” (Information Services Division, 2011).

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.

This report represents interim screening round data from 1 April 2012 to 31 March 2013.

Aim of Screening Programme

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

Eligible Population

Women aged 50-70 years are invited for a routine screen once every three years. Women aged over 70 years are screened on request.

The Screening Test

The screening method used consists of two mammographic views.
The test is a straightforward procedure involving two images 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 units that visit pre-established sites across the NHS Greater Glasgow and Clyde area.

Screening Pathway

Every woman registered with a GP receives 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. A woman can request a screening appointment when she turns 50 providing her practice is not being screened in the next six months. The West of Scotland Breast Screening Centre also contacts all long-stay institutions to offer screening to eligible residents.

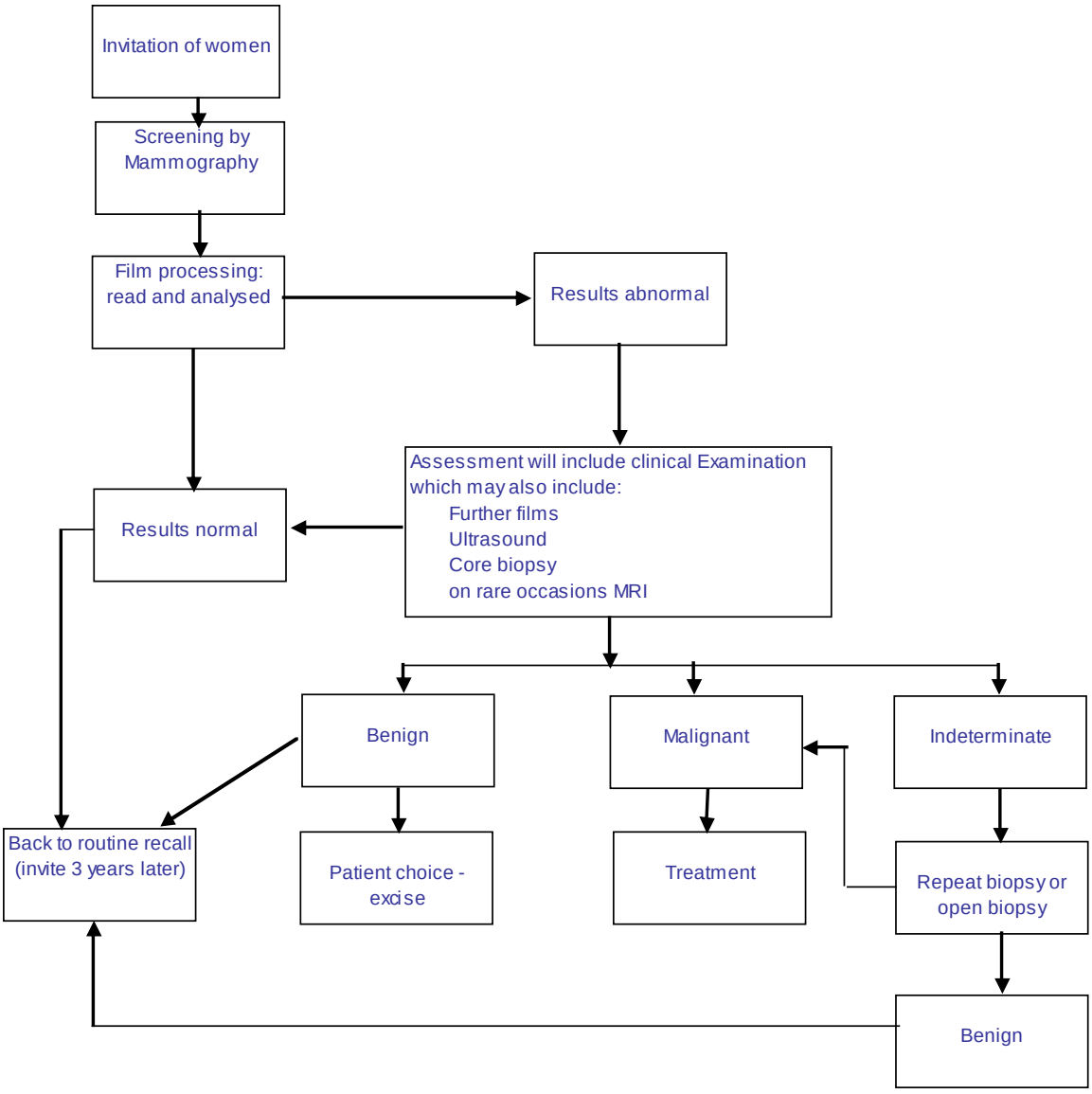
The mammograms taken during the screening visit are examined and the results sent to the woman and her GP. A proportion of women attending for screening will be recalled if the mammogram was technically inadequate or will be asked to go to an assessment clinic for further tests if a potential abnormality has been detected. Tests may include further imaging, clinical examination and possibly ultrasound and biopsy if required.

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, 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, Victoria ACH, Stobhill ACH and Royal Alexandra Hospital and a small proportion of women with palpable tumours are referred for treatment to local breast teams.

Figure 2.1 Screening pathway



Delivery of NHSGGC Breast Screening Programme

In 2012/13, there were 158,700 women eligible for breast screening across the area of Greater Glasgow and Clyde **(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 band and CH(C)P

CHP	Total Screening Population - 3 year round					Screening Population per year[2]
	50-54	55-59	60-64	65-70	50-70	
East Dunbartonshire	4,549	4,051	3,631	4,072	16,303	5,434
East Renfrewshire	3,752	3,304	2,812	3,194	13,062	4,354
Glasgow North East	6,887	5,472	4,351	4,717	21,427	7,142
Glasgow North West	6,749	5,586	4,461	4,585	21,381	7,127
Glasgow South	8,376	7,139	5,426	5,684	26,625	8,875
Inverclyde	3,406	2,767	2,502	2,789	11,464	3,821
North Lanarkshire [1]	752	643	599	679	2,673	891
Renfrewshire	7,128	6,061	5,410	5,952	24,551	8,184
South Lanarkshire [1]	2,340	2,234	1,861	1,853	8,288	2,763
West Dunbartonshire	3,713	3,364	2,795	3,054	12,926	4,309
NHSGG&C	**47,652**	**40,621**	**33,848**	**36,579**	**158,700**	**52,900**

Source: CHI - Extracted August 2013

Note:

[1] NHS Greater Glasgow and Clyde only

[2] Screening population is the total population aged 50-70 divided by 3 years

Table 2.2 shows the numbers and the proportion of the eligible population invited; numbers screened and the uptake rate split by Community Health (and Care) Partnership (CH(C)P) area. 152,447 women registered with a practice in NHS Greater Glasgow and Clyde area were invited to attend breast screening over three years. These include women resident in other NHS board areas as data cannot be excluded from analysis.

105,294 (69.1%) women attended breast screening during the previous three years. This represents a decrease of 0.7% since 2011/12 when uptake was 69.8%. The minimum standard is 70%. There were 737 (0.7%) women who were diagnosed with breast cancer following screening.

Table 2.2 NHSGGC Breast Screening Programme interim activity data for 2012/13 by CH(C)P area

CH(C)P	Number invited[1]	Number attended[1]	Number Cancers Detected[1]	% Attend of those invited	% Cancers of those Attended	% Cancers of those Invited
East Dunbartonshire CHP	14,502	11,138	96	76.8%	0.9%	0.7%
East Renfrewshire CHCP	11,253	8,682	57	77.2%	0.7%	0.5%
Glasgow North East	21,020	13,225	101	62.9%	0.8%	0.5%
Glasgow North West	21,596	13,718	106	63.5%	0.8%	0.5%
Glasgow South	27,917	18,325	122	65.6%	0.7%	0.4%
North Lanarkshire CHP	2,417	1,769	30	73.2%	1.7%	1.2%
South Lanarkshire CHP	7,240	5,033	40	69.5%	0.8%	0.6%
Inverclyde CHP	11,065	7,655	47	69.2%	0.6%	0.4%
Renfrewshire CHP	22,873	16,844	73	73.6%	0.4%	0.3%
West Dunbartonshire CHP	12,564	8,905	65	70.9%	0.7%	0.5%
Total	**152,447**	**105,294**	**737**	**69.1%**	**0.7%**	**0.5%**

Source: West of Scotland Breast Screening data

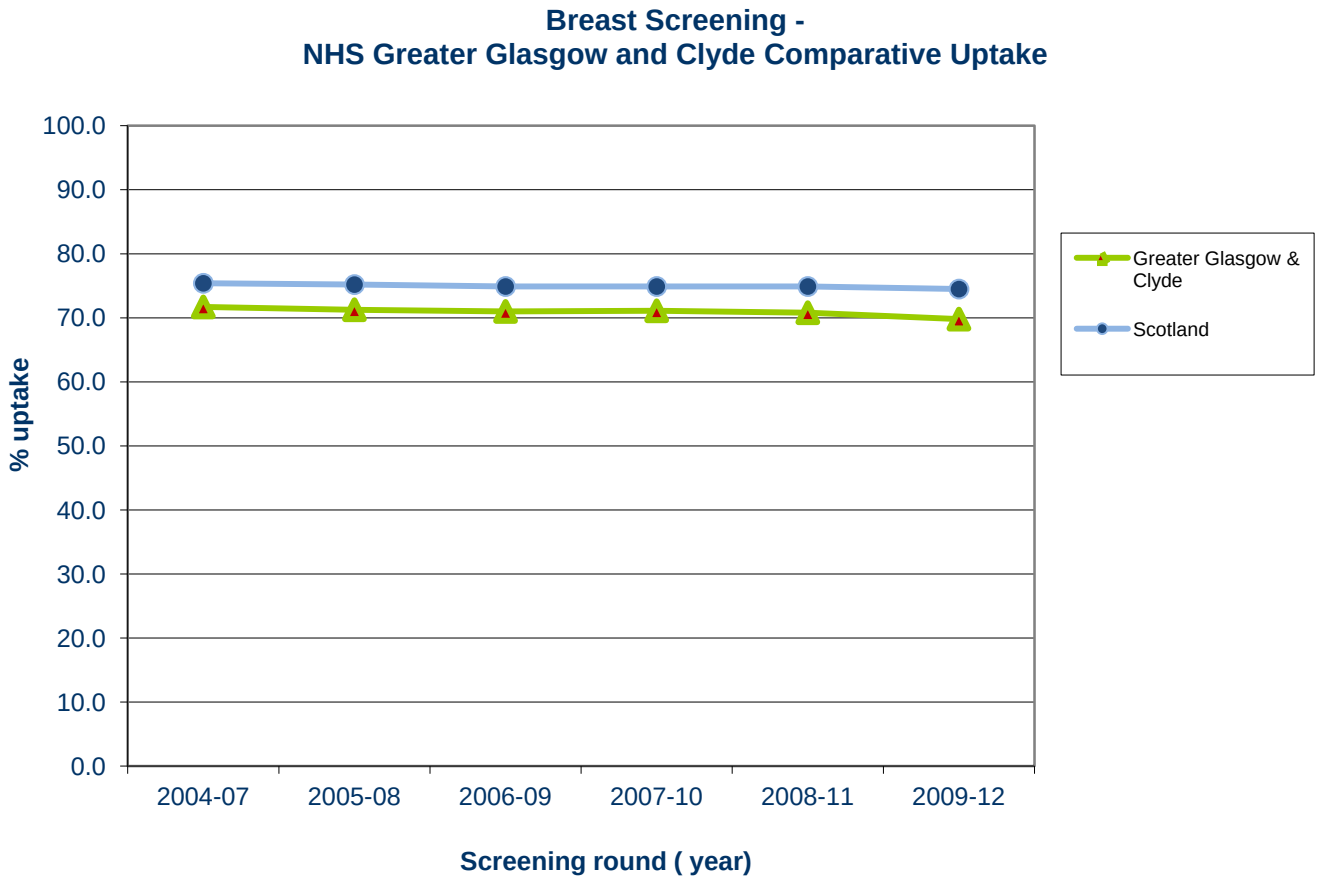
Greater Glasgow: Round commenced January 2010; completed August 2013

Inverclyde, Renfrewshire, West Dunbartonshire, Argyll & Bute (Formerly Argyll & Clyde): Round commenced April 2009; completed March 2012

Note NHS GGC and Total Screening numbers will be 1 out: this is due to a practice that does not sit within a particular CHP. The patient was screened and no cancers found.

Figure 2.2 shows NHS Greater Glasgow and Clyde trends in uptake in breast screening compared to Scottish average. The uptake for the three year rounds 2004/07 to 2008/11 remained slightly above the minimum standard of 70% at 71%, compared to the Scottish average of 74%. The three year round 2009/2012, uptake decreased to 69.8% in NHS Greater Glasgow and Clyde.

Figure 2.2 Comparative trends in uptake in breast screening between NHS Greater Glasgow and Clyde and Scotland



Greater Glasgow & Clyde	71.7	71.3	71.0	71.1	70.8	69.8
Scotland	**75.4**	**75.2**	74.9	**74.9**	74.9	**74.5**

Source: Scottish Breast Screening Programme (SBSP) Information System - KC62 Returns

Notes:

[1] Only routine appointments are included in the above figures. Self /GP referral and early recall appointments are excluded.

[2] Breast Screening year runs from 1st April to 31st March.

[3] Women are invited to attend screening once every three years and NHS Boards are not necessarily screened evenly throughout the three year period.

[4] During 2003-04, a phased extension of the age range for routine invitation (from 50-64 to 50-70 years) began. To reflect the expansion of the age range, three year rolling figures are reported from 2004.

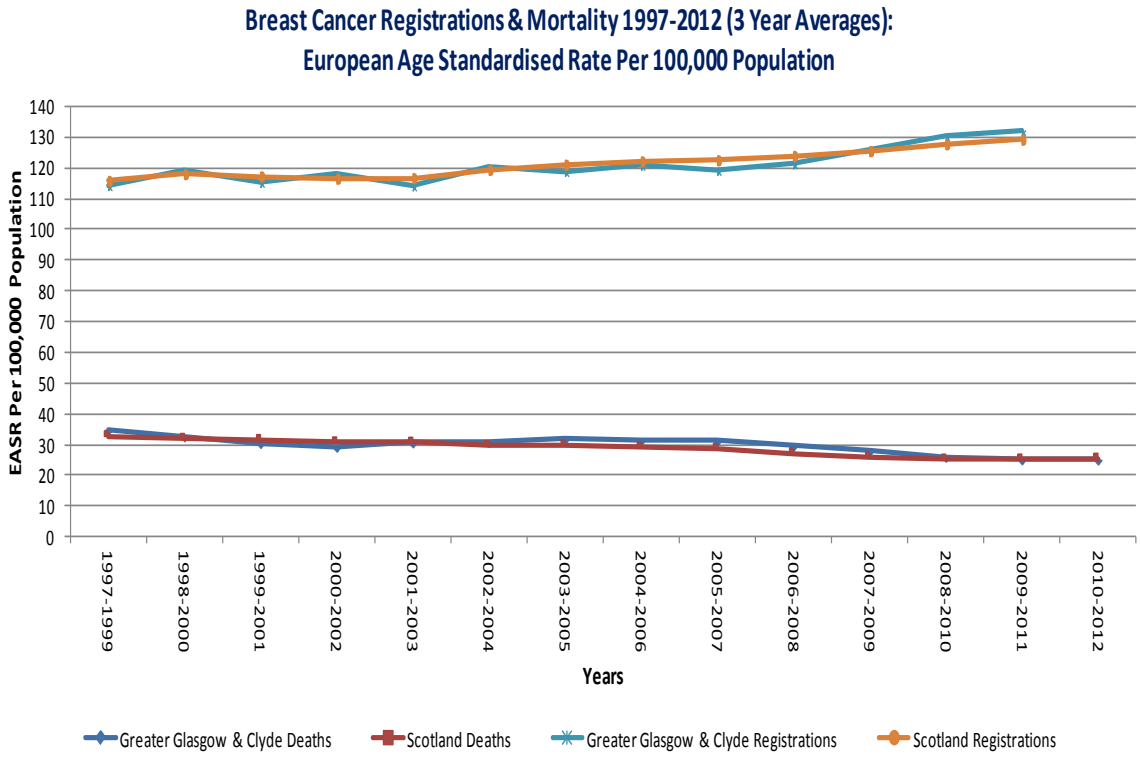
[5] New NHS Board areas including parts of former Argyll & Clyde.

Breast Cancer Morbidity and Mortality

In 2011, the number of new breast cancers registered in NHS Greater Glasgow and Clyde was 974 (**see Table 2.3**). This gives a standardised incidence rate of 126.7 per 100,000 per population which is lower than that for Scotland (130.1).

Figure 2.3 illustrates a steady increase in the incidence rate of breast cancers across Scotland and that NHS Greater Glasgow and Clyde is following the same trend. **Figure 2.3** also illustrates that the age standardised death rates for NHS Greater Glasgow and Clyde and Scotland are gradually declining.

Figure 2.3 Breast Cancer Registrations for Period 1997 – 2012



Source: Scottish Cancer Registry, ISD, 2013

Table 2.3 shows that the number of deaths from breast cancer in NHS Greater Glasgow and Clyde and Scotland. In 2012, there were 237 deaths from breast cancer, giving a standardised rate of 26.6 per 100,000 population. This is slightly higher than that for Scotland (25.8).

42% of breast cancers are preventable. Women who drink more drink 1 – 2 units of alcohol a day and women who are more than three stone overweight after the menopause have a higher risk of developing breast cancer. 30 minutes of exercise five times a week helps maintain a healthy weight and reducing alcohol intake will help minimise the risk of developing breast cancer.

.

Table 2.3: Breast cancer registrations and deaths across NHS Greater Glasgow and Clyde for period 1997 - 2012

Scotland

Registration

Year	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
Number	3,466	3,624	3,687	3,733	3,623	3,722	3,905	3,976	4,061	4,145	4,129	4,308	4,409	4,489	4,574	
EASR	112.9	115.6	118.5	119.7	113.3	116.3	120.1	121.4	121.3	123.3	122.5	125.6	128.1	129.2	130.1	
- Lower 95% CI	*109.0*	*111.7*	*114.5*	*115.7*	*109.5*	*112.4*	*116.2*	*117.5*	*117.4*	*119.5*	*118.7*	*121.7*	*124.2*	*125.3*	*126.2*	
- Upper 95% CI	*116.9*	*119.6*	*122.5*	*123.7*	*117.2*	*120.2*	*124.1*	*125.4*	*125.2*	*127.3*	*126.4*	*129.5*	*132.0*	*133.2*	*134.0*	

Deaths

Year	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
Number	1154	1142	1129	1116	1143	1105	1138	1082	1144	1108	1062	1043	1002	1022	1036	1063
EASR	33.3	32.7	31.9	30.9	31.6	29.6	30.6	28.5	30.1	28.5	27.1	25.8	25.0	24.5	25.9	25.8
- Lower 95% CI	*31.3*	*30.7*	*29.9*	*29.0*	*29.7*	*27.8*	*28.8*	*26.7*	*28.2*	*26.7*	*25.4*	*24.2*	*23.4*	*23.0*	*24.2*	*24.2*
- Upper 95% CI	*35.4*	*34.7*	*33.9*	*32.9*	*33.6*	*31.5*	*32.6*	*30.3*	*31.9*	*30.3*	*28.9*	*27.5*	*26.7*	*26.2*	*27.6*	*27.5*

Greater Glasgow & Clyde

Registration

Year	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
Number	841	875	843	942	788	900	882	933	878	940	896	936	1,045	1,030	974	
EASR	113.6	116.3	112.6	128.5	104.7	120.6	117.1	123.8	115.5	123.1	118.8	121.8	136.4	133.3	126.7	
- Lower 95% CI	*105.7*	*108.3*	*104.7*	*120.0*	*97.1*	*112.5*	*109.1*	*115.6*	*107.7*	*115.0*	*110.9*	*113.8*	*127.9*	*125.0*	*118.6*	
- Upper 95% CI	*121.9*	*124.6*	*120.8*	*137.3*	*112.5*	*129.1*	*125.3*	*132.2*	*123.7*	*131.4*	*127.1*	*130.1*	*145.1*	*141.9*	*135.1*	

Deaths

Year	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
Number	288	297	279	240	252	258	284	266	284	285	259	247	237	220	219	237
EASR	35.3	36.6	32.4	28.9	30.1	28.7	33.1	30.5	31.7	31.9	30.0	26.9	26.8	24.2	24.4	26.6
- Lower 95% CI	*31.1*	*32.3*	*28.5*	*25.1*	*26.3*	*25.1*	*29.1*	*26.7*	*27.9*	*28.1*	*26.2*	*23.4*	*23.3*	*20.9*	*21.1*	*23.1*
- Upper 95% CI	*39.8*	*41.1*	*36.6*	*32.9*	*34.2*	*32.7*	*37.3*	*34.6*	*35.8*	*35.9*	*34.0*	*30.6*	*30.5*	*27.7*	*28.0*	*30.3*

Deaths EASR: age-standardised incidence rate per 100,000 person-years at risk (European standard population) Source: National Records of Scotland (NRS) Data extracted: September 2013

Registrations EASR: age-standardised incidence rate per 100,000 person-years at risk (European standard population) Source: Scottish Cancer Registry, ISD Data extracted: March 2013

Interval Cancers

The screening histories of women attending breast screening became available following work carried out by central IT teams. This allowed data linkage to identify potential interval breast cancers.

For the period 2009 to 2012, a total number of 4,145 breast cancers were detected. 507 (12.2%) were potential interval cancers; 1,250 (30.2%) were screen detected and 2,388 (57.6%) were symptomatic (Table 2.4). Table 2.4 also shows a year on year increase in the number of cancers detected since 2009 to 2012.

Table 2.4 Numbers and percentages of breast cancers diagnosed from 2009 to 2012 by mode of detection and year

	Year (Diagnosis)									
Mode of Detection	**2009**	**%**	**2010**	**%**	**2011**	**%**	**2012**	**%**	**Total**	**%**
Screen detected	280	47.1	302	50.2	319	56.3	349	55.9	**1,250**	**30.2%**
Symptomatic	595	100.0	602	100.0	567	100.0	624	100.0	**2,388**	**57.6%**
Interval Symptompatic	122	20.5	120	19.9	133	23.5	132	21.2	**507**	**12.2%**
All Cancers	**997**		**1,024**		**1,019**		**1,105**		**4,145**	

Source: West of Scotland Breast Cancer Screening IT System, Cancer Audit

The screening histories for the West of Scotland Breast Screening Centre will be reviewing the mammograms of the women diagnosed with interval breast cancers to identify true negative and false negative results (see Audit protocol in Appendix 2.1).

Digital Mammography

One digital mammography Unit was installed in the static Centre in 2010 followed by two more in 2013. There are plans to install three more digital mammography units in mobile vans by 2014/15. Planning and preparation for the IT infrastructure will progress.

In September 2011, the West of Scotland Breast Screening Unit became one of six contributors to the Health Technology Assessment (HTA) funded UK trial assessing the potential benefit of the addition of tomosynthesis to the process of assessment. 1,000 women to took part in a two year tomography trial. This trial has now completed and publication of results is awaited.

Health Improvement

To capitalise on the planned national Detect Cancer Early social marketing campaign, NHS Greater Glasgow & Clyde has developed a local social marketing campaign to reinforce the DCE breast cancer messages and encourage women to take up breast screening. This will involve:

1. updating the current pre-notification letter to reinforce the breast cancer messages. A pre-notification letter is currently sent to women two weeks prior to their screening appointment;

2. engaging with women by telephone who are due to be invited for screening to attend their screening appointment. Gain an understanding of the reasons why women do not take up screening and using this information to inform future work.

3. issuing text reminders to women before their appointment with the aim to reduce non attendance rates.

4. target community groups and schools, using a co-ordinated approach so that interventions are timed to coincide with mobile van visits and also any advertising and PR activities.

5. adapt local leaflets and posters with national campaigns messages.

6. promoting the benefits of reducing alcohol intake, increasing physical activity and maintaining a healthy weight to reduce risk of development breast cancer .

7. issue press releases to local press to reinforce messages and also report any improvement in uptake rates, use of case studies.

There are also plans to invite women to take part in an Act Well Study to receive lifestyle coaching for 12 weeks in 2014.

Challenges and Future Priorities

- Implementation of digital mammography.
- Implementation of NHS Scotland's review of breast screening service.
- Implementation of audit of interval cancers.
- Implementation of social marketing campaign, health interventions and health improvement initiatives to raise awareness of, and encourage women to participate in the breast screening programme.
- Staff to continue to provide information to and support women on making healthier lifestyle changes.

APPENDIX 2.1

NHSGGC CONFIDENTIAL AUDIT OF INTERVAL BREAST CANCERS

DRAFT PROTOCOL

Date created: 05/03/2013	Approved by:
Next review date:	Date Approved:
Version: draft v0.4(July 2013)	Author: D Lyden

INTRODUCTION

The aim of the breast screening programme is to reduce incidence and mortality from breast cancer. It is recognised that in order to assess the effectiveness of the breast screening programme the audit of the screening histories of women with breast 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.

AIM

The aim of the audit is to identify interval breast cancers and review their screening mammograms in order to determine whether any of the activities of the programme could be improved.

OBJECTIVES

- To identify interval cancers
- To obtain information for the cases - demographic details, screening history and outcome.
- To undertake a review of screening histories.
- To identify any factors which may have contributed to any anomaly in the screening history.

METHODS

Identification of interval breast cancers

Data collection

- Demographic details: current name, previous name, date of birth, postcode, case number, CHI number, GP name and address at time of cancer registration, date of death, date of cancer registration.

- WoSB to provide Screening history: screening date, result of the mammograms and recommendations

- Breast Screen Review: WoSBS will review available mammograms and report on outcome and whether the review would impact on case management.

- Clinical staging: MDT summary

Sources of data

- Information Services to run a report from ACADME listing women aged 50 – 77 diagnosed with breast cancer that were not screen detected screening history.

  Dataset: CHI, Name, DOB, Date Diagnosed, Diagnosis

- West of Scotland Breast Screening to provide list of women screened within three years from diagnosis.

  Dataset: CHI, Name, DOB, date screened,

- WOSCAN provide most recent 6 months cancer staging data:

  Dataset: CHI, Name, DOB, Postcode

T0	No evidence	
Tis	Carcinoma in situ (CIS)	
T1	Tumour up to 2 cm	
T2	Tumour >2cm; = 5cm	
T3	Tumour >5cm	
T4	Tumour of any size with direct extension to chest wall and/or to skin (ulceration of skin nodules)	
TX	Primary tumour cannot be assessed	
Not known/recorded		

Code	Value	Explanatory Notes
N0	No regional lymph nodes metastasis	
N1	Metastases to movable ipsilateral Level I, II axillary lymph node(s)	
N2	Metastases in ipsilateral Level I, II axillary lymph node(s) that are clinically fixed or matted; or in clinically detected* ipsilateral internal mammary lymph node(s) in the absence of clinically evident axillary lymph node metastasis.	Fixed nodal metastasis. * Detected by clinical examination or by imaging studies (excluding lymphoscintigraphy) and having characteristics highly suspicious for malignancy or a presumed pathological macrometastasis based on fine-needle aspiration biopsy with cytological examination.
N3	Metastasis in ipsilateral infraclavicular (Level III axillary) lymph node(s), with or without Level I, II axillary lymph node involvement, or in clinically detected* ipsilateral internal mammary lymph node(s) with clinically evident Level I, II axillary lymph node metastasis; or metastasis in ipsilateral supraclavicular lymph node(s), with or without axillary or internal mammary lymph node involvement.	Nodal metastasis above the clavicle. * Detected by clinical examination or by imaging studies (excluding lymphoscintigraphy) and having characteristics highly suspicious for malignancy or a presumed pathological macrometastasis based on fine-needle aspiration biopsy with cytological examination.
NX	Regional lymph nodes cannot be assessed (e.g. previously removed)	
9999		

Code	Value
M0	No evidence of distant metastases
M1	Distant metastases present
9999	Not known

Audit procedure

1. Information Services provide 6 monthly list of breast cancers (sourced from ACADME) diagnosed within the previous 6 months.

2. Board Screening Co-ordinator sends a request to Dr Hilary Dobson, Clinical Director, West of Scotland Breast Screening Centre for list of screening histories of NHSGGC residents for previous round.

3. Information Services will match ACADME data with breast screening data to remove any screen detected cancers and women who did not take up screening within 4 years of diagnosis.

4. Information Services sends yearly request to WOSCAN for cancer staging data of women identified for audit.

5. West of Scotland Breast Screening Centre will review the mammograms of women identified for audit.

Audit Meeting

6. Audit data will be recorded on a pass-worded protected database for future reference and further analysis if required.

7. The audit statistics will be presented to the Breast Screening Steering group and in the Breast Screening Programme annual report.

APPENDIX 2.1.1

IBA1 Interval Cancer Audit Form
Membership of the Group

Appendix 2.1.1

CONFIDENTIAL

NHS Greater Glasgow and Clyde
Audit of Interval Breast Cancers

CHI Number: Date of Birth:

Post Code:

Practice Code:

Date of Diagnosis:

Data provided by West of Scotland Breast Screening Centre:

Time of last mammogram screen

	Last screened 3 years ago	
	Last screened 2 years	
	Last screened 1 year	
	Last screened less than 1 year	

Review of Index Mammogram (interval breast cancers only)

Date of mammogram	
Technical	
Occult	
True negative	
False negative	
False subtle negative	
Other	

Impact on management Yes ☐ No ☐ Not known ☐

If yes, please specify:	

DATA PROVIDED BY WOSCAN

TMN (Cancer) Stage

T0	No evidence	
Tis	Carcinoma in situ (CIS)	
T1	Tumour up to 2 cm	
T2	Tumour >2cm; = 5cm	
T3	Tumour >5cm	
T4	Tumour of any size with direct extension to chest wall and/or to skin (ulceration of skin nodules)	
TX	Primary tumour cannot be assessed	
Not known/recorded		

Code	Value	
N0	No regional lymph nodes metastasis	
N1	Metastases to movable ipsilateral Level I, II axillary lymph node(s)	
N2	Metastases in ipsilateral Level I, II axillary lymph node(s) that are clinically fixed or matted; or in clinically detected* ipsilateral internal mammary lymph node(s) in the absence of clinically evident axillary lymph node metastasis.	
N3	Metastasis in ipsilateral infraclavicular (Level III axillary) lymph node(s), with or without Level I, II axillary lymph node involvement, or in clinically detected* ipsilateral internal mammary lymph node(s) with clinically evident Level I, II axillary lymph node metastasis; or metastasis in ipsilateral supraclavicular lymph node(s), with or without axillary or internal mammary lymph node involvement.	
NX	Regional lymph nodes cannot be assessed (e.g. previously removed)	
9999		
M0	No evidence of distant metastases	
M1	Distant metastases present	
9999	Not known	

Date of Death	
Cause of Death	

Comments	

Signed:	
Print Name:	

Membership of the Breast Cancer Audit Group:

Dr Emilia Crighton, NHSGGC Board's Breast & Cervical Screening Co-ordinator
Dr Hilary Dobson, Clinical Lead, West of Scotland Breast Cancer Centre
Catriona Pagliari, Consultant Radiologist, WOSBS
Marion Martin, Office Manager, WOSBS
Donna Wilson, Administration Manager, WOSBS
Paul Burton, Senior Information Analyst, Information Services
Denise Lyden, Project Officer, Public Health

Appendix 2.2

Members of Breast Screening Steering Group (As at June 2013)

Dr Emilia Crighton	Consultant in Public Health Medicine (Chair)
Miss Donna Wilson	Administration Manager
Ms Claire Donaghy	Health Improvement Senior
Dr Hilary Dobson	Clinical Director
Mrs Fiona Gilchrist	Assistant Programmes Manager, Screening Dept
Mrs Annette Little	Information Analyst
Miss Denise Lyden	Project Officer
Ms Janet Mair	Regional Registration Manager
Mrs Lin Calderwood	H&IT Service Delivery Manager
Dr Alan Mitchell	Clinical Director
Ms Ann Mumby	Superintendent Radiographer
Ms Elaine Murray	Health Improvement Assistant
Mrs Eilidh O'Neill	Health Visitor, West Dunbartonshire CHP
Mrs Elizabeth Rennie	Programmes Manager, Screening Dept

SUMMARY

CHAPTER 3: BOWEL SCREENING PROGRAMME

- The programme invites all men and women between the ages of 50 – 74 years registered with a General Practice every two years. This chapter presents the full two year screening round report.

- 374,907 residents in NHS Greater Glasgow and Clyde were invited to participate in the Bowel Screening programme over two years between April 2011 and March 2013.

- 185,932 screening kits were completed and returned to the Bowel Screening laboratory for analysis. This gives an estimated uptake of 49.6%, representing a slight decrease of 0.1% reported in 2011/2012 when uptake was 49.7%.

- Overall, the lowest uptake was among the most deprived areas at 40.7%. The lowest uptake for bowel screening was among the residents living in the most deprived areas in Glasgow CHP sectors North East (39.6%); North West (39.9%) and South (39.5%). Highest uptake was among residents living in the more affluent areas of West Dunbartonshire; East Dunbartonshire; East Renfrewshire and Renfrewshire where uptake exceeded 60%.

- The percentage uptake among females at 52.3% was higher than the male population at 46.8%. The lowest uptake of 38.4% was among the 50-54 year old male population group.

- Of the 5,866 patients screened positive, 5,380 patients were pre-assessed prior to colonoscopy. 208 patients did not respond to the offer of a colonoscopy pre-assessment.

- A letter is sent to patients and their GP who refuse or do not turn up for colonoscopy asking them to get in touch within 6 months if they change their mind. Otherwise they will be removed from the waiting list. We also inform the Bowel Screening Centre so that the patient is invited to take part in bowel screening in two years.

- The overall positivity rate was higher among men at 3.9% compared to women at 2.5%. Compared to all other groups, the male population age group of 70 to 74 had the highest positivity rate of 5.7%.

- 4,653 (86.4%) patients completed colonoscopy investigations by 31 March 2013.

- In collaboration with the University of Glasgow, a research project investigated the efficacy of a populated based colorectal cancer screening programme and analysed the outcomes in screen detected and non screen detected tumours. The findings concluded that screen detected patients had a more favourable outcome compared to individuals with non screen detected tumours. It was recommended that further studies are needed to improve the response rate to the screening invitation and also the sensitivity of the current test (Mansouri et al, 2013).

- Of the 2,025 people with learning disability that were invited to take part in the bowel screening programme, 27.6% (561) completed the bowel screening test. 17 patients received positive results representing a positivity rate of 3.8%.

- Of the total eligible population invited to take part in bowel screening, 280 cancers were detected.

- In 2011, the most recent year for which completed data is available, the number of new colorectal cancers registered in NHS Greater Glasgow and Clyde was 522 for men and 398 for females. This gives a standardised incidence rate of 78.0 and 43.0 respectively per 100,000 populations.

- In 2012, the number of deaths from colorectal cancer in NHS Greater Glasgow and Clyde was 165 for male population and 191 in the female population. This gives a standardised rate of 22.7 and 18.1 respectively per 100,000 populations.

- Of the 3,410 of colorectal cancers diagnosed between 2009 and 2012, 2,948 were symptomatic and 625 were detected through the bowel screening programme. 263 were potential interval cancers.

- As part of the national Detect Cancer Early marketing campaign, Health Improvement Teams will develop localised programmes of work to increase participation of bowel screening programme.

- Two local pilot studies are also planned for 2013 to explore whether uptake of the bowel cancer screening test in men in the most socio-economically deprived areas in North West sector and Renfrewshire can be increased by a short intervention and encouragement to participate in the programme.

CHAPTER 3: BOWEL SCREENING PROGRAMME

Background

Colorectal (Bowel) Cancer is the third most common cancer in Scotland after prostate (for men), lung (for both men and women) and breast (women) cancers (ISD Scotland, 2010*).* Every year in Scotland over 3,400 people are diagnosed with the disease. In NHS Greater Glasgow and Clyde, 920 people were diagnosed with bowel cancer in 2011 (Table 3.6).

The Scottish Bowel Screening Programme was fully implemented across Scotland in 2009.

Aim of the screening programme

The purpose of bowel screening by guaiac Faecal Occult Blood test (gFOBt) is to detect colorectal cancers at the earliest possible time so that treatment may be offered promptly. It is believed that very early detection of colorectal cancers in this way can result in more effective treatment which may be more likely to reduce deaths from colorectal cancer. In addition, the removal of precancerous lesions could lead to a reduction in the incidence of colorectal cancer.

Eligible population

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

The screening test

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

Screening pathway

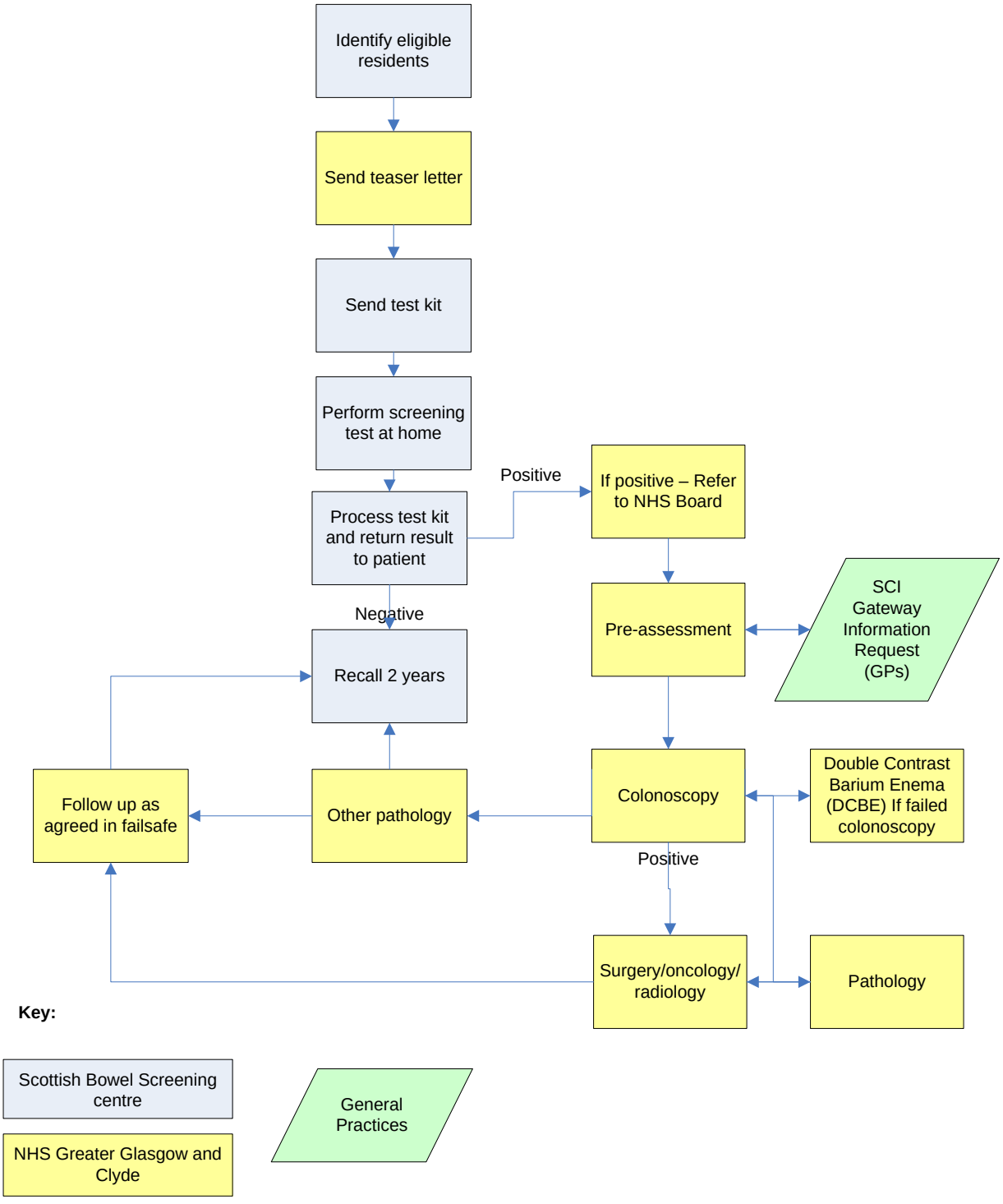
Eligible NHS Greater Glasgow and Clyde residents that are due to be invited to take part in the bowel screening programme are sent a “teaser” letter before they are sent an invitation letter and screening kit. The letter explains the programme and encourages participants to take the test.
The National Bowel Screening Centre in Dundee issue screening kits to all eligible residents of NHS Greater Glasgow and Clyde to carry out the screening test at home. The kits are then posted by return to the National Laboratory for processing.

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

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

A letter is sent to patients and their GP that refuse or do not turn up for colonoscopy asking them to get in touch within 6 months if they change their mind, otherwise they will be removed from the waiting list. We also inform the Bowel Screening Centre so that the patient is invited to take part in bowel screening in two years

Figure 3.1 Overview of bowel screening pathway



Delivery of NHSGGC bowel screening programme

From 1 April 2011 to 31 March 2013, 374,907 residents in NHS Greater Glasgow and Clyde were invited to participate in the Bowel Screening programme (see **Table 3.1**). Of the total population invited, 125,783 (33.5%) lived in the most deprived areas.

Table 3.1 Number of eligible population invited to participate in the bowel screening programme.

	Most Deprived		SIMD		Least Deprived		
CH(C)P	**1**	**2**	**3**	**4**	**5**	**Unassigned[2]**	**Total**
East Dunbartonshire	1,412	4,261	3,636	7,292	21,500	54	38,155
East Renfrewshire	1,716	2,218	3,107	3,222	19,586	33	29,882
Glasgow North East	33,826	5,702	4,488	5,493	1,832	180	51,521
Glasgow North West	21,912	8,820	6,354	5,382	8,700	76	51,244
Glasgow South	27,237	13,952	9,851	7,558	4,539	94	63,231
Inverclyde	11,255	3,997	4,240	5,268	2,790	91	27,641
North Lanarkshire[1]	735	418	2,137	2,409	351	6	6,056
Renfrewshire	12,638	10,239	9,358	9,659	15,440	76	57,410
South Lanarkshire[1]	6,222	4,071	2,161	3,769	3,034	44	19,301
Stirling(GGC pt) [1]				5			5
West Dunbartonshire	8,830	9,717	6,328	3,480	1,572	71	29,998
Unassigned[2]						463	463
Total NHS GGC	**125,783**	**63,395**	**51,660**	**53,537**	**79,344**	**1,188**	**374,907**

Source: Bowel Screening IT system (Data extracted August 2013)

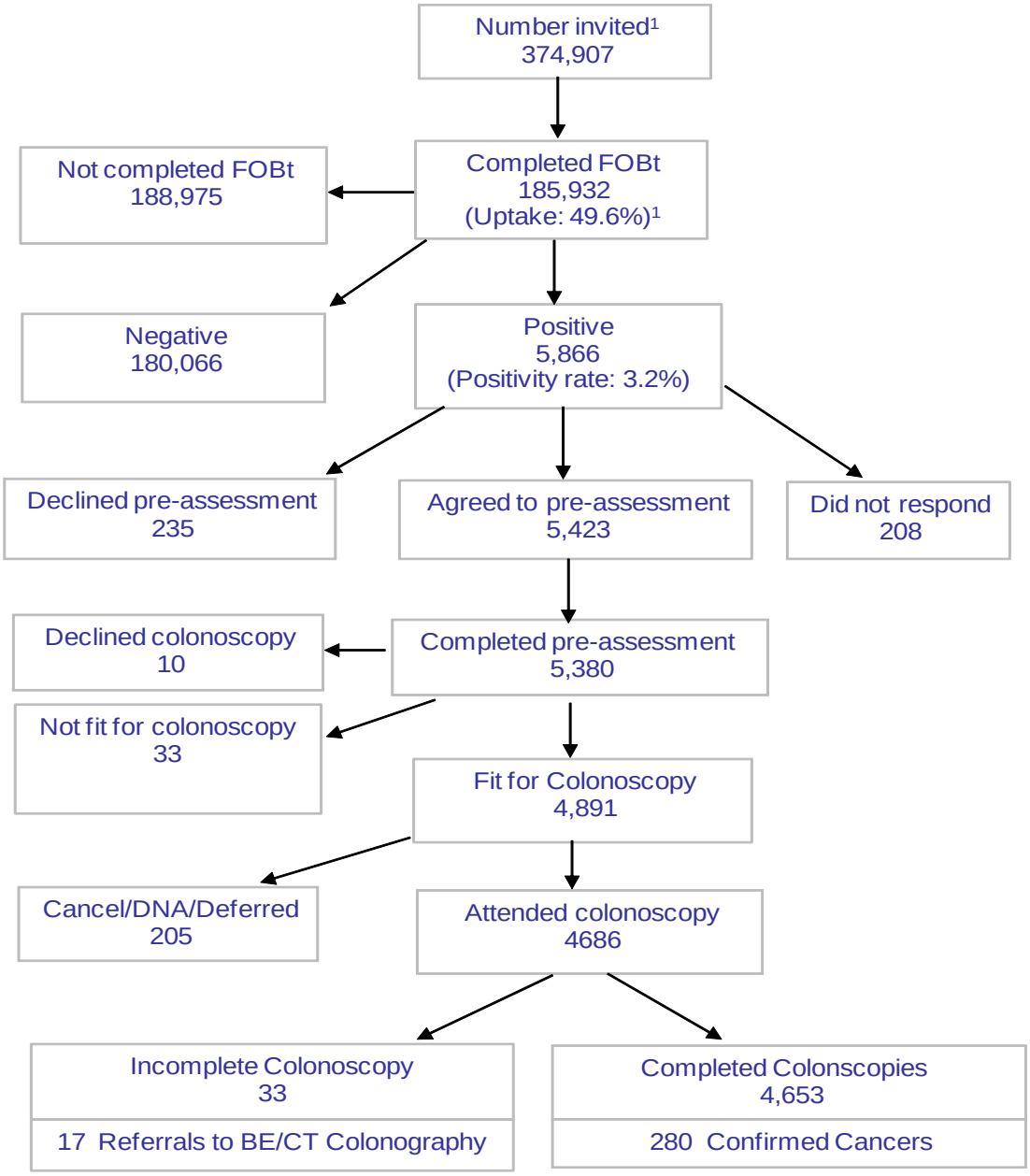
Notes:

1 NHSGGC residents only

2 Unable to assign CHP or SIMD due to incomplete/incorrect postcode.

Figure 3.2 illustrates the bowel screening activity. 185,932 screening kits were completed and returned to the Bowel Screening laboratory for analysis. This gives an estimated uptake of 49.6%, representing a slight decrease of 0.1% reported in 2011/2012 when uptake was 49.7%.

Figure 3.2 NHSGGC Bowel Screening activity 1 April 2011 to 31 March 2013



Source: NHS Greater Glasgow and Clyde Bowel Screening IT System (Extracted: August 2013)

Note:

[1] It was estimated that residents would complete the test within 6 weeks of teaser letter being issued. Therefore the approximate percentage uptake is based on total number of results from 1 April 2011 - 31st March 2013 against the number of kits issued for the same period.

Table 3.2 shows the bowel screening uptake by CH(C)P area and by deprivation. Overall, the lowest uptake was among the most deprived areas at 40.7%. The lowest uptake for bowel screening was among residents living in the most deprived areas in Glasgow CHP sectors North East (39.6%); North West (39.9%) and South (39.5%). Highest uptake was among residents living in the more affluent areas of West Dunbartonshire; East Dunbartonshire; East Renfrewshire and Renfrewshire where uptake exceeded 60%.

Table 3.2 NHSGGC Bowel screening uptake by CH(C)P and deprivation category

	Most Deprived		SIMD		Least Deprived		
CH(C)P	**1**	**2**	**3**	**4**	**5**	**Unassigned[2]**	**Total**
East Dunbartonshire	43.7	47.8	53.4	59.8	62.1	51.9	58.5
East Renfrewshire	40.0	47.9	53.5	56.1	61.7	66.7	58.0
Glasgow North East	39.6	44.0	49.6	54.3	55.9	33.9	43.1
Glasgow North West	39.9	45.1	44.8	49.1	56.7	40.8	45.2
Glasgow South	39.4	44.2	48.7	53.9	57.3	25.5	44.9
Inverclyde	43.7	49.6	52.4	58.3	58.6	34.1	50.2
North Lanarkshire[1]	44.6	50.2	53.2	56.5	59.3	66.7	53.6
Renfrewshire	41.3	49.4	52.5	57.6	61.9	50.0	52.9
South Lanarkshire[1]	44.5	49.2	54.9	57.6	60.2	52.3	51.7
Stirling(GGC pt) [1]	0.0	0.0	0.0	60.0	0.0	0.0	60.0
West Dunbartonshire	42.2	49.6	53.6	56.4	62.8	39.4	49.7
Unassigned[2]						32.4	32.4
Total NHS GGC	**40.7**	**47.1**	**51.0**	**56.0**	**60.7**	**37.0**	**49.6**

Source: Bowel Screening IT system (Data extracted August 2013)

Notes:

1 NHSGGC residents only

2 Unable to assign CHP or SIMD due to incomplete/incorrect postcode.

Table 3.3 shows that the percentage uptake among females at 52.3% was higher than the male population at 46.8%. The lowest uptake of 38.4% was among the 50-54 year old male population group.

Table 3.3 NHSGGC Bowel screening uptake and positivity rate by age and gender

	Uptake			Positvity		
Age Group	Female	Male	Overall both sexes	Female	Male	Overall both sexes
50-54	45.3	38.4	41.8	1.9	2.7	2.3
55-59	51.2	45.1	48.2	2.0	3.5	2.7
60-64	56.7	51.2	54.0	2.5	3.7	3.1
65-69	59.0	54.4	56.8	2.9	4.5	3.6
70-74	54.7	52.9	53.9	3.6	5.7	4.5
75+	47.8	49.4	48.5	4.1	5.0	4.5
Overall average	**52.3**	**46.8**	**49.6**	**2.5**	**3.9**	**3.2**

Source: Bowel Screening IT system (Data extracted August 2013)

The overall positivity rate was higher among men at 3.9% compared to women at 2.5%. Compared to all other groups, the male population age group of 70 to 74 had the highest positivity rate of 5.7%. This was higher than the national average 2.5% reported in the Scottish Bowel Screening Programme Statistics (ISD, 2011). There is a gradient in the positivity rate across deprivation categories. The positivity rate for residents living in the most deprived areas was 4.4% compared to 2.0% for residents living in least deprived areas (**Table 3.4**).

Table 3.4 FOBt positivity rates by CHCP and deprivation category

	Most Deprived		SIMD		Least Deprived		
CH(C)P	1	2	3	4	5	Unassigned[2]	Overall
East Dunbartonshire	5.2	2.9	3.3	2.1	2.1	0.0	2.3
East Renfrewshire	3.9	3.5	3.6	2.2	2.1	0.0	2.4
Glasgow North East	4.8	4.4	3.0	3.0	2.1	0.0	4.2
Glasgow North West	4.7	3.6	2.9	2.7	1.8	9.7	3.4
Glasgow South	4.3	3.6	2.9	2.0	1.6	0.0	3.3
Inverclyde	4.0	3.4	2.7	2.8	2.4	3.2	3.3
North Lanarkshire[1]	5.5	5.7	2.6	2.7	3.4	0.0	3.2
Renfrewshire	4.0	3.5	2.6	2.8	2.0	2.6	2.8
South Lanarkshire[1]	4.5	3.5	3.4	2.4	2.9	0.0	3.4
Stirling[1]	0.0	0.0	0.0	0.0	0.0	0.0	0.0
West Dunbartonshire	3.7	3.5	3.5	2.1	1.9	0.0	3.3
Unassigned[2]						4.0	4.0
Overall NHS GGC	**4.4**	**3.6**	**3.0**	**2.5**	**2.0**	**2.5**	**3.2**

Source: Bowel Screening IT system (Data extracted August 2013)

Notes:

1 NHSGGC residents only

2 Unable to assign CHP or SIMD due to incomplete/incorrect postcode.

Of the 5,866 patients screened positive, 5,380 patients were pre-assessed prior to colonoscopy. 208 patients did not respond to the offer of a colonoscopy pre-assessment (**Figure 3.2**).

4,653 (86.4%) patients completed colonoscopy investigations by 31 March 2013. 10 patients refused to take up the offer of a colonoscopy. If they remain eligible for bowel screening, they will be invited to participate in screening in two years. Of the total eligible population invited to take part in bowel screening, 280 cancers were detected **(Figure 3.2)**.

Of the 2,025 people with learning disability that were invited to take part in the bowel screening programme, 27.6% (561) completed the bowel screening test (**Table 3.5**). 17 patients received positive results representing a positivity rate of 3.8%. No cancer was diagnosed.

Table 3.5 NHSGGC Bowel Screening activity among people with learning disability

	Female	Male	Total
Invited to participate	919	1,116	2,035
Completed Kits	274	287	561
Positive Result	9	8	17
Uptake (%)	29.8	25.7	27.6
Postiivity Rate (%)	3.3	2.8	3.0

Source: Bowel Screening IT system (Data extracted August 2013); Learning Disability LES (November 2012)

Morbidity and mortality from colorectal cancer

In 2011, the most recent year for which completed data is available, the number of new colorectal cancers registered in NHS Greater Glasgow and Clyde was 522 for men and 398 for females **(see Table 3.6).** This gives a standardised incidence rate of 78.0 and 43.0 respectively per 100,000 populations.

Figure 3.3 shows that since 2004/06 there has been a steady increase in the incidence rate of colorectal cancers in the male population across Scotland and NHS Greater Glasgow and Clyde. There has been a slight decrease in 2011 in the female population across Scotland and that NHS Greater Glasgow and Clyde is following the same trend.

In 2012, the number of deaths from colorectal cancer in NHS Greater Glasgow and Clyde was 165 for male population and 191 in the female population **(see Table 3.6)**. This gives a standardised rate of 22.7 and 18.1 respectively per 100,000 populations. **Figure 3.3** shows that the rate of deaths has remained consistent since 2004/06.

Figure 3.3 Colorectal cancer incidence rates for 1997 to 2011 and mortality rates for 1997 to 2012 for NHS Greater Glasgow and Clyde and Scotland

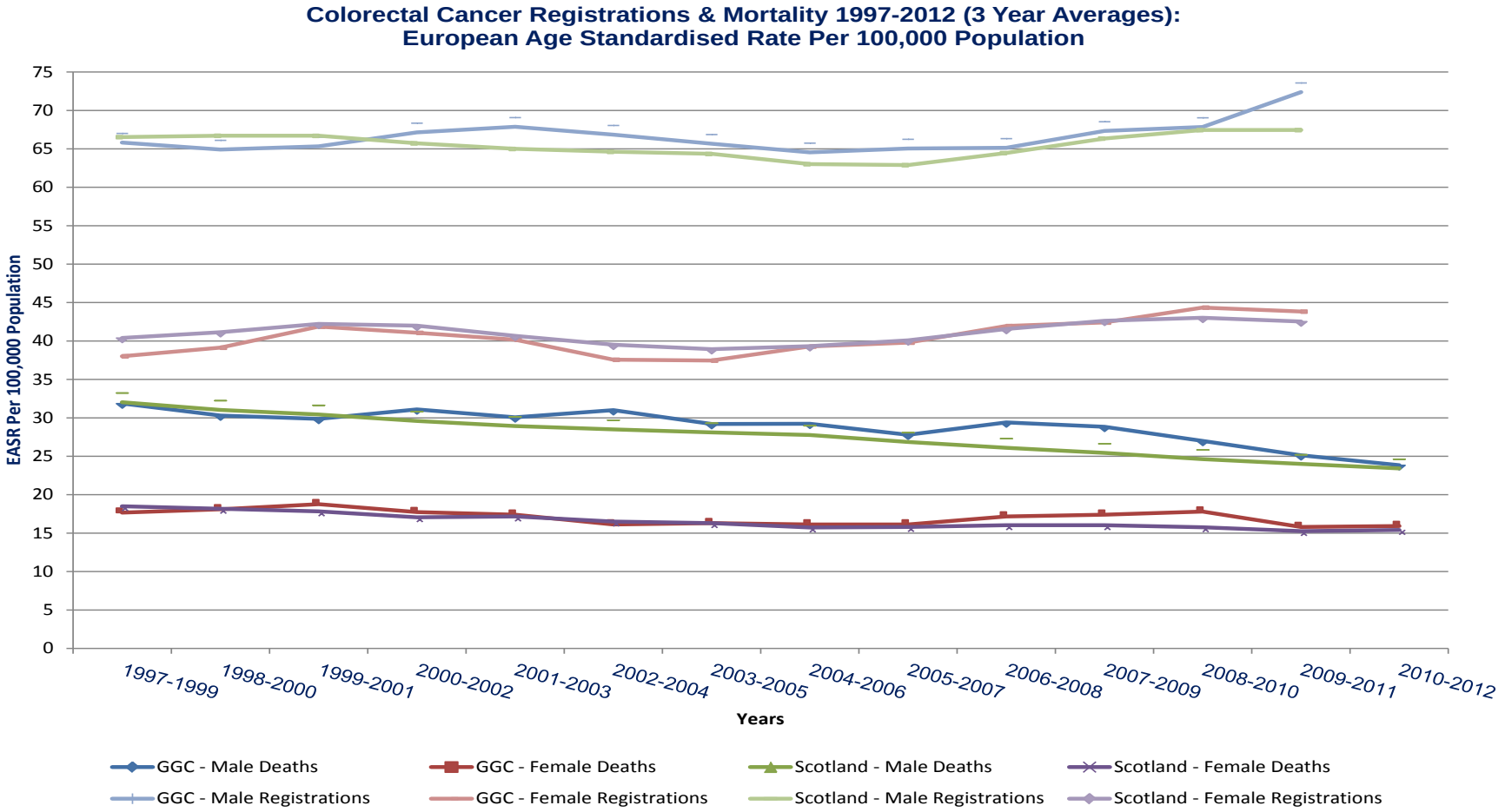


Table 3.6 Colorectal cancer incidence rates for 1997 to 2011 and mortality rates for 1997 to 2012 for NHS Greater Glasgow and Clyde

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
Greater Glasgow & Clyde																
MALES																
Deaths																
Number	219	194	175	197	184	203	183	213	172	182	186	203	183	159	179	165
Standardised rate per 100,000 pop	36.0	31.3	28.3	31.3	30.0	32.0	28.2	32.8	26.6	28.3	28.5	31.4	26.6	23.0	25.8	22.7
Lower 95% Confidence Interval	*31.3*	*27.0*	*24.2*	*27.0*	*25.7*	*27.7*	*24.2*	*28.5*	*22.8*	*24.3*	*24.5*	*27.2*	*22.9*	*19.5*	*22.1*	*19.3*
Upper 95% Confidence Interval	*41.0*	*35.9*	*32.7*	*35.9*	*34.5*	*36.6*	*32.5*	*37.4*	*30.8*	*32.6*	*32.8*	*35.9*	*30.7*	*26.7*	*29.8*	*26.4*
Registrations																
Number	428	406	387	412	415	428	436	406	410	425	428	421	478	448	522	
Standardised rate per 100,000 pop	69.6	65.6	62.2	66.9	66.9	67.7	69.1	63.8	64.1	65.7	65.3	64.4	72.3	66.8	78.0	
Lower 95% Confidence Interval	*63.1*	*59.3*	*56.1*	*60.5*	*60.5*	*61.4*	*62.6*	*57.6*	*58.0*	*59.5*	*59.2*	*58.3*	*65.9*	*60.7*	*71.4*	
Upper 95% Confidence Interval	*76.4*	*72.2*	*68.7*	*73.6*	*73.5*	*74.3*	*75.8*	*70.2*	*70.6*	*72.2*	*71.7*	*70.8*	*79.0*	*73.2*	*84.9*	
FEMALES																
Deaths																
Number	185	181	177	192	204	156	166	165	156	168	165	178	175	177	127	191
Standardised rate per 100,000 pop	17.2	17.8	18.0	18.5	19.8	14.9	17.5	16.0	15.4	17.0	16.0	18.5	17.7	17.2	12.5	18.1
Lower 95% Confidence Interval	*14.7*	*15.1*	*15.3*	*15.9*	*17.0*	*12.5*	*14.7*	*13.5*	*12.9*	*14.4*	*13.5*	*15.7*	*15.0*	*14.6*	*10.3*	*15.5*
Upper 95% Confidence Interval	*20.0*	*20.6*	*21.0*	*21.5*	*22.9*	*17.5*	*20.4*	*18.8*	*18.1*	*19.8*	*18.7*	*21.5*	*20.6*	*20.1*	*15.0*	*20.9*
Registrations																
Number	367	345	386	365	414	361	344	351	361	391	357	419	408	408	398	
Standardised rate per 100,000 pop	36.5	36.7	40.9	39.8	44.9	38.4	37.1	37.2	38.1	42.6	38.7	44.6	43.9	44.6	43.0	
Lower 95% Confidence Interval	*32.6*	*32.7*	*36.6*	*35.5*	*40.4*	*34.3*	*33.0*	*33.1*	*34.0*	*38.2*	*34.6*	*40.1*	*39.5*	*40.1*	*38.7*	
Upper 95% Confidence Interval	*40.6*	*41.0*	*45.4*	*44.3*	*49.7*	*42.8*	*41.4*	*41.5*	*42.4*	*47.2*	*43.1*	*49.2*	*48.6*	*49.3*	*47.6*	

Notes:

Colorectal Cancer (ICD10: C18-C20)

Mortality Source: National Records of Scotland (NRS) Data extracted: September 2013

Registrations Source: Scottish Cancer Registry, ISD Data extracted: March 2013

Table 3.7 Colorectal cancer incidence rates for 1997 to 2011 and mortality rates for 1997 to 2012 for Scotland

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
Scotland																
MALES																
Deaths																
Number	889	848	870	839	835	842	830	844	855	835	812	829	825	782	824	837
Standardised rate per 100,000 pop	33.0	31.3	31.8	30.0	29.5	29.3	28.0	28.2	28.1	27.0	25.5	25.8	25.0	23.1	23.9	23.3
Lower 95% Confidence Interval	*30.9*	*29.2*	*29.7*	*28.0*	*27.6*	*27.3*	*26.1*	*26.3*	*26.2*	*25.2*	*23.7*	*24.0*	*23.3*	*21.4*	*22.2*	*21.7*
Upper 95% Confidence Interval	*35.2*	*33.4*	*34.0*	*32.1*	*31.6*	*31.3*	*30.0*	*30.2*	*30.0*	*28.9*	*27.3*	*27.6*	*26.8*	*24.7*	*25.6*	*24.9*
Registrations																
Number	1803	1785	1819	1884	1847	1817	1902	1909	1894	1889	2015	2137	2164	2211	2236	
Standardised rate per 100,000 pop	67.4	65.8	66.4	67.9	65.8	63.5	65.7	64.7	62.6	61.7	64.3	67.3	67.4	67.6	67.3	
Lower 95% Confidence Interval	*64.3*	*62.8*	*63.4*	*64.8*	*62.8*	*60.6*	*62.8*	*61.7*	*59.8*	*59.0*	*61.5*	*64.5*	*64.6*	*64.8*	*64.5*	
Upper 95% Confidence Interval	*70.6*	*68.9*	*69.5*	*71.0*	*68.9*	*66.5*	*68.8*	*67.6*	*65.5*	*64.6*	*67.2*	*70.3*	*70.3*	*70.5*	*70.2*	
FEMALES																
Deaths																
Number	781	791	792	757	780	713	752	706	695	715	727	736	730	719	702	764
Standardised rate per 100,000 pop	18.2	18.7	18.6	17.2	17.7	16.3	17.5	15.7	15.7	15.8	15.9	16.4	15.8	15.1	14.9	16.2
Lower 95% Confidence Interval	*16.9*	*17.3*	*17.2*	*15.9*	*16.4*	*15.1*	*16.2*	*14.5*	*14.5*	*14.6*	*14.7*	*15.1*	*14.6*	*14.0*	*13.7*	*15.0*
Upper 95% Confidence Interval	*19.6*	*20.1*	*20.0*	*18.5*	*19.1*	*17.7*	*18.9*	*16.9*	*17.0*	*17.1*	*17.2*	*17.6*	*17.1*	*16.3*	*16.1*	*17.5*
Registrations																
Number	1,609	1,532	1,626	1,687	1,688	1,601	1,553	1,613	1,594	1631	1708	1771	1806	1815	1750	
Standardised rate per 100,000 pop	40.4	39.6	41.2	42.7	42.8	40.5	38.7	39.3	38.8	39.9	41.6	43.2	43.1	42.8	41.8	
Lower 95% Confidence Interval	*38.3*	*37.5*	*39.1*	*40.5*	*40.7*	*38.4*	*36.7*	*37.3*	*36.8*	*37.8*	*39.5*	*41.1*	*41.0*	*40.7*	*39.7*	
Upper 95% Confidence Interval	*42.6*	*41.7*	*43.4*	*44.9*	*45.0*	*42.6*	*40.8*	*41.4*	*40.8*	*42.0*	*43.7*	*45.4*	*45.2*	*44.9*	*43.9*	

Notes:

Colorectal Cancer (ICD10: C18-C20)

Mortality Source: National Records of Scotland (NRS)
Data extracted: September 2013

Registrations Source: Scottish Cancer Registry, ISD
Data extracted: March 2013

Table 3.8 shows the numbers and rates of potential interval colorectal cancers diagnosed from 2009 to 2012 by mode of detection and Dukes staging. Of the 3,410 colorectal cancers diagnosed over 4 years, 2,948 were symptomatic and 625 were detected through the bowel screening programme. 263 were identified as interval cancers giving a rate of 77.1 per 1,000 colorectal cancers.

Table 3.8 Numbers and rates of interval colorectal cancers by Dukes staging for period 2009 to 2012

	Dukes Staging							
Mode of Detection	A	B	C1	C2	D	Not known	Total	1,000 Invasive Cancers
Interval	44	64	73	9	15	58	263	77.1
Screening	211	146	133	10	12	113	625	183.3
Symptomatic	276	670	508	90	113	841	2,498	732.6
All Cancers	539	882	721	110	142	1,016	3,410	

Source: Bowel Screening IT system, Cancer Audit extract December 2013

Note: data to be validated

Table 3.9 illustrates the staging of screen detected colorectal cancers by staging category.

Table 3.9 Staging category of screen detected colorectal cancers by gender

Gender	Dukes Staging										Poyp Cancers		Not Known	
	A		B		C1		C2		D					
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Male	67	38.3	46	26.3	36.0	20.6	1.0	0.6	5.0	2.9	11.0	6.3	9	5.1
Female	43	41.0	28	26.7	19.0	18.1	2.0	1.9	3.0	2.9	6.0	5.7	4	3.8
Total	**110**	**39.2**	**74**	**26.4**	**55.0**	**19.6**	**3.0**	**1.1**	**8.0**	**2.9**	**17.0**	**6.1**	**13**	**4.6**

Source: NHS Greater Glasgow and Clyde Bowel Screening IT System (Extracted: August 2013)

Note: data to be validated

A review of the first round of the bowel screening results was undertaken in collaboration with the University of Glasgow (Mansour, D. et al, 2013) found that interval cancers are more common in females and more likely to be right sided or rectal.

They are more likely to have both adverse tumour features such as venous invasion, and adverse host features, such as the presence of an elevated SIR and hence have a poorer prognosis. Further work is required to explore whether this is because they represent a subset of aggressive fast growing tumours or are tumours that are missed by the screening test itself. See Appendix 3.1 for more details.

Research

Another research project with University of Glasgow investigated the efficacy of a populated based colorectal cancer screening programme and analysed the outcomes in screen detected and non screen detected tumours (see Appendix 3.1). The findings concluded that screen detected patients had a more favourable outcome compared to individuals with non screen detected tumours. It was recommended that further studies are needed to improve the response rate to the screening invitation and also the sensitivity of the current test (Mansouri et al, 2013).

Information systems

The bowel screening programme is supported by a NHSGGC in-house IT application. The data collected allows staff to monitor service performance and track patients through the process from point of referral to diagnosis and treatment for colorectal cancer. The application also enables staff to monitor progress against quality assurance standards and NHS Quality Improvement Scotland Standards.

Health Improvement

As part of the national Detect Cancer Early marketing campaign, Health Improvement Teams will develop localised programmes of work in relation to bowel screening to support the campaign and increase uptake of the bowel screening programme. This will involve local awareness raising initiatives, for example, roadshows, visiting community groups and health centres to discuss the programme with members of the community. Community engagement will include raising the issue of lifestyle change to prevent bowel cancer, highlighting key messages on the signs and symptoms to look out for and call to action. National leaflets and posters will be distributed across primary care and acute settings, community centres and via Healthy Working Lives networks

Two local pilot studies are also planned for 2013 to explore whether uptake of the bowel cancer screening test in men in the most socio-economically deprived areas in North West sector and Renfrewshire can be increased by a short intervention and encouragement to participate in the programme. The pilot will target men aged 50-74. Further follow up from the National Bowel Screening Centre will provide feedback on how many of the bowel screening tests kits were reordered and completed.

Challenges and future priorities

- Continue to monitor and audit the performance of the programme
- To encourage uptake of the programme through social marketing and health improvement activities

Appendix 3.1

Research Projects

Mansouri, D., McMillan, D.C., Morrison, D., Crighton, E.M., Horgan, P.G. 2013
Efficacy of a population based colorectal cancer screening programme and analysis of outcomes in screen detected and non-screen detected tumours

Background

Population based faecal occult blood test (FOBt) screening for colorectal cancer reduces cancer specific mortality through the detection of early stage disease. However, programmes are limited by uptake and the characteristics of the test itself. The aim of the present study was to compare features of screen detected and non screen detected tumours and assess the effect on cancer specific mortality.

Methods

Prospectively maintained databases of both the prevalence round of a biennial population based FOBt screening programme and a regional cancer audit database were analysed. Mortality data was obtained from the national registry.

Results

Of the 395,097 males and females aged 50 to 70 years invited to screening, 203,886 (52%) responded. 6085 (3%) tested positive and 4632 (76%) attended for colonoscopy. A total of 951 patients were diagnosed with cancer within two years of screening invite: 378 (40%) screen detected and 573 (60%) non screen detected. Of the non screen detected patients, 376 (66%) were non responders, 134 (23%) were FOBt negative and 63 (11%) did not attend or did not have cancer diagnosed at colonoscopy. Therefore, estimated FOBt sensitivity was 77% and specificity was 99%. Comparing screen detected and non screen detected patients, screen detected patients were more likely to be male, less social economically deprived, have a tumour with a lower Dukes stage, and more likely to have a left sided tumour (all $p>0.05$).

In addition, screen detected patients were more likely to undergo an operation with a curative intent, less likely to undergo an emergency procedure, and less likely to die within 30 days of their procedure (all p<0.001). This remained significant on multivariate survival analysis (Cox proportional hazards) including age, sex, deprivation, emergency presentation, tumour site and stage, and curative surgery (p<0.001).

Conclusions

Independent of established prognostic factors, screen detected patients have more favourable outcomes than those with non screen detected tumours. Therefore, further studies to improve the response rate to a screening invitation and the sensitivity of the current screening test are warranted.

Mansouri, D., McIlveen, E., McMillan, D.C., Morrison, D., Crighton, E.M., Horgan, P.G. 2013 ***Interval versus Screen-detected colorectal cancer: Comparison of host and tumour prognostic factors and outcome***

Abstract

Aims:

Interval cancers (INT) are tumours that develop within two years of a negative colorectal cancer faecal occult blood screening test (FOBt). The aim of this study was to compare tumour and host factors, such as an elevated preoperative systemic inflammatory response (SIR) in screen-detected (SD) and INT cancers and assess their impact on cancer-specific survival.

Methods

All individuals who completed an FOBt screening test in a single NHS health board were included. Screening details were cross-referenced with a local cancer audit database to identity those with INT tumours. An elevated SIR was calculated using the neutrophil to lymphocyte ratio (NLR>5).

Results

In the first round of screening 203 886 pts responded to the screening invitation of which 6085(3.0%) were positive.

595 pts were diagnosed with cancer with 2 years of screening invite (412 SD;134 INT;49 did not attend for screening colonoscopy following a postive test or had cancer missed at colonoscopy). Comparing SD and INT tumours (n=546), INT tumours were more likely to be in females, right sided, rectal, a more advanced tumour stage, present as an emergency and less likely to undergo a procedure with a curative intent (all p<0001). When those who had a procedure with a curative intent were examined separately (n=474) INT tumours had more advanced t-stage, n-stage (both p<0.001) and were more likely to have poorer differentiation, venous invasion, margin involvement, undergo an emergency operation and have an elevated SIR (all p<0.05). With a median follow-up of 2.3 years, SD pts had improved cancer-specific survival versus INT patients (p<0.001). However, this did not retain significant on multivariate analysis (Cox proportional hazards) including tumour stage, site, emergency procedure, curative intent and the SIR (p=0.294).

Conclusions: Interval cancers are more common in females and more likely to be right sided or rectal. They are more likely to have both adverse tumour features such as venous invasion, and adverse host features, such as the presence of an elevated SIR and hence have a poorer prognosis. Further work is required to explore whether this is because they represent a subset of aggressive fast growing tumours or are tumours that are missed by the screening test itself.

Appendix 3.2

Members of Bowel Screening Steering Group (As at May 2013)

Dr Emilia Crighton	Consultant in Public Health Medicine, Chair
Mr John Anderson	Consultant Surgeon
Mrs Margaret Anderson	Lead Nurse - Endoscopy
Dr Stuart Ballantyne	Consultant Radiographer
Mrs Claire Donaghy	Health Improvement Senior
Dr Fraser Duthie	Lead Clinician for Pathology
Mr Ian Finlay	Consultant Surgeon - Bowel Screening Lead
Mr Patrick Finn	Consultant Colorectal and General Surgeon
Mrs Fiona Gilchrist	Assist Programmes Manager, Screening Dept
Dr Derek Gillen	Lead Clinician for Endoscopy (until May 2013)
Dr Neil Jamieson	Lead Clinician for Endoscopy
Dr Rachel Green	Associate Medical Director
Mr Alan Hunter	General Manager
Mrs Annette Little	Information Analyst
Mrs Karen Loudon	Clinical Service Manager
Miss Denise Lyden	Project Officer
Mrs Lin Calderwood	H&IT Service Delivery Manager
Ms Joyce McFadyen	Health Records Manager
Mrs Susan McFadyen	Acting General Manager
Mr Nelson McFarlane	Clinical Service Manager
Mrs Tricia McKenna	Colorectal Nurse Endoscopist
Dr John Morris	Consultant Gastroenterologist
Dr Kenneth O'Neill	Clinical Director, South Sector CHP
Dr Fat Wui Poon	Lead Clinician for Radiology
Mrs Elizabeth Rennie	Programmes Manager, Screening Dept

SUMMARY

CHAPTER 4: PREGNANCY SCREENING

- There were 15,857 women booked to attend antenatal clinics across NHS Greater Glasgow and Clyde. 14,074 women were from NHS Greater Glasgow and Clyde residents and 1,783 women lived outwith the Board area. The pregnancy screening activity is recorded in the PNBS IT application.

- 63.3% (8,909) of first antenatal booking appointments were offered within 12 weeks gestational age and 24.4% (3,433) between 13 to 16 weeks gestational age.

- 14,074 women booked for their first antenatal screening, 93% (13,086) had taken up haemoglobinopathies screening.

- Data on the number of carriers and fetuses at risk of sickle cell disease and thalassaemia through screening is not available for 2012/13.

- An estimate of the percentage uptake of each of the communicable diseases screening tests has been calculated by dividing the number requesting the test by the total number of samples.

- Uptake across NHS Greater Glasgow and Clyde is greater than 99% for all four of the screening tests (HIV, Hepatitis B, Rubella and Syphilis).

- In 2012/13, the overall uptake for Down Syndrome was 70.4%. 3,765 (37.9%) samples were taken from women in their first trimester, and 6,146 (70.6%) samples were taken from women in the second trimester. The uptake of first trimester tests was lower in the Glasgow based hospitals due to the delayed implementation of the first trimester screening that started in November 2012.

- 77.1% of pregnant women had taken up congenital anomalies screening

- 2.2% of women were assigned to the ‘higher chance’ of Down Syndrome group. Following the second trimester Down Syndrome screening, 3.7% of women were assigned to the 'higher chance' of Down Syndrome group, and 2.4% of women had an elevated AFP giving a 'higher chance' of a neural tube defect.

- 10,847 fetal anomaly scans performed, 149 anomalies were identified and of that number 44 were considered to be of clinical relevance once the baby was born. The outcomes for 25 anomalies are not known.

- 309 amniocentesis samples were analysed by the Cytogenetics Laboratory. 35 abnormalities were detected (11.3% of samples) and 20 of those (6.5% of total tests) had a diagnosis of Down Syndrome.

- 103 chorionic villus biopsies were analysed by the Cytogenetics Laboratory in 2012/13. 38 abnormalities were detected (36.9% of tests) and 25 of those (24.2% of tests) had a diagnosis of trisomy (Down Syndrome).

- An audit was undertaken for the period 1 April 2011 to 31 March 2012 to identify why less than half of children resident in NHS Greater Glasgow and Clyde with Down Syndrome were not detected antenatally.

- All women who had a subsequent Down Syndrome affected pregnancy who were eligible for pregnancy screening were offered it.

- 48.8% of the 43 children affected with Down Syndrome during 1 April 2011 – 31 March 2012 were diagnosed antenatally as women declined either the screening test or the diagnostic test following a high chance result.

CHAPTER 4: PREGNANCY SCREENING

Aims of pregnancy screening programmes

Antenatal haemoglobinopathies screening for sickle cell and thalassaemia aims to identify couples who are at risk of having an affected child and thereby offer them information on which to base reproductive choices.

Communicable diseases in pregnancy screening aims to identify infection and ensure a plan for treatment and management of affected individuals and their babies is put in place at the earliest opportunity. Screening allows undiagnosed infection to be identified and 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.

Down Syndrome and other congenital anomalies screening aims to detect Down's syndrome and other congenital anomalies 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

The pregnancy screening programmes are offered universally to all pregnant women at the first booking visit. Women are offered the tests, not because they have been at risk, but because they are pregnant.

The screening tests

Appendix 4.1 illustrates the gestational age when pregnancy tests are carried out.

Antenatal haemoglobinapthies screening*:* The pregnant woman and her partner are asked to complete a family origin questionnaire (FOQ). The information from the questionnaire is used to assess the risk of either parent being a carrier for sickle cell and other haemoglobin variants. In addition, a blood test is taken at first antenatal booking 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 will also be offered testing. The full screening pathway is shown in Appendix 4.2.

Screening for sickle cell disorders and thalassaemia should be offered to all women as early as possible in pregnancy, and ideally by 10 weeks.

Communicable diseases in pregnancy screening: Testing for HIV, hepatitis B, syphilis infection and immunity to rubella is carried out at first antenatal booking when a blood sample is taken. The full screening pathway is shown in Appendices 4.3 – 4.7.

Screening for **Down Syndrome** can be carried out using two different screening methods depending on gestational age. The screening tests, using blood and ultrasound scans, together with maternal risk factors, are used to derive an overall risk of having a baby with Down Syndrome. The full screening pathway is shown in Appendix 4.8. Ultrasound scanning is used to look for other **congenital anomalies**.

The decision to accept screening for Down Syndrome and other congenital anomalies raises particular moral and ethical issues for women. Uptake of Down Syndrome or other congenital anomalies screening depends on whether women would wish further investigation or management.
An estimate of the percentage uptake has been calculated by dividing the number of tests by the total number of women booked for maternity care.

Delivery of NHSGGC pregnancy screening programmes

Each NHS Board has a statutory requirement to submit data on antenatal activity. In NHS Greater Glasgow and Clyde, there were 15,857 women booked to attend antenatal clinics across NHS Greater Glasgow and Clyde (**Table 4.1)**. 14,074 (94.7%) women booked into antenatal clinics were NHS Greater Glasgow and Clyde residents.

Table 4.1 Number of women booked for their first antenatal appointments in NHS Greater Glasgow and Clyde 1 April 2012 to 31 March 2013

Maternity Unit	First appointed referrals NHSGGC residents	First appointed referrals not NHSGGC residents	First appointed referrals total	Bookers NHSGGC residents	Bookers Not NHSGGC residents	Bookers Total
Not assigned to a maternity unit	146	53	199	144	51	195
Princess Royal Maternity	5,444	1,248	6,692	4,834	1,067	5,901
Royal Alexandra Hospital	3,414	384	3,798	3,207	347	3,554
Southern General Hospital	6,618	422	7,040	5,889	318	6,207
Total	**15,622**	**2,107**	**17,729**	**14,074**	**1,783**	**15,857**

Source: Pregnancy & Newborn Screening System, October 2013

Table 4.2 shows that 63.3% (8,909) of first antenatal booking appointments were offered within 12 weeks gestational age and 24.4% (3,433) between 13 to 16 weeks gestational age.

Table 4.2 Gestational age at first antenatal booking appointment by maternity unit for period 1 April 2012 to 31 March 2013[1,2]

Maternity Unit	Not Recorded	<=12Wks 6Days	13Wks 0Days - 16Wks 6Days	17Wks 0Days - 20Wks 6Days	21Wks 0Days - 24Wks 6Days	25Wks 0Days - 30Wks 6Days	>=31Wks 0Days	Total
Not assisgned to unit	45	55	29	8	4	3	0	144
Princess Royal Maternity Hospital	316	3,002	1,233	164	59	23	37	4,834
Royal Alexandra Hospital	145	2,683	265	55	15	25	19	3,207
Southern General Hospital	374	3,169	1,906	259	69	57	55	5,889
Total	**880**	**8,909**	**3,433**	**486**	**147**	**108**	**111**	**14,074**
% Total	**6.3%**	**63.3%**	**24.4%**	**3.5%**	**1.0%**	**0.8%**	**0.8%**	

Source: Pregnancy & Newborn Screening System, October 2013
NHS Greater Glasgow & Clyde Hospitals & Residents

NHSGGC Antenatal Haemoglobinopathies Screening Programme

Table 4.3 shows that, of the 14,074 women booked for their first antenatal screening, 93% (13,086) had taken up haemoglobinopathies screening.

Table 4.3 NHSGGC haemoglobinopathies screening activity for the period 1 April 2011 to 31 March 2012

Maternity Unit	Number of Bookers[b]	Consent[c]	% Consented	FOQ Completed [a]	% Uptake (a/b)
Not assigned to a maternity unit	144	114	79.2	109	75.7
Princess Royal Maternity Hospital	4,834	4451	92.1	4249	87.9
Royal Alexandra Hospital	3,207	3142	98.0	3098	96.6
Southern General Hospital	5,889	5683	96.5	5630	95.6
Total	**14,074**	**13390**	**95.1**	**13086**	**93.0**

Source: Pregnancy & Newborn Screening System, October 2013
NHS Greater Glasgow & Clyde Hospitals & Residents

FOQ = Family Origin Questionnaire

Data on the number of carriers and fetuses at risk of sickle cell disease and thalassaemia through screening is not available for 2012/13.

NHSGGC Communicable Diseases in Pregnancy Screening Programme

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.

The number of women referred for booking cannot be used as the denominator to calculate uptake as it is does not accurately represent the number of women who have been offered screening. Some women would not have been offered screening because they have had an early pregnancy loss. A small number of women will transfer out of the health board area.

Table 4.4 shows that uptake across NHS Greater Glasgow and Clyde is greater than 99% for all four of the screening tests.

Table 4.4 NHSGGC Communicable diseases tests and results

1st April 2012 - 31st March 2013					Results					
	total number of samples	No. requesting individual test	No. not requesting individual test	uptake	Antibody detected[1,2,3]		antibody not detected [4]		insufficient not tested [5]	
	(N)	(N)	(N)	%	(N)	%	(N)	%	(N)	%
HIV	15,931	15,784	147	99.1	11	0.07	15758	99.8	15	0.1
HBV	15,931	15,830	101	99.4	79	0.5	15745	99.5	16	0.1
Rubella	15,931	15,891	40	99.8	14,952	94.1	927	5.8	12	0.08
Syphilis	15,931	15,838	93	99.8	4	0.02	15820	99.9	14	0.09

Sources: West of Scotland Regional Virus Laboratory; NHSGGC Microbiology Laboratories (Clyde)

Notes:

1. 10 of the 11 HIV infections were previously known about
2. 31 of the 79 HBV infections were previously known about
3. Rubella antibody detected means that the woman is immune to rubella
4. No antibody detected means that the woman is susceptible to rubella and should be offered immunisation with MMR vaccine after delivery
5. 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.

NHSGGC Down Syndrome and other congenital anomalies screening programme

Table 4.5 shows that 9,911 samples were tested for Down Syndrome, representing an overall uptake of 70.4%. 3,765 samples were taken from women in their first trimester, and 6,146 samples were taken from women in the second trimester. The uptake of first trimester tests was lower in the Glasgow based maternity units due to the delayed implementation of the first trimester screening that started in November 2012.

Table 4.5: Uptake rate of Down Syndrome tests, and type of screening test for the period 2012/2013

Maternity Unit	Number of Bookers	1st trimester	2nd trimester	Total number samples analysed	Overall uptake
PRM	**4,834**	1,312	3,125	4,437	**91.8%**
Royal Alexandra Hospital	**3,207**	1,289	216	1,505	**46.9%**
Southern General Hospital	**5,889**	1,164	2,805	3,969	**67.4%**
Not assigned to a unit	**144**	0	0	0	**0**
Total	**14,074**	**3,765**	**6,146**	**9,911**	**70.4%**

Source: West of Scotland Regional Prenatal Screening Service

77.1% of pregnant women had taken up congenital anomalies screening **(Table 4.6).**

Table 4.6 Uptake rate for other congenital anomalies (fetal anomaly scan) for the period 31 March 2012 to 1 April 2013

Maternity Unit	Number of bookers	Number of Consents	Consented %	Number of fetal anomaly scans	Fetaly anomaly scan %	Uptake
Not assigned to a unit	144	120	83.3%	77	64.2%	53.5%
Princess Royal Maternity Hospital (PRM)	4,834	4,637	95.9%	3,666	79.1%	75.8%
Royal Alexandra Hospital (RAH)	3,207	3,089	96.3%	2,622	84.9%	81.8%
Southern General Hospital (SGH)	5,889	5,580	94.8%	4,482	80.3%	76.1%
Total	**14,074**	**13,426**	**95.4%**	**10,847**	**80.8%**	**77.1%**

Source: Pregnancy & Newborn Screening System, October 2013

Table 4.7 shows the number and proportion of women initially assigned to each of the 'higher chance' groups following the first trimester and second trimester screening Down Syndrome screening requiring diagnostic tests. Among those who had first trimester Down Syndrome screening, 2.2% of women were assigned to the 'higher chance' of Down Syndrome group. Following the second trimester Down Syndrome screening, 3.7% of women were assigned to the 'higher chance' of Down Syndrome group, and 2.4% of women had an elevated AFP giving a 'higher chance' of a neural tube defect.

Table 4.7 Number and proportion of women initially assigned to the 'higher chance' anomaly groups by type of screening tests

CUB Screening		
	N	%
- Higher Chance' of Down's syndrome	82	2.2
2nd Trimester Screening		
	N	%
- Higher Chance' of Down's syndrome	229	3.7
- NTD (AFP≥ 2.0 MOM)	145	2.4

Source: West of Scotland Regional Prenatal Screening Service

NHS Quality Improvement Scotland Standards: Pregnancy and Newborn Screening 2005, recommends that less than 5-7% screening tests for Down Syndrome should be assessed as higher chance. Therefore, laboratory based screening in NHS Greater Glasgow and Clyde does achieve these standards.

Table 4.8 shows that of the 10,847 fetal anomaly scans performed, 149 anomalies were detected and of that number 44 were confirmed. The outcomes for 25 anomalies are not known.

Table 4.8 Outcome of fetal anomaly scans performed for the period 1 April 2011 to 31 March 2012

Maternity Unit	Fetal anomaly scan performed	Fetal anomaly detected	Fetal anomaly detected %	Anomaly confirmed	No anomalies (further scans)	No anomaly detected postnatally	Outcome not known
Not assigned to a unit	77	0	0.0	0	0	0	0
Princess Royal Maternity Hospital	3,666	44	1.2	13	0	19	10
Royal Alexandra Hospital	2,622	59	2.3	25	3	22	13
Southern General Hospital	4,482	46	1.0	6	4	17	2
Total	**10,847**	**149**	**1.4**	**44**	**7**	**58**	**25**

Source: Congenital Anomalies Surveillance Tool, Pregnancy & Newborn Screening System, October 2013
NHS Greater Glasgow & Clyde Hospitals & Residents

First Antenatal Appointment 1st April 2012 - 31st March 2013 (Excluding Pregnancy Losses Unless Scan Performed)

Table 4.9 shows that 309 amniocentesis samples were analysed by the Cytogenetics Laboratory. Some women whose indication for amniocentesis has been recorded as "maternal age" have also been screened; however, it was not possible to separate the data. 35 abnormalities were detected (11.3% of samples) and 20 of those (6.5% of total tests) had a diagnosis of trisomy (Down Syndrome).

Table 4.9 Cytogenetics analysis of amniocentesis outcomes of samples by indication type for the period 1 April 2012- 31 March 2013

	Biochemical Screening	Maternal Age	Abnormalities on Scan	Other	Total
Number of women (= number of tests)	188	45	59	17	309
% total referral reasons	60.8%	14.6%	19.1%	5.5%	100%
Number with normal results	175	44	41	14	274
Number with diagnostic trisomy	6	1	13	0	20
% number with diagnostic trisomy	3.2%	2.2%	22.0%	0.0%	6.5%
Number of other non trisomy abnormalities	7	0	5	3	15
Total number of abnormalities	**13**	**1**	**18**	**3**	**35**
% total number of abnormalities	**6.91%**	**2.22%**	**30.51%**	**17.65%**	**11.33%**

Source: Cytogenetics Laboratory

Table 4.10 shows that 103 chorionic villus biopsies were analysed by the Cytogenetics Laboratory in 2012/13. 38 abnormalities were detected (36.9% of tests) and 25 of those (24.3% of tests) had a diagnosis of trisomy (Down Syndrome).

Table 4.10 Cytogenetics analysis outcomes of chorionic Villus Biopsy samples by indication for the period 1 April 2012 to 31 March 2013

	Referral Type				
	Biochemical Screening	**Maternal Age**	**Abnormalities on Scan**	**Other**	**Total**
Number of women (= number of tests)	11	10	53	29	103
% total referral reasons	10.7%	9.7%	51.5%	28.2%	100.0%
Number with normal results	10	10	21	24	65
Number with diagnostic trisomy	1	0	24	0	25
% total with diagnostic trisomy	9.1%	0.0%	45.3%	0.0%	24.3%
Number of other non trisomy abnormalities	0	0	8	5	13
Total number of abnormalities	**1**	**0**	**32**	**5**	**38**
% total number of abnormalities	**9.1%**	**0.0%**	**60.4%**	**17.2%**	**36.9%**

Source: Cytogenetics Laboratory

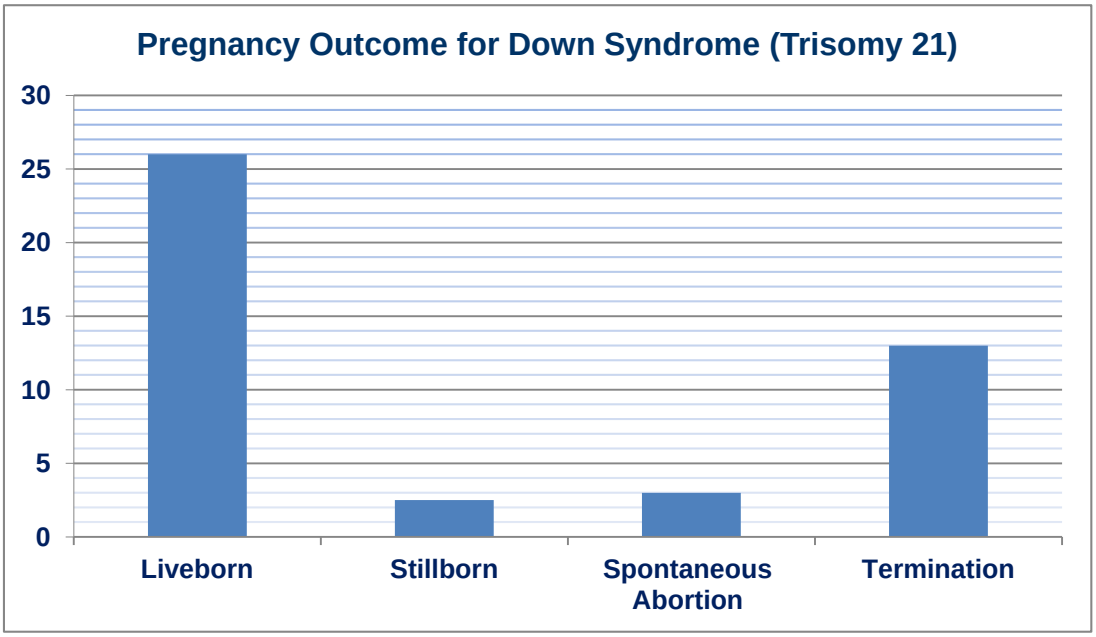
Audit review of the data relating to the process of screening and detection of Trisomy 21 for period 1 April 2011 to 31 March 2012

In May 2013, an audit was undertaken to identify why less than half of children resident in NHS Greater Glasgow and Clyde with Down Syndrome were not detected antenatally. The Quality Indicator Standards recommend that 95% of cases should be detected antenatally (Simpson, L and Robins, J, 2013).

Data was analysed for the period 1 April 2011 to 31 March 2012.

A total of 43 cases of Down's Syndrome were reported in NHS Greater Glasgow and Clyde in 2011-2012. Sixty percent of cases were live born (n=26), thirty percent were terminated (n=13), seven percent spontaneously aborted (n=3) and two percent were stillborn (n=1) (**Figure 4.1**).

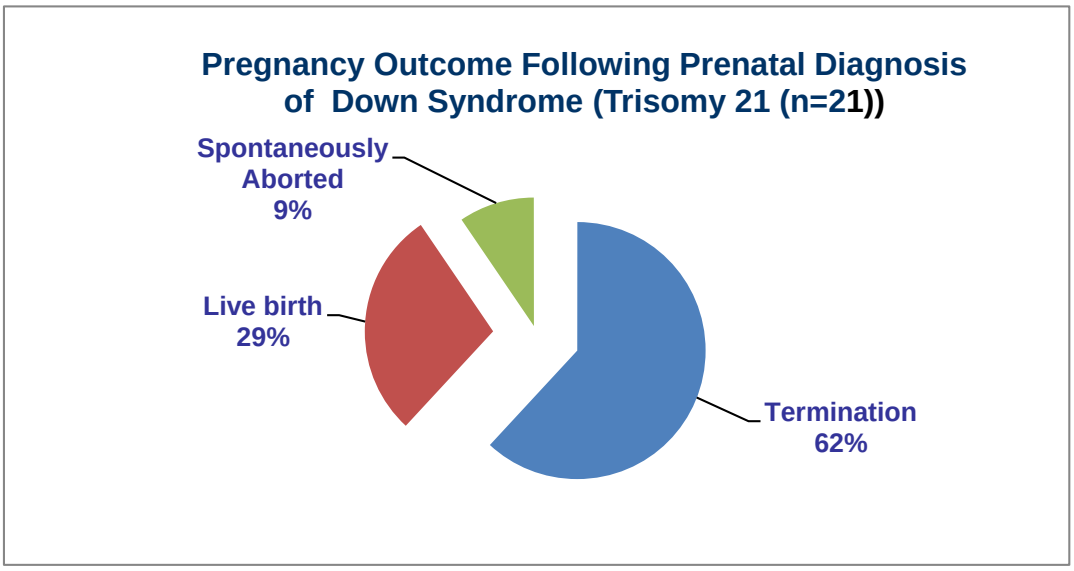
Figure 4.1 Pregnancy outcome for the 43 confirmed cases of Down Syndrome in NHS Greater Glasgow and Clyde between 1 April 2011 – 31 March 2012



Source: Simpson, L and Robins, J. (2013)

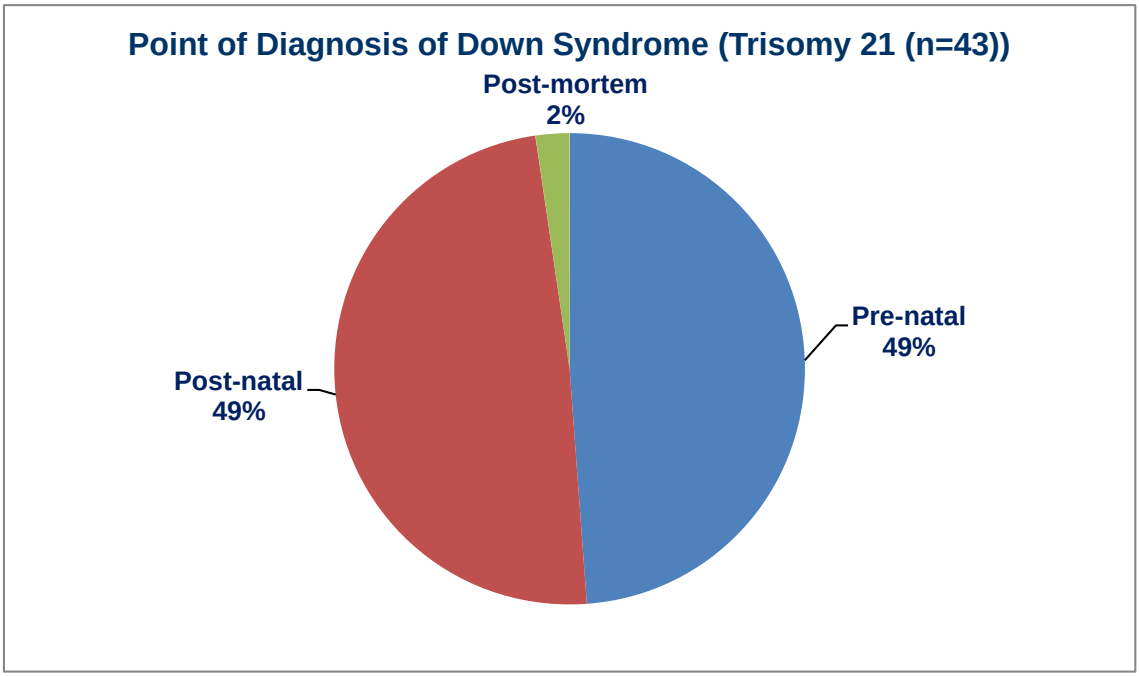
Diagnosis of twenty-one cases of Trisomy 21 (Down Sydrome) (48.8%) occurred prenatally. Thirteen pregnancies who received a T21 diagnosis were terminated (61.9%), six proceeded to birth (28.6%) and two spontaneously aborted (9.5%) (**Figure 4.2**). Twenty-one cases were diagnosed at birth (48.8%) and one case diagnosed at post-mortem (2.3%) (**Figure 4.3**).

Figure 4.2 Pregnancy outcome following diagnosis of Downs Syndrome (Trisomy 21)



Source: Simpson, L and Robins, J. (2013)

Figure 4.3 Point at which Down Syndrome (Trisomy 21) was detected



Source: Simpson, L and Robins, J. (2013)

From the live born infants with a Down Syndrome diagnosis, it was possible to determine whether diagnosis occurred prenatally via screening (first and second trimester), diagnostic testing (amniocentesis, chorionic villi sampling) or after birth.

Total screening outcome

All women who had a subsequent affected child were offered screening if they were eligible, i.e. within the gestational time limits. This was 38 (88.4%) of the 43 cases. Three (7.0%) women were offered a diagnostic test in the first instance and two (4.7%) pregnancies spontaneously aborted before screening was offered (Table 4.11).

Table 4.11.Total number of pregnancies offered screening or diagnostic test

Outcome	Number of Down Syndrome Cases
Offered Screening	38
Straight to Diagnostic	3
Spontaneous Abortions	2
Total	**43**

Source: Simpson, L and Robins, J. (2013)

Of those that were offered screening, 26 (68.4%) accepted screening, ten (26.3%) declined, one (2.6%) was found to be greater than 22 weeks gestation at booking thus out with screening parameters; and one (2.6%) underwent a termination of pregnancy based on ultrasound` findings. No diagnostic test was performed in this instance (**Table 4.12**).

Table 4.12.Screening process outcome for all affected pregnancies in Greater Glasgow and Clyde from 1 April 2011-31 March 2012

Pregnancy Screening Outcome	Number of pregnant women
Accepted Screening	26
Declined Screening	10
Late Gestation at Booking	1
Termination after Screening: No Diagnostic	1
Total	**38**

Source: Simpson, L and Robins, J. (2013)

From the 38 women offered pregnancy screening, ten (26.3%) declined any form of screening and nine women (23.6%) declined a diagnostic test after a high chance result. Together this equates to 50% of women refusing screening or a diagnostic test (**Table 4.13**).

Table 4.13 Point during pregnancy that screening and diagnostic tests were declined

Point of Declining Screening/ Diagnostic Test	Number of pregnant women
At Booking	10
After screening (high risk result)	9
Total	**19**

Source: Simpson, L and Robins, J. (2013)

Results by pregnancy outcome

Live Births

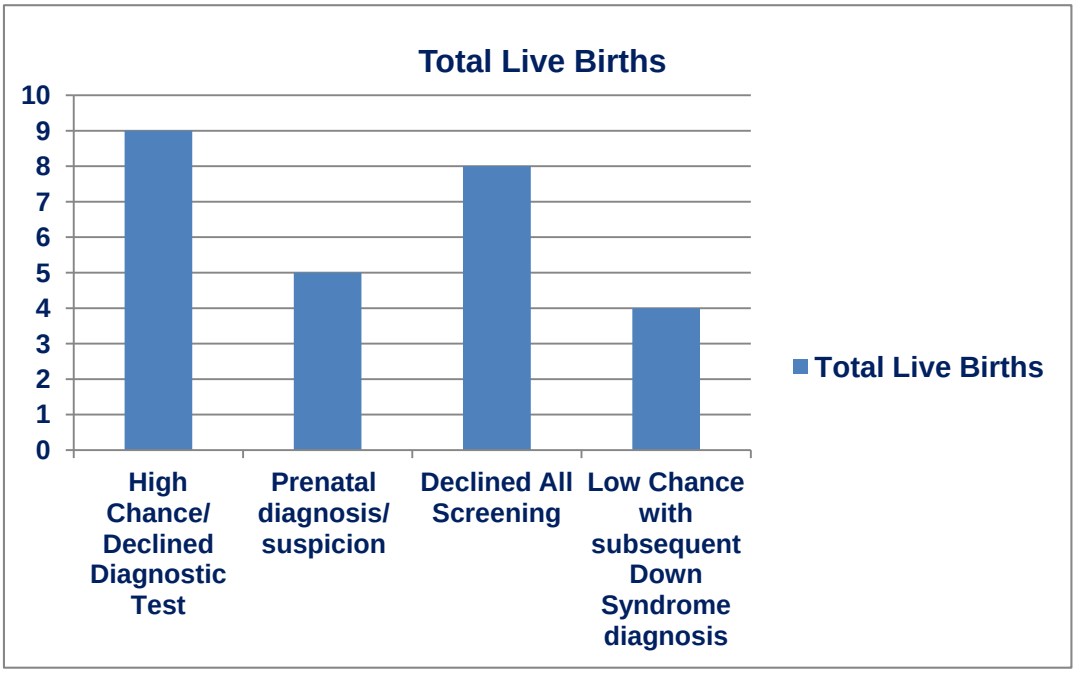
With 43 cases diagnosed, 26 were live born (60.5%). From this subset (n=26) nine (34.6%) received a high chance screening result but declined a diagnostic test. Five (19.2%) received a prenatal diagnosis or aroused clinical suspicion and eight (30.8%) declined any form of screening or diagnostic testing. Four patients (15.4%) received a low chance result yet had an affected child (**Table 4.14**) (**Figure 4.4**).

Table 4.14 Data obtained from patient files to determine screening uptake and outcome for the 26 live infants with a Down Syndrome diagnosis in the Greater Glasgow and Clyde region between 1 April 2011 – 31 March 2012

Total Live Births	Number (n = 26)	Percentage (60.5%)
Declined diagnostic test after 'high chance' result	9	34.6%
Prenatal diagnosis or raised clinical suspicion	5	19.2%
Declined all Screening/ Diagnostic Tests	8	30.8%
'Low chance' result with subsequent T21 diagnosis	4	15.4%

Source: Simpson, L and Robins, J. (2013)

Figure 4.4 Screening outcome from the 26 cases of Down Syndrome live born infants in NHS Greater Glasgow and Clyde 1 April 2011 – 31 March 2012

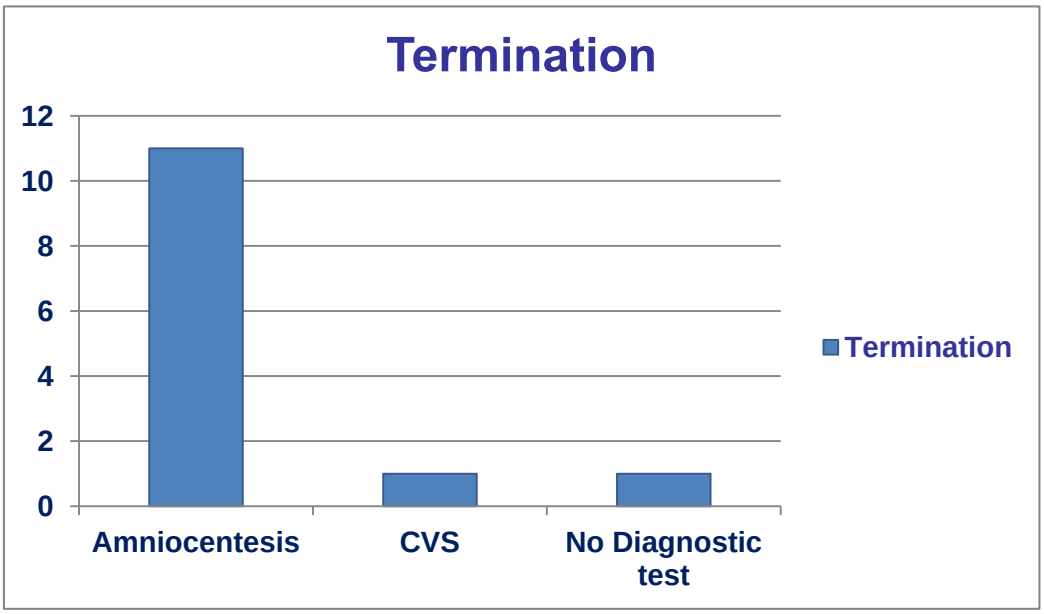


Source: Simpson, L and Robins, J. (2013)

Termination of pregnancy

Thirteen (30.2%) of the total diagnosed cases with Down Syndrome (n =43) resulted in termination. Eleven (84.6%) had an amniocentesis, one (7.7%) opted for chorionic villis sampling (CVS) and one (7.7%) proceeded straight to termination based on ultrasound scan findings (**Figure 4.5**).

Figure 4.5 Diagnostic procedure undertaken for T21 diagnosis in 13 confirmed cases in the Greater Glasgow and Clyde region

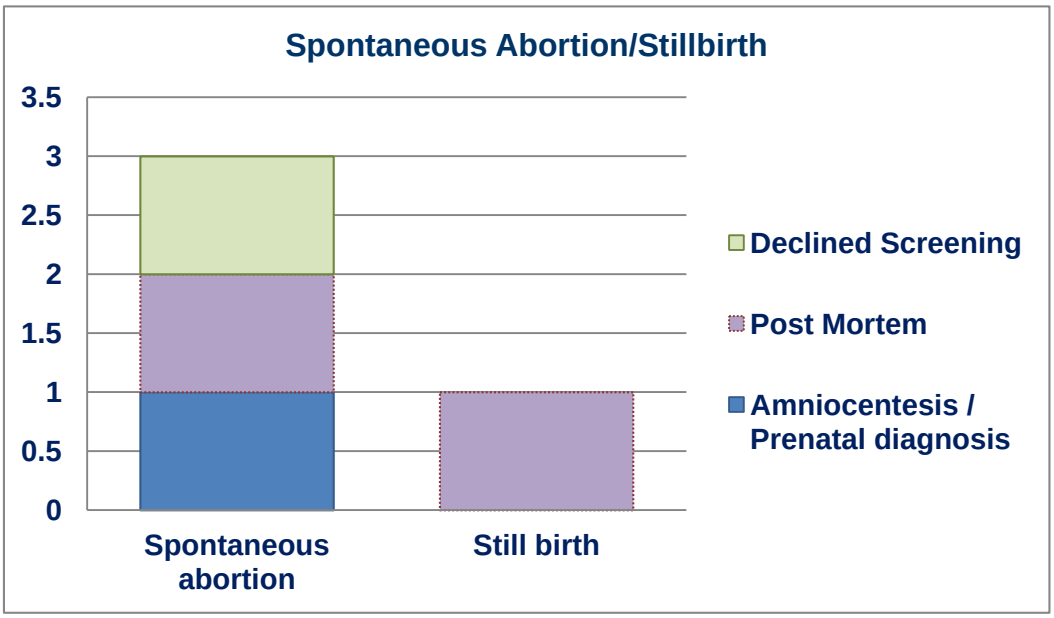


Source: Simpson, L and Robins, J. (2013)
Note: One case proceeded straight to termination based on ultrasound alone without a confirmed diagnosis. Trisomy 21 was confirmed at post-mortem.

Pregnancy loss

The remaining four cases (9.3%) of the total (n = 43) consisted of three spontaneous abortions (75%) and one still birth (25%). One of the pregnancy losses received a prenatal diagnosis via amniocentesis, one at post mortem and one declined diagnosis. However, clinical suspicion was raised in this instance even without a definitive diagnosis (**Figure 4.6**).

Figure 4.6 Diagnostic procedure for the fetal losses with confirmed trisomy 21 diagnosis



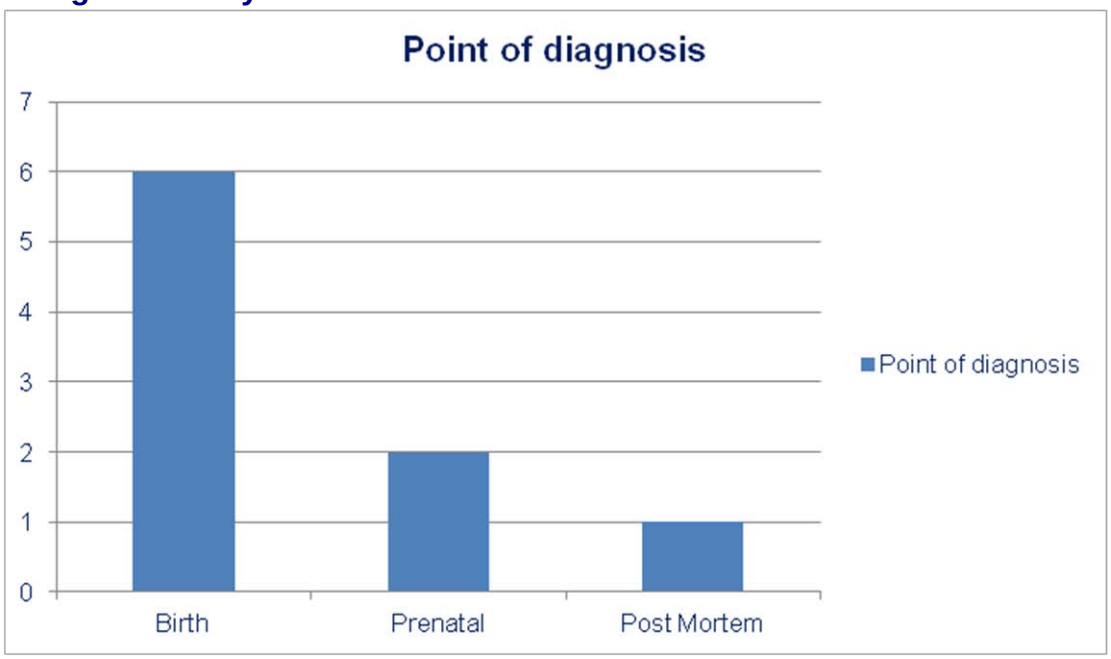
Source: Simpson, L and Robins, J. (2013)

Results by Region

Clyde Region

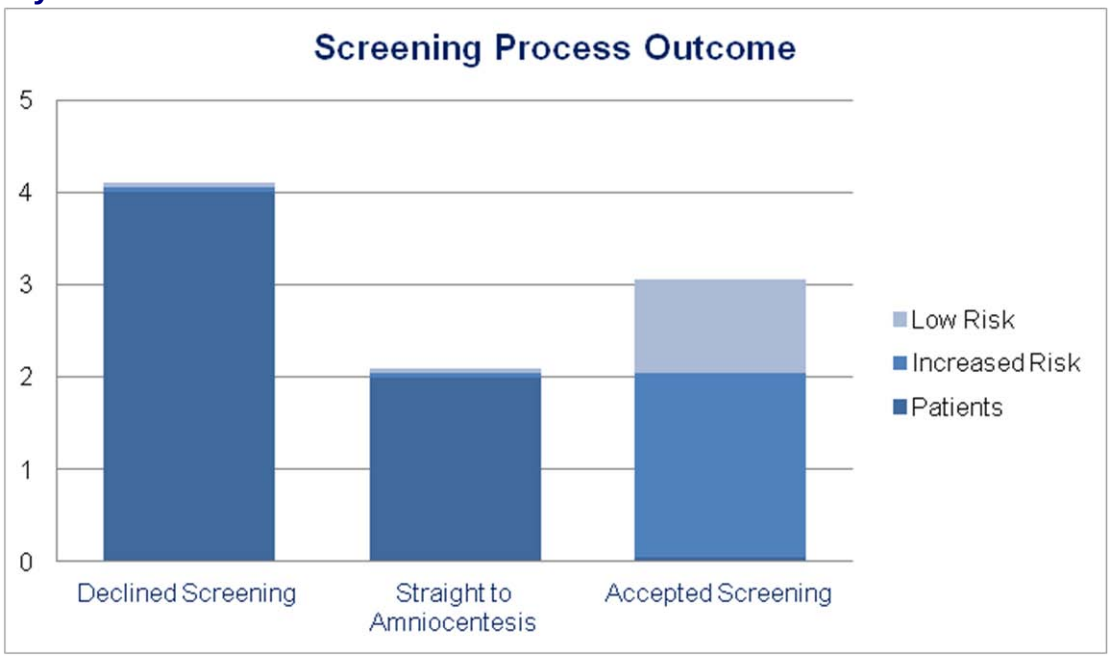
The region of Clyde was covered by the Royal Alexandra Hospital and had nine (20.9%) patients in total receive a T21 diagnosis from the 43 cases. From these nine, four declined screening (44.4%); two proceeded straight to amniocentesis (22.2%) and three patients accepted screening (33.3%). Two of those that accepted screening received a high chance result and declined a diagnostic test. One patient received a low chance result yet had a subsequent affected child (**Figure 4.7**). Six children were diagnosed at birth, two prenatally and one at post mortem (**Figure 4.8**) (**Table 4.15**).

Figure 4.7 Point of diagnosis for pregnancies within NHS Greater Glasgow and Clyde



Source: Simpson, L and Robins, J. (2013)

Figure 4.8 Number of patients that opted for prenatal screening, diagnostic testing and results obtained in the NHS Greater Glasgow and Clyde



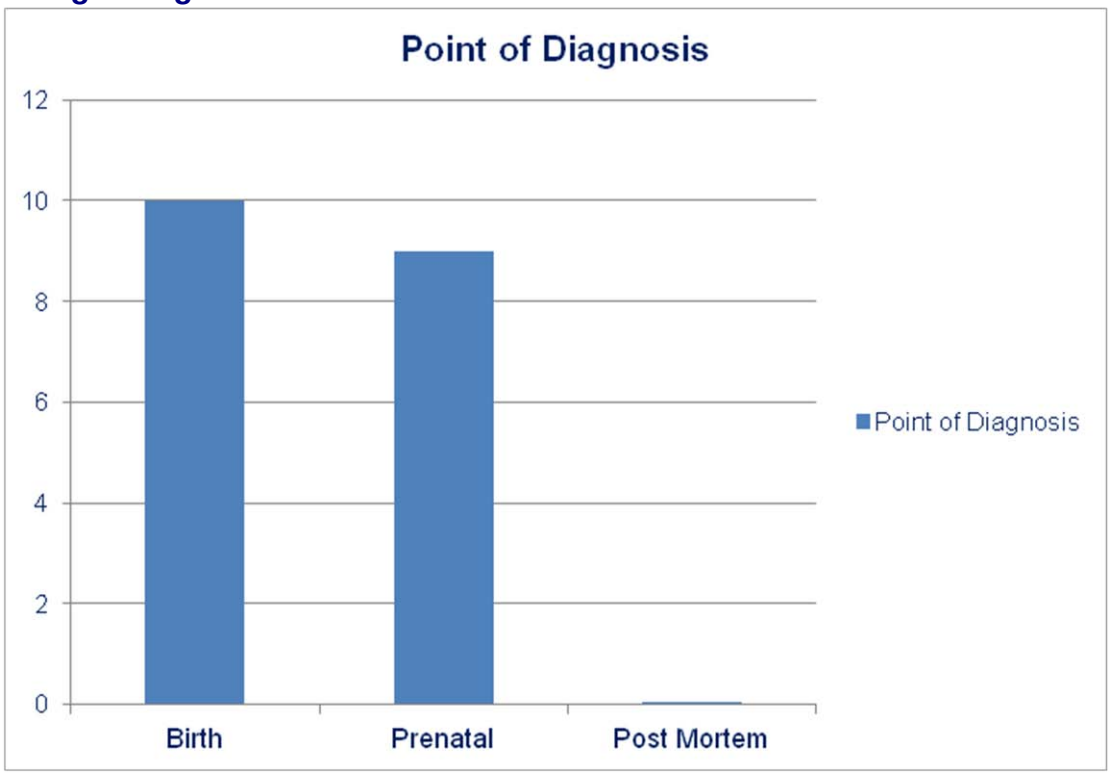
Source: Simpson, L and Robins, J. (2013)

Glasgow South and West

South and west Glasgow maternities were covered by the Southern General Hospital. Here a total of 19 diagnoses of Down Syndrome were received (**Table 4.15**) (**Figure 4.9**). A total of 12 live births were recorded and two of these had a prenatal diagnosis (16.7%), four (33.3%) accepted screening and received a high risk result however declined screening; four (33.3%) declined all screening and two (16.7%) had a low chance screening result yet had a subsequent affected child (**Figure 4.10**).

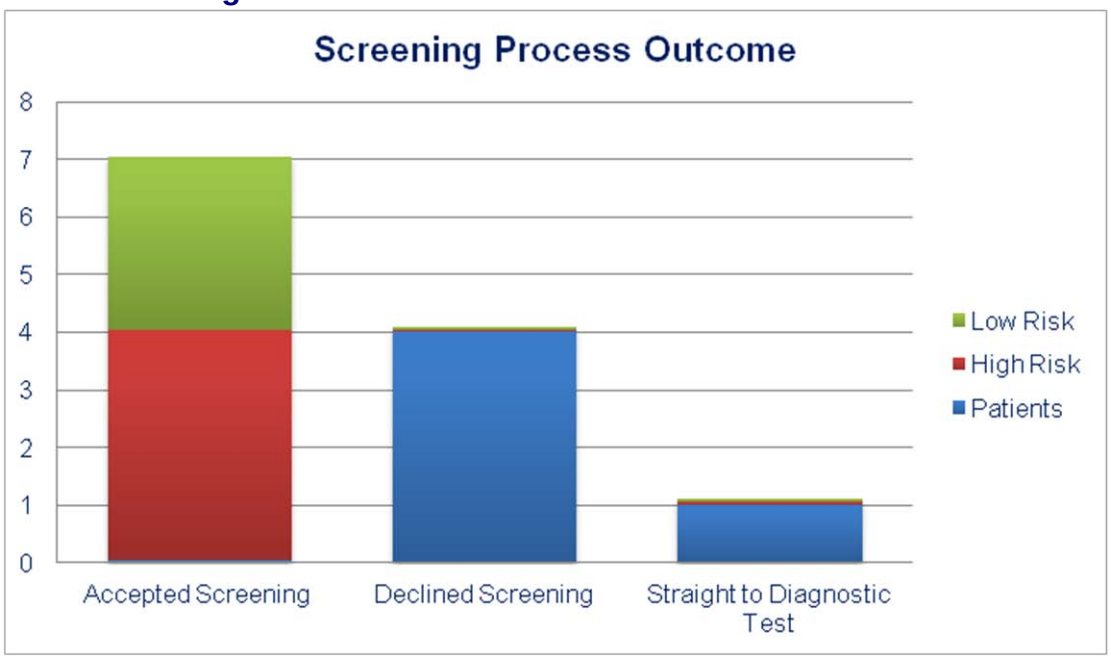
Nine (47.4%) of the total 19 maternities in this region were diagnosed prenatally, seven of these proceeded to termination and two were live births. There were no spontaneous abortions or stillbirths (**Figure 4.9**).

Figure 4.9.Point of diagnosis for affected pregnancies in South and West Glasgow region



Source: Simpson, L and Robins, J. (2013)

Figure 4.10 Screening and diagnostic process for maternities in South and West Glasgow

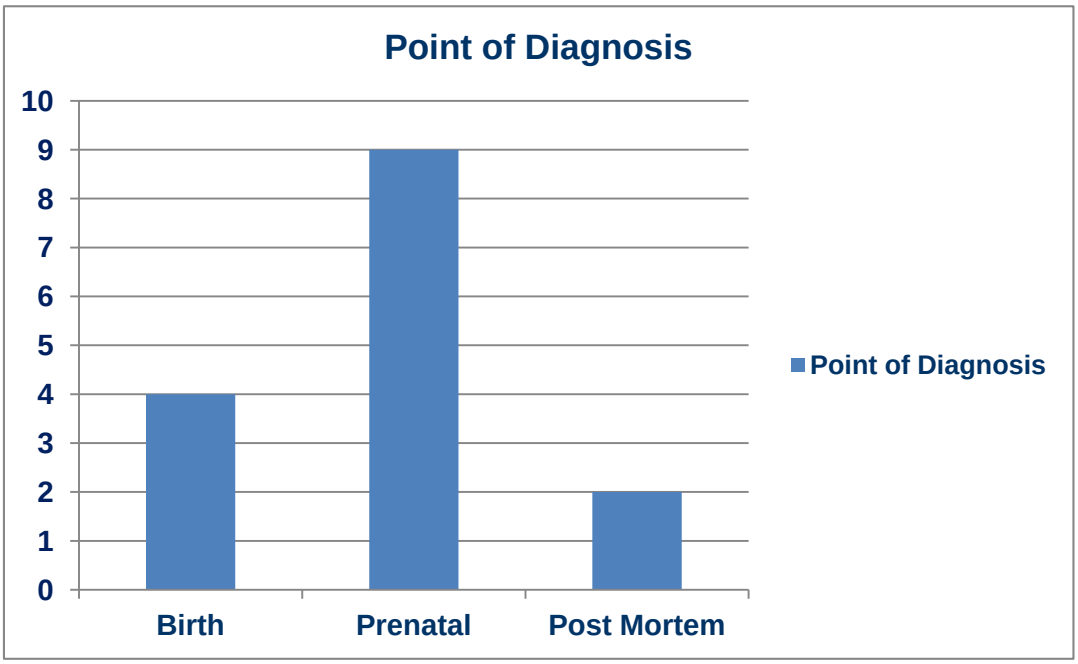


Source: Simpson, L and Robins, J. (2013)

Glasgow North and East

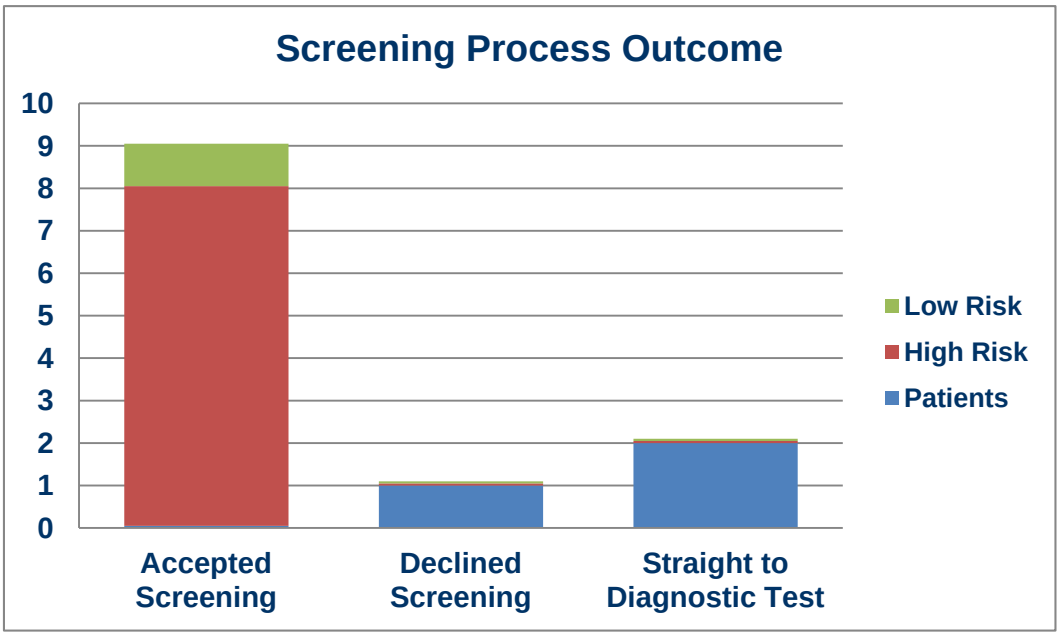
Maternities in this region were covered by the Princess Royal Maternity Hospital. A total of 15 cases of Down Syndrome were diagnosed. Seven live births were recorded (46.7%) and six (40%) received a high chance result; one (6.7%) received a low chance result yet had an affected child. Three (20%) opted for prenatal diagnosis and three declined a diagnostic test (**4.12**). Five (33.3%) pregnancies were diagnosed prenatally and terminated. There were three (20%) spontaneous abortions (**Table 7**). The point of diagnosis in each of the early pregnancy losses was different. One opted for amniocentesis, one declined all screening/ diagnostic tests (clinical suspicion evident from case notes) and one was diagnosed at post mortem (**Figure 4.11**).

Figure 4.11 Point of diagnosis for pregnancies in the North and East region



Source: Simpson, L and Robins, J. (2013)

Figure 4.12 Screening and diagnostic process outcome for maternities in the North and East Region of Glasgow.



Source: Simpson, L and Robins, J. (2013)

Note:
Three of the patients who accepted screening subsequently declined a diagnostic test

Additional Results

From the 43 cases of Down Syndrome recorded in NHS Greater Glasgow and Clyde, 20 pregnancies (46.5%) had an additional malformation (**Tables 4.15 and 4.16**). Seven (35%) of these were atrioventricular canal defects. Consent was obtained for all patients for the fetal anomaly scan (FAS). This defect can be detected during the four chamber heart view.

Table 4.15 Addition malformations detected in affected cases and whether they were detected at Ultrasound

Point of Diagnosis	Outcome	Additional Malformations	Consent to FAS	Detectable at Scan	Detected
Birth	Live	Q202, Q 212	y	Q 212	x
Prenatal	Live	Q211, D1810	y	D1810	y
Birth	Live	Q212	y	Q212	x
Prenatal	Termination	D1810	y	D1810	y
Birth	Live	Q211, D1810	y	D1810	y
Prenatal	Termination	D1810	y	D1810	y
Prenatal	Live	Q431, Q212	y	Q212	x
Prenatal	Termination	D1810, Q701	y	D1810	y
Prenatal	Live	Q410	y	Q410	y
Birth	Live	Q256	y	X	x
Birth	Live	Q212	y	Q212	x
Prenatal	Termination	D1810	y	D1810	y
Birth	Live	Q2310	y	X	x
Prenatal	Termination	Q210, Q430	y	X	-
Prenatal	Termination	Q030	y	Q030	x
Prenatal	Spontaneous Abortion	Q210	y	Q210	x
Prenatal	Spontaneous Abortion	Q212	y	Q212	y
Birth	Live	Q212, Q250	y	Q212	x
Prenatal	Termination	D1810	y	D1810	y
Birth	Live	Q211	y	Q211	X
Prenatal	Live	Q212	y	Q212	X
				D1810	y

Source: Simpson, L and Robins, J. (2013)

Table 4.16 ICD10 codes for congenital malformations detected in children that were diagnosed with Down Syndrome

ICD10 CODE	Condition
D1810	Cystic Hygroma
Q212	Av Canal Defect
Q256	Pulmonary Artery Stenosis
Q211	Atria septal defect (ASD)
Q210	Ventricular septal defect (VSD)
Q430	Meckel's Diverticulum
Q701	Webbed Fingers
Q431	Hirschsprung Disease
Q202	Double Outlet at Left Ventricle
Q030	Obstructive Aqueduct of Sylvius
Q410	Duodenal Atresia
Q250	Patent DuctusArterosis
Q2310	Bicuspid Aortic Valve

Source: Simpson, L and Robins, J. (2013)

Audit Findings

- All women who had a subsequent Down Syndrome affected pregnancy who were eligible for pregnancy screening were offered it.
- Depending on gestation at booking, either the 1st Trimester test or 2nd trimester test was offered.
- 60.5% (n =26) of the cohort of women offered screening (n=38) accepted.
- 23.3% (n= 10) of the cohort of women offered screening (n=38) declined.

- 20.9% (n = 9) of women who initially accepted screening declined a diagnostic test after a high chance result.

- Combination of those that declined screening and those that declined a diagnostic test (n=19) results in 50% of women declining screening and diagnosis. If 50% of the affected pregnancies are declining screening then only 50% of the pregnancies in NHSGGC during this period can be detected prenatal. This identifies why only half of the children affected with Down Syndrome during 1st April 2011 – 31st March 2012 were diagnosed antenatally.

- Main reasons for declining the test were that they believed they were not at risk, miscarriage risk from diagnostic test and would not consider termination.

- The most likely outcome after a Down Syndrome diagnosis was termination – 61.9% (n=13).

- 26 live births occurred but only five (11.6%) were diagnosed prenatally. Seventeen (65.4%) declined any form of screening or diagnosis and four (15.4%) were given a low chance result.

- All women who received a low chance result and proceeded to have an affected child underwent 2nd trimester Quadruple serum testing.

- Cut off for increased result was decreased from 1 in 250 to 1 in 150 in September 2011. It was noted that two of the high chance results i.e. greater than 150 would have received a ‘low chance’ result had this been implemented at that time thus increasing the false negative rate of the quadruple serum test.

- Four of the pregnancies were twin pregnancies therefore unless a diagnostic test was performed then screening could not be reliable.

- All women consented to the fetal anomaly scan.

- 46.5% (n=20) had an additional anomaly, 17 of which were potentially detectable at scan.

- Within this cohort of the T21 affected pregnancies, 100% of cystic hygroma's were detected, 14.3% (n=1) of atrioventricular(AV) canal defects were detected and 100% (n=1) of duodenal atresia were also correctly identified. The National Protocols (NSC) from NHS Scotland Screening programme – Fetal anomaly and Down Syndrome Screening state that 50% of cardiac anomalies should be detected however it did not include AV canal defects.

  No information was available relating to these defects. Applying this 50% detection rate for AV canal defects then it was clear that detection rate was poor.

- Data collection was difficult as the three maternity hospitals record data via three separate methods.

- The Pregnancy and Newborn Screening (PNBS) software had limited information and was inadequate for the collection of data. Alternative information systems had to be researched and case notes requested in 41.8% of cases.

- Staff members stated that PNBS was inadequate to record data as they were often met with an error message when attempting to input information. It also has no facility to record multiple scans and record any additional comments in relation to appointments.

- Quality of the information obtained was best from the written case notes. Although laborious, difficult to obtain and time-consuming the data recorded here was detailed and thorough.

Recommendations

- Reviewing the PNBS software and removing errors. Permit the ability to upload multiple scans and add a comments box to enable additional information to be recorded.

- Ensure that there is universal software used throughout NHS Greater Glasgow and Clyde to unify the capture of information and antenatal care.

- All demographics and consent need to be collected and validated at booking appointments and must be included in the PNBS in order to tighten data to reflect women's choices.

- Generate a feedback sheet in an attempt to identify the main failings of PNBS in order to improve efficiency of antenatal services.

- Clinical correspondence should be uploaded to the system, clinical portal or both. Access to the patient's record and correspondence between health providers eliminates the need to request case notes as all file will be electronically available.

- Promote early presentation to antenatal services in order to utilise first trimester screening and only use second trimester screening if necessary to decrease false negative results.

- Review the change to levels that determine a high chance and low chance results. Two women were given a high chance result when the cut off was 1 in 250 and had they been pregnant when the new 1 in 150 cut off was implemented then they would have been given a low chance result because their actual risk was above 150 and below 250. They would not have been offered a diagnostic test and therefore remain undiagnosed until birth. An audit should be undertaken to access the risk levels women received in the current year and determine if they would have benefited before the new cut off was introduced. An audit should be conducted into the detection of AV canal defects across NHS Greater Glasgow and Clyde. These defects have a strong association with chromosome abnormalities especially T21. NSC guidelines recommend that 50% of serious cardiac anomalies be detected yet does not mention AV canal defect. Investigation of detection rates should be analyzed. Detection rate has been shown to improve by measuring the ratio of atria to ventricular length (AVL) when presented with a four chamber view. Cut off for AVL ratio of>0.6 was chosen and resulted in an 82.6% detection rate. Further study should be carried out into this aspect of ultrasound screening.

- Women need better counselling from healthcare providers regarding the incidence of Down Syndrome, purpose of screening and what a Down Syndrome diagnosis means. One patient stated that she believed she was not at risk therefore declined screening; however at age 38 she had a maternal age risk of approximately 1 in 100. No explanation of risk for maternal age was offered to her.

- Those that fear miscarriage risk from diagnostic testing should be considered for maternal fetal DNA analysis, especially if it is their first pregnancy combined with high maternal age; or it is a pregnancy after assisted conception. Specific defined criteria should be assessed, defined and implemented. Cost of the test is an obstacle for availability on NHS; however it should be reserved for priority cases. If not available then it should be made known to women that this test is an option should they wish to cover the cost privately.

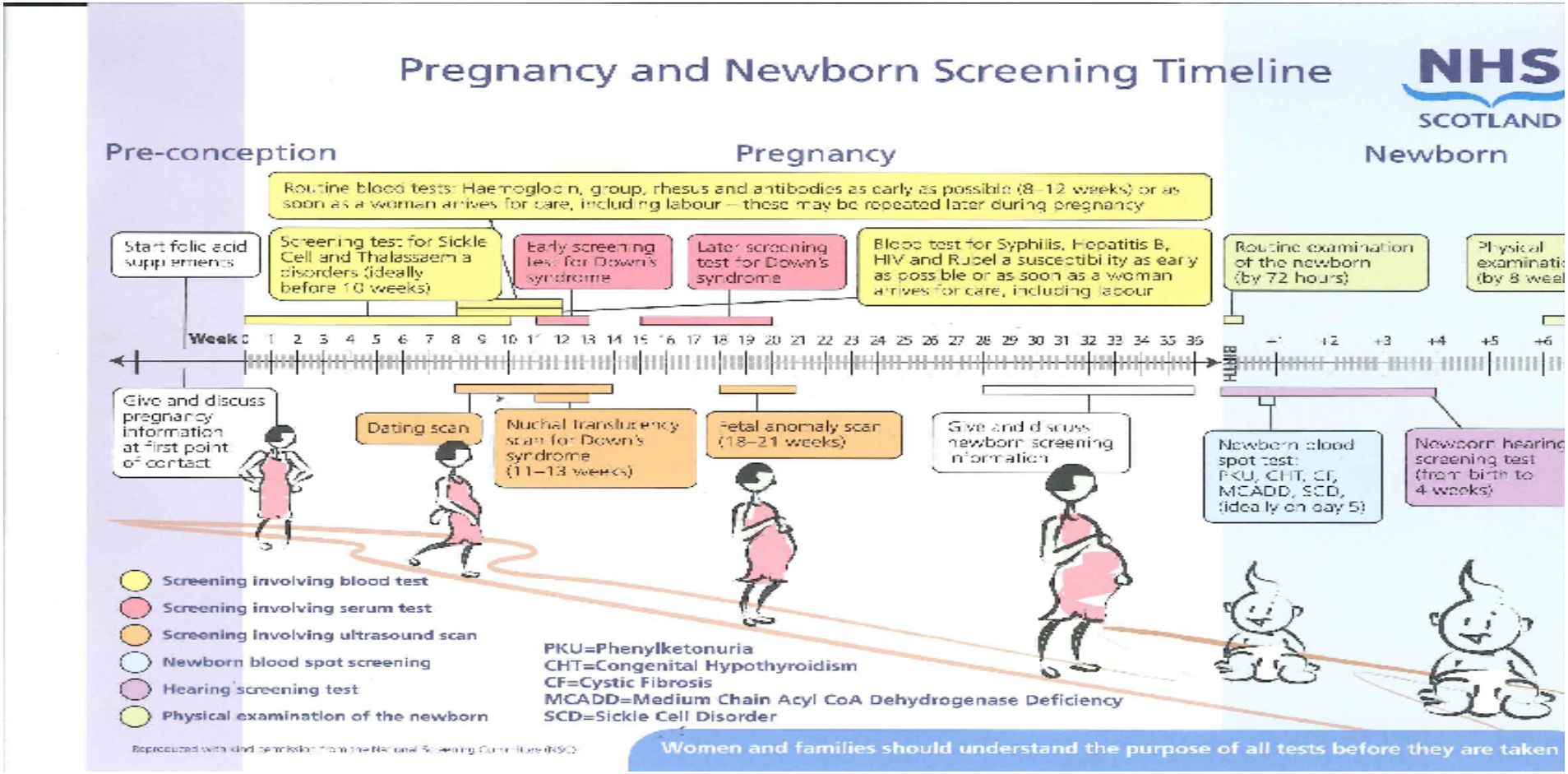
Information systems

PNBS IT application is used to support all pregnancy and newborn screening programmes. The application brought improvements in both the reporting and management of cases identified through the programme. It introduced additional failsafe mechanisms into the screening programme.

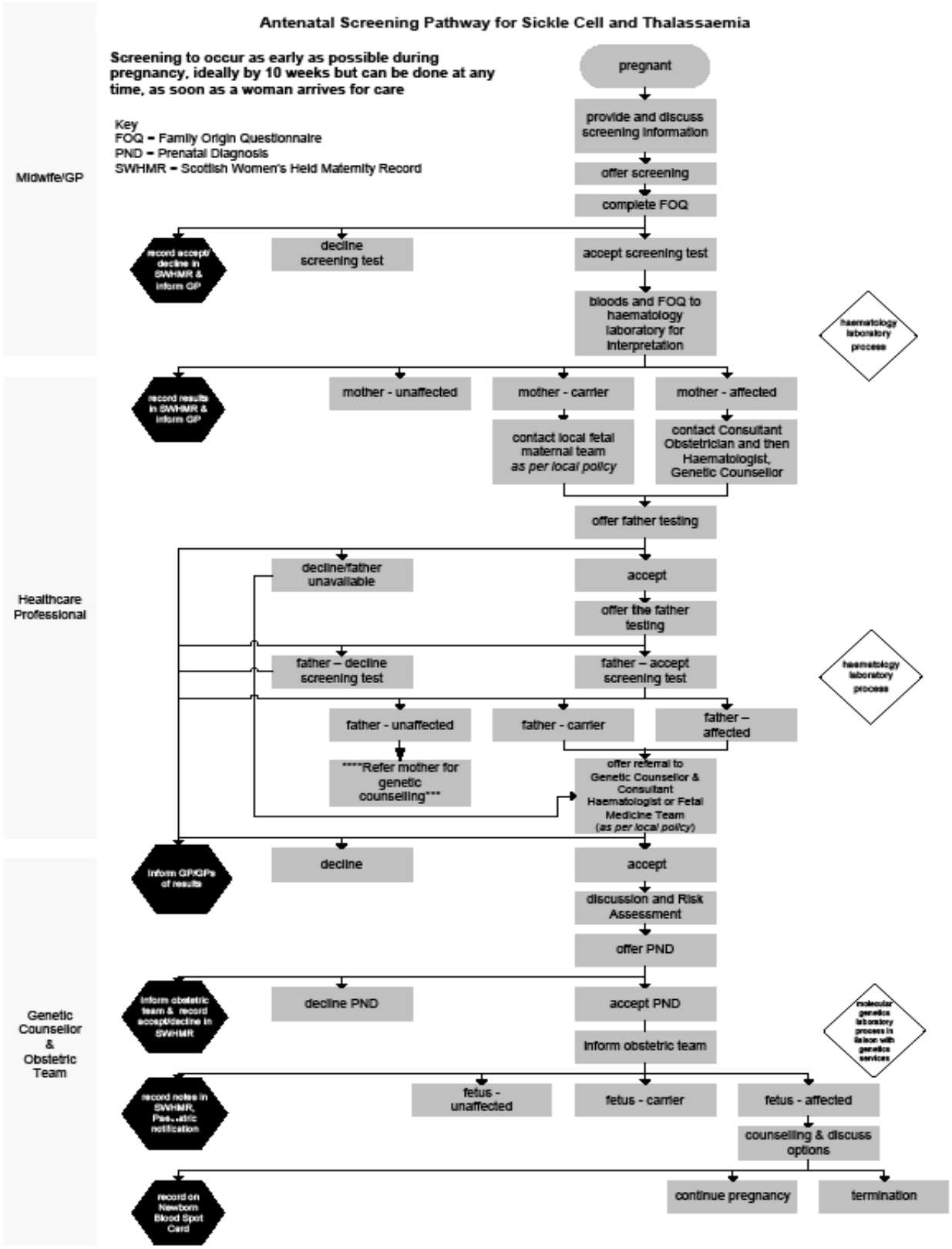
Challenges and Priorities

- Improving data completeness
- First trimester Down Syndrome screening for all Glasgow residents

APPENDIX 4.1


Pregnancy and Newborn Screening Timeline
NHS SCOTLAND
Pre-conception
Pregnancy
Newborn
Routine blood tests: Haemoglobin, group, rhesus and antibodies as early as possible (8–12 weeks) or as soon as a woman arrives for care, including labour – these may be repeated later during pregnancy
Start folic acid supplements
Screening test for Sickle Cell and Thalassaemia disorders (ideally before 10 weeks)
Early screening test for Down's syndrome
Later screening test for Down's syndrome
Blood test for Syphilis, Hepatitis B, HIV and Rubella susceptibility as early as possible or as soon as a woman arrives for care, including labour
Routine examination of the newborn (by 72 hours)
Physical examination (by 8 weeks)
Week
Give and discuss pregnancy information at first point of contact
Dating scan
Nuchal translucency scan for Down's syndrome (11–13 weeks)
Fetal anomaly scan (18–21 weeks)
Give and discuss newborn screening information
Newborn blood spot test: PKU, CHT, CF, MCADD, SCD, (ideally on day 5)
Newborn hearing screening test (from birth to 4 weeks)
Screening involving blood test
Screening involving serum test
Screening involving ultrasound scan
Newborn blood spot screening
Hearing screening test
Physical examination of the newborn
PKU=Phenylketonuria
CHT=Congenital Hypothyroidism
CF=Cystic Fibrosis
MCADD=Medium Chain Acyl CoA Dehydrogenase Deficiency
SCD=Sickle Cell Disorder
Women and families should understand the purpose of all tests before they are taken

Appendix 4.2


Antenatal Screening Pathway for Sickle Cell and Thalassaemia
Screening to occur as early as possible during pregnancy, ideally by 10 weeks but can be done at any time, as soon as a woman arrives for care
Key
FOQ = Family Origin Questionnaire
PND = Prenatal Diagnosis
SWHMR = Scottish Women's Held Maternity Record
Midwife/GP
Healthcare Professional
Genetic Counsellor & Obstetric Team
pregnant
provide and discuss screening information
offer screening
complete FOQ
decline screening test
accept screening test
record accept/decline in SWHMR & inform GP
bloods and FOQ to haematology laboratory for interpretation
haematology laboratory process
record results in SWHMR & inform GP
mother - unaffected
mother - carrier
mother - affected
contact local fetal maternal team as per local policy
contact Consultant Obstetrician and then Haematologist, Genetic Counsellor
offer father testing
decline/father unavailable
accept
offer the father testing
father – decline screening test
father – accept screening test
haematology laboratory process
father - unaffected
father - carrier
father – affected
"""Refer mother for genetic counselling"""
offer referral to Genetic Counsellor & Consultant Haematologist or Fetal Medicine Team (as per local policy)
inform GP/GPs of results
decline
accept
discussion and Risk Assessment
offer PND
inform obstetric team & record accept/decline in SWHMR
decline PND
accept PND
inform obstetric team
molecular genetics laboratory process in liaise with genetics services
record notes in SWHMR, Paediatric notification
fetus - unaffected
fetus - carrier
fetus - affected
counselling & discuss options
record on Newborn Blood Spot Card
continue pregnancy
termination

Appendix 4.3

NHS Greater Glasgow and Clyde

Offering Routine Antenatal Communicable Disease Screening Tests

"The primary aim of screening women for these conditions is to ensure a plan for treatment and management for affected individuals and their babies".
NHS QIS Clinical Standards, Pregnancy and Newborn Screening

On confirmation of pregnancy woman is referred for antenatal care

Woman issued with information pack detailing expected care and routine tests, *at least 48 hours in advance of booking visit (Standard 3b.3)*

Woman requests more information or refuses one or more screening tests

Health care worker confirms woman has read information leaflet, offers blood tests, obtains consent and informs woman when and how she will receive her results *(within 21 days, Standard 3c.1,2,4,5)*

Overarching Principles – Pregnancy Screening
Relevant information, which outlines the benefits and risks of screening should be provided in a user-friendly manner so that women and their partners can make an informed choice. This information should be provided by her midwife with additional support from appropriate specialists as necessary. Contact details below.

Woman declines one or more screening tests. Consent for tests accepted, and decision about those declined, is documented

Blood is taken and tests ordered for those tests where consent is given
Is it imperative that the Pregnancy and Newborn Screening IM&T system is used to ensure tests can be tracked and failsafes are in place.
The PNBS system should be updated if a previously declined test is later accepted.

Women who **decline** one or more tests, should be **re-offered** testing early in the third trimester, between 28-31 weeks. .
Women who book late should be offered screening at the first opportunity.
See **Appendix 1 for Late Booking Protocol.**
All test results for a woman should be known prior to delivery and definitely before discharge

Test is indeterminate or unsatisfactory. *Counselling and/or further tests provided within 5 days of any indeterminate/unsatisfactory test. (Standard 3d.1)*

The laboratory sends result to a named person who will make arrangements to recall women to site *for repeat blood test within 5 days (Standard3d.1)*

SIGNIFICANT TEST RESULTS
- Seronegative or equivocal result for rubella
- Carrier of hepatitis B
- Positive syphilis serology
- Positive for HIV infection

REFER TO SIGNIFICANT TEST RESULT CARE PATHWAY FOR EACH INFECTION

Test is negative. *Woman informed by letter of negative screening tests within 21 days (Standard 3c5). Confirmation that woman has received screening tests results should be recorded at subsequent antenatal visits.*

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 woman develops symptoms of hepatitis or an STI she should be referred to the relevant professional (hepatologist/SHA) for appropriate assessment.

Special Needs in Pregnancy (SNIPs) –RAH – 0141 314 6199 or 0141 887 9111 then page 56311 **VOL** – 01389 817 270
IRH – 01475 504 833 **Glasgow** - 0141 221 5267 or 0141 211 5366 or 0141 211 5337 (secretary)

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

Version No:	V5.2
Approved by:	Communicable Diseases in Pregnancy Steering Group
Date Approved:	April 2011
Next revision date:	April 2012

Appendix 4.4

NHS Greater Glasgow and Clyde

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 routinely notifies outpatient manager (or deputy) at maternity unit responsible for woman's antenatal care.
All antibody negative rubella results are issued to obstetric team within 15 working days. (Standard 3e.4)

↓

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 in woman's notes *within 5 days of woman receiving result. (Standard 3d.1)*

↓

Prior to discharge the postnatal ward offers:

- Contraception advice
- MMR consent and immunisation if appropriate.
- If MMR not given, information to be included in the postnatal discharge summary for the attention of the GP

Version No:	V4.2
Approved by:	Communicable Diseases in Pregnancy Steering Group
Date Approved:	December 2011
Next revision date:	December 2012

Appendix 4.5

NHS Greater Glasgow and Clyde

Protocol for Significant Laboratory Results

HEPATITIS B

Woman is found to be hepatitis B surface antigen positive

Virologist sends a letter and copy of report to:

- the named outpatient manager, or deputy, at the maternity unit responsible for woman's antenatal care
- the nominated hepatitis B Obstetrician at the maternity unit
- cc'd to Sandyford Shared Care Support Service – Tel: 0141 211 8634
- the GP (if patient registered)

The Public Health Protection Unit (PHPU) is notified electronically on a weekly basis.

All screen positive samples are confirmed and issued to the named clinician within 15 days of the screening test. (Standard 3e.2)

The nominated obstetricians for hepatitis B will ensure that the woman's named obstetrician carries out the following:

The woman is recalled and repeat blood tests to confirm identity are carried out

The woman is *informed of the result within 21 days of screening test (Standard 3c.4)* and understands the meaning of the result and need for immunisation of baby.

The woman is immediately referred to the local hepatitis service for clinical review and advice

Sandyford Shared Care Support Service will co-ordinate the screening of family members and contract tracing.

The woman is given an appointment to attend for review at 26 weeks.

The hepatitis B status and management plan is clearly documented in the Neonatal section of the Yellow Alert Sheet which starts every inpatient maternity record

Refer to the NHS GGC Obstetric Guidelines – 'Hepatitis B positive Management of women identified through antenatal screening' (May 2012)

Healthcare worker ensures appropriate instructions received from the laboratory for follow up of baby are documented in relevant place in mother's notes.

Maternity staff inform the paediatric team to ensure appropriate treatment is given within 24 hours of birth. Immunisation form completed and faxed or emailed (GG-UHB.HepatitisB@nhs.net) to Community Screening Department within 48 hours of immunisation.

Before discharge from the maternity unit, a check should be made that the woman has already attended the hepatitis service and if not, a further appointment at 2 months is made.

Community Screening Department records immunisation and recalls child for all subsequent immunisations. GP refers child at 12 months to appropriate paediatrician, for blood test to check immunity

Paediatrician checks blood test and informs Community Screening department of result.

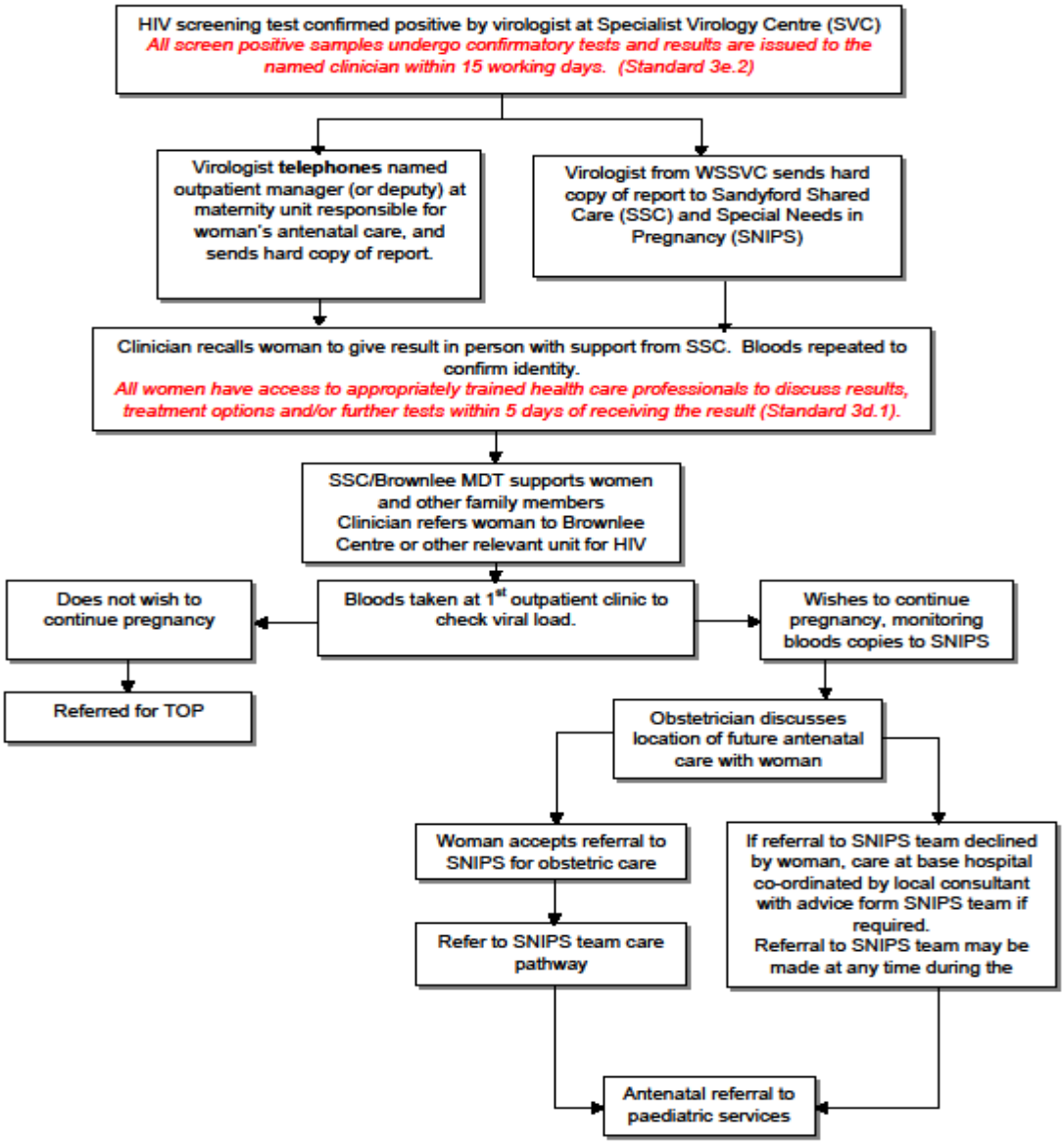
Version No:	V5.1
Approved by:	Communicable Diseases in Pregnancy Steering Group
Date Approved:	June 2013
Next revision date:	June 2014

Appendix 4.6

NHS Greater Glasgow and Clyde

Protocol for Significant Laboratory Results

HIV



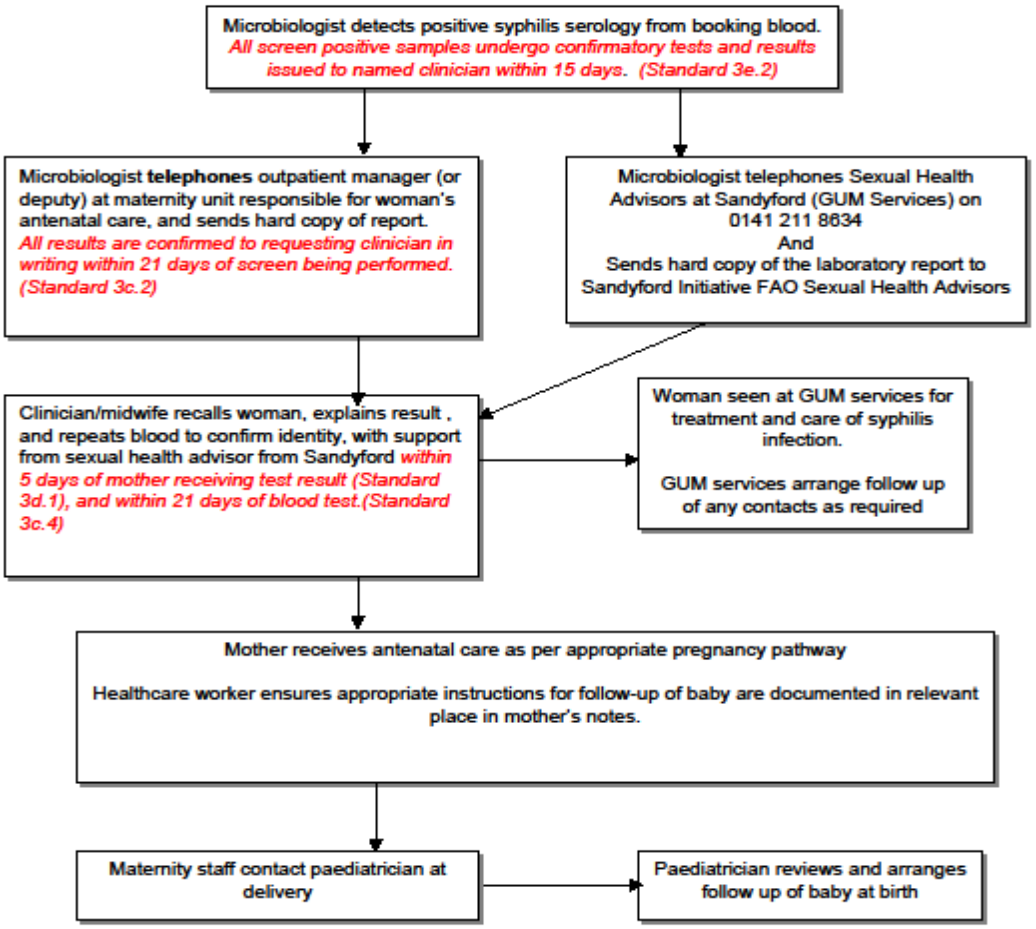
Version No:	V4.2
Approved by:	Communicable Diseases In Pregnancy Steering Group
Date Approved:	December 2012
Next revision date:	December 2013

Appendix 4.7

NHS Greater Glasgow and Clyde

Protocol for Significant Laboratory Results

SYPHILIS



Version No:	V4.2
Approved by:	Communicable Diseases in Pregnancy Steering Group
Date Approved:	December 2011
Next revision date:	December 2014

Appendix 4.8

NHS Greater Glasgow and Clyde

Appendix 1
Managing Communicable Diseases Screening Tests in Late Bookers

Late bookers are women who present for the first time on or after 24 weeks pregnancy. This is the stage at which the baby is potentially viable if early labour occurred.

The results of the communicable disease screening tests could affect the management at or after delivery, therefore **all communicable disease screening test results** for a woman should be **known prior to delivery and certainly before discharge.**

If a woman presents to maternity services as a late booker i.e. on or after 24 weeks it is important to ensure that screening has been offered and results are received:

1) The woman presents to the antenatal clinic, and there is no immediate risk of delivery:

- Seek informed consent for screening (HIV, Syphilis, hepatitis B, rubella)
- Fill **one 9ml purple topped EDTA bottle** and complete a virology request form, clearly indicating which tests (HIV, Rubella, Syphilis hepatitis B) are to be carried out. Even if a woman does not consent to all four tests, please fill one 9ml purple topped EDTA bottle. Do not send two 5ml bottles, or other combinations to make up to 9 ml, the machines in the lab won't accept them and the sample will not be processed.
- Ensure tests are recorded on PNBS
- Mark the sample as URGENT and telephone the West of Scotland Virology Centre to let them know it is in the system **(Tel: 0141 211 0080)**.
- Send the sample to the virus lab, via normal routine processes
- Ensure that the name and contact details of the person and a deputy who will be responsible for any positive results are clearly appended
- Note that to view a result on portal a CHI number is essential.

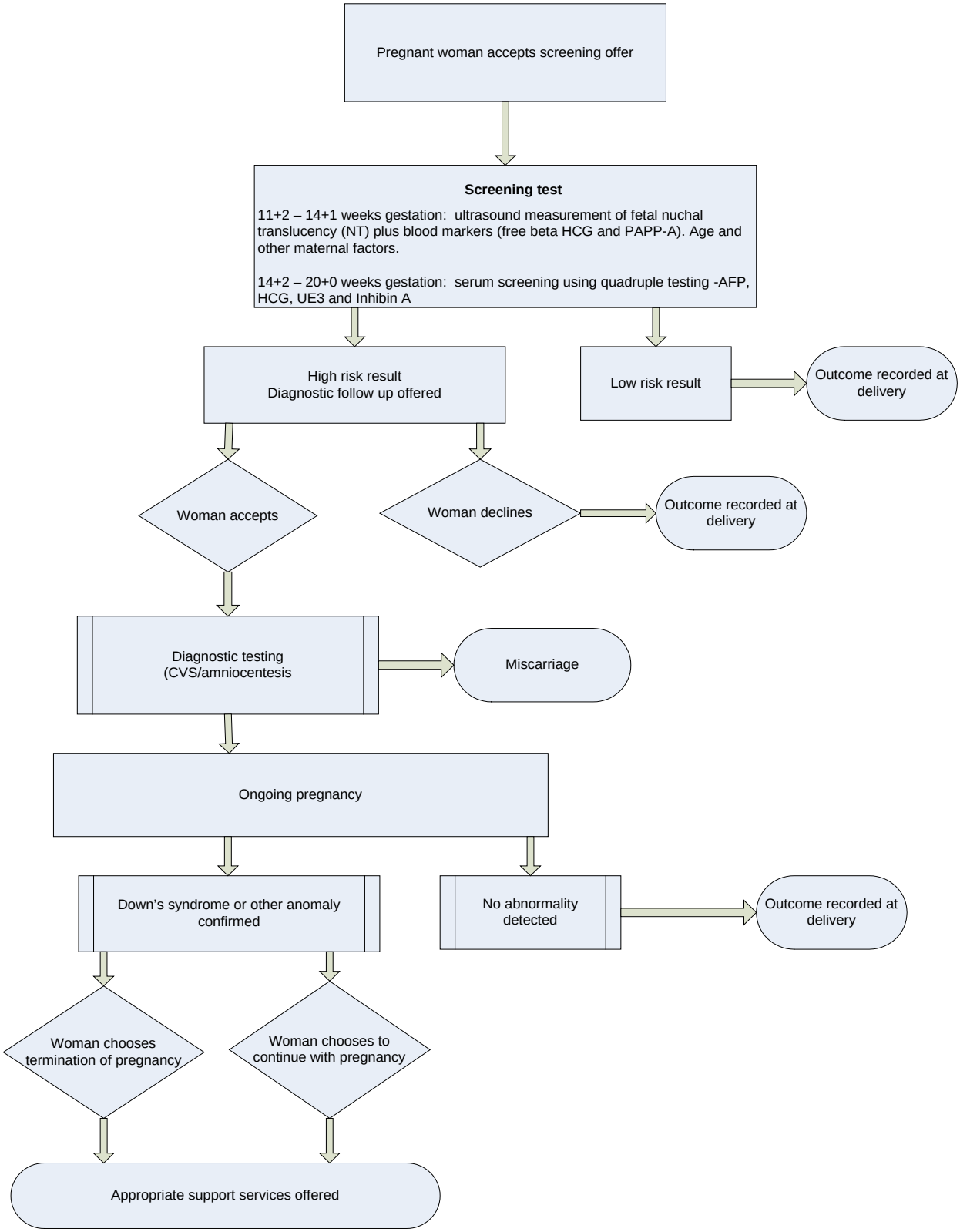
2) The woman presents to maternity assessment i.e. in pain, bleeding etc therefore the risk of delivery is high

- Seek informed consent for screening (HIV, Syphilis, hepatitis B, rubella)
- Fill **one 9ml purple topped EDTA bottle** and complete a virology request form, clearly indicating which tests (HIV, Rubella, Syphilis hepatitis B) are to be carried out.

Version No:	Draft Version 2.1
Approved by:	Communicable Diseases in Pregnancy Steering Group
Date Approved:	*January 2013*
Next revision date:	

Appendix 4.9

Down's syndrome screening pathway



Appendix 4.10

Members of Pregnancy Screening Steering Group

Dr Emilia Crighton	Consultant in Public Health Medicine (Chair)
Louise Brown	West of Scotland Pregnancy Laboratory
Bruce Barnett	Assistant General Manager, Laboratory Medicine
Dr Margaret J Cartwright	Chief Biomedical Scientist
Dr Elizabeth Chalmers	Consultant Haematologist
Dr Rosemarie Davidson	Consultant Clinical Geneticist
Ian Fergus	Site Technical Manager, Diagnostics
Elaine Gardiner	Lead Sonographer
Cathy Harkins	Lead Midwife
Marilyn Horne	Deputy Health Records Manager
Denise Lyden	Project Officer
Dr Alan Mathers	Clinical Director, Women's and Children's
Marie-Elaine McClair	Lead Midwife
Eleanor McColl	HI&T Screening Service Delivery Manager
Michelle Mclauchlan	General Service Manager
Dr Louisa McIlwaine	Consultant Haematologist
Diane Paterson	Lead Midwife
Elizabeth Rennie	Screening Programmes Manager
Dr Jim Robins	Consultant Obstetrician, Clyde
Elizabeth Terrace	Clinical Service Manager
Joanne Thorpe	Lead Midwife (Argyll and Bute)
Margaretha Van Mourik	Consultant Genetic Counsellor
Dr Nicola Williams	Head of Molecular Genetics

Appendix 4.11

Members of Communicable Diseases Steering Sub Group (As at March 2013)

Dr Gillian Penrice	Public Health Protection Unit (Chair)
Ms Maxine Anderson	Counsellor
Dr David Bell	Consultant in Infectious Diseases
Mrs Jacquie Campbell	General Manager
Mrs Louise Carroll	Programme Manager HIV/STIs
Ms Flora Dick	Special Needs (SNIPS) Midwife
Ms Catherine Frew	Data Analyst
Mr Sam King Sexual	Health Advisor
Mrs Annette Little	Information Analyst
Miss Denise Lyden	Project Officer
Dr Alan Mathers	Clinical Director Obstetrics and Gynaecology
Ms Victoria Mazzoni	Senior Community Midwife
Mrs Marie-Elaine McClair	Clinical Nurse Manager
Ms Christine McGee	Community Midwife
Mrs Marion McNabb	Lead Community Midwife
Mrs Diane Paterson	Lead Midwife
Ms Linda Rhodick	Medical Secretary/Data Co-ordinator
Dr James Robins	Consultant Obstetrician & Gynaecologist
Ms Samantha Shepherd	Clinical Scientist
Dr Andrew Thomson	Consultant Obstetrician & Gynaecologist
Mr Roger Wong	Clinical Co-ordinator

SUMMARY

CHAPTER 5: NEWBORN SCREENING

- 13,915 babies were eligible for newborn bloodspot screening in NHS Greater Glasgow and Clyde. 13,680 were screened, that is 98.3% of the total eligible population.
- Results were not available for the 235 (1.7%) babies that moved into the NHSGGC Board area.
- In 2012/13, of the 14,424 bloodspot samples received, 14,410 were normal. 176 (1.2%) bloodspot specimens could not be analysed due to insufficient amounts of blood on the bloodspot card and had to be repeated.
- There were eight babies with congenital hypothyroidism, five babies with cystic fibrosis. There were four positive cases of sickle cell and 88 babies identified as potential carriers for haemoglobinopathies.
- 74% of babies had white UK ancestry, 6.7% had South Asian ancestry and 3.8% had mixed background ancestry.
- 172 (1.2%) samples received had taken more than seven days to arrive at the laboratory.
- 98% of cards received with a CHI number in 2012/13 compared to 24% in 2007/08.
- 14,903 babies were eligible for newborn hearing screening. 14,475 babies in NHS Greater Glasgow and Clyde were screened for hearing loss giving an uptake of 97%.
- 403 (3%) babies did not complete the screening programme. These included babies who did not attend for screening or moved away from their current home address or transferred to another Board area.
- 1,163 (8%) babies required a second stage follow up and, of these, 216 (1.5%) babies were referred to audiology.
- 31 babies were confirmed with a hearing loss (0.2% of the screened population).

CHAPTER 5: NEWBORN SCREENING

Newborn Bloodspot screening aims to identify, as early as possible, abnormalities 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; congenital hypothyroidism; cystic fibrosis; sickle cell haemoglobinopathy and medium chain acyl-CoA dehydrogenase deficiency.

Universal Newborn Hearing screening aims to detect early permanent congenital hearing impairment. In addition, babies with mild and unilateral losses are also being identified and receive ongoing review.

Eligible population

Newborn Bloodspot and Universal Newborn Hearing screening programmes are offered to all newborns.

The screening tests

Newborn bloodspot screening: 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, have a blood transfusion or are born prematurely and when repeat testing is required. Newborn siblings of patients who have medium-chain acyl-CoA dehydrogenase deficiency are offered diagnostic testing at 24 – 28 hours of age as well as routine testing.

Blood is taken by the community midwife from the baby's heel using a bloodletting device and collected on a bloodspot card consisting of special filter paper. It is then sent to the National Newborn Screening Laboratory in Southern General Hospital for analysis. The blood is analysed for markers of the five conditions: phenylketonuria, congenital hypothyroidism, cystic fibrosis, sickle cell disorders and medium chain acyl-CoA dehydrogenase deficiency.

Detailed pathway is shown in Appendix 5.1.

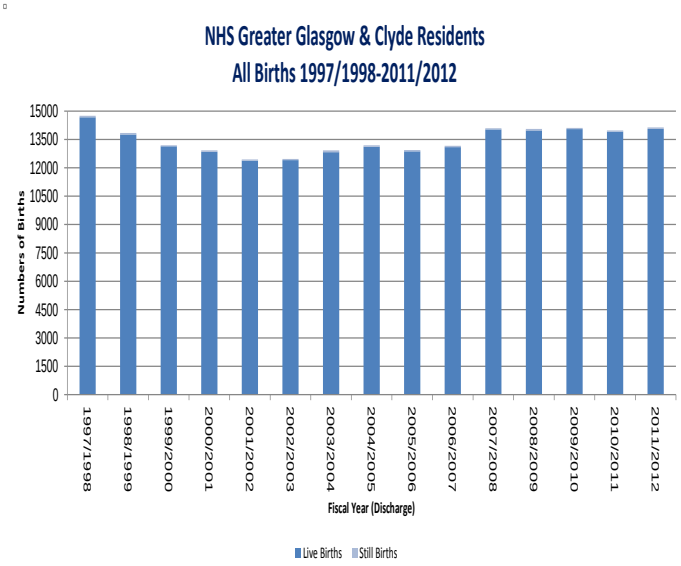
Universal Newborn Hearing screening: There are two types of equipment used to screen babies' hearing in the Greater Glasgow and Clyde area. Automated Auditory Brainstem Response (AABR) is used in the hospital setting and Otoacoustic Emissions (OAE) is used in the community setting. In the hospital setting 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.

Detailed screening pathway is shown in Appendix 5.2

Delivery of NHSGGC Newborn Bloodspot Screening programmes

Figure 5.1 shows that the number of live births has gradually increased year on year from 12,401 in 2002/03 to 14,053 in 2011/2012. This represents an increase of 11.3%.

Figure 5.1 Number of live and still births across NHS Greater Glasgow and Clyde over a 15 year period from 1997/98 to 2011/12

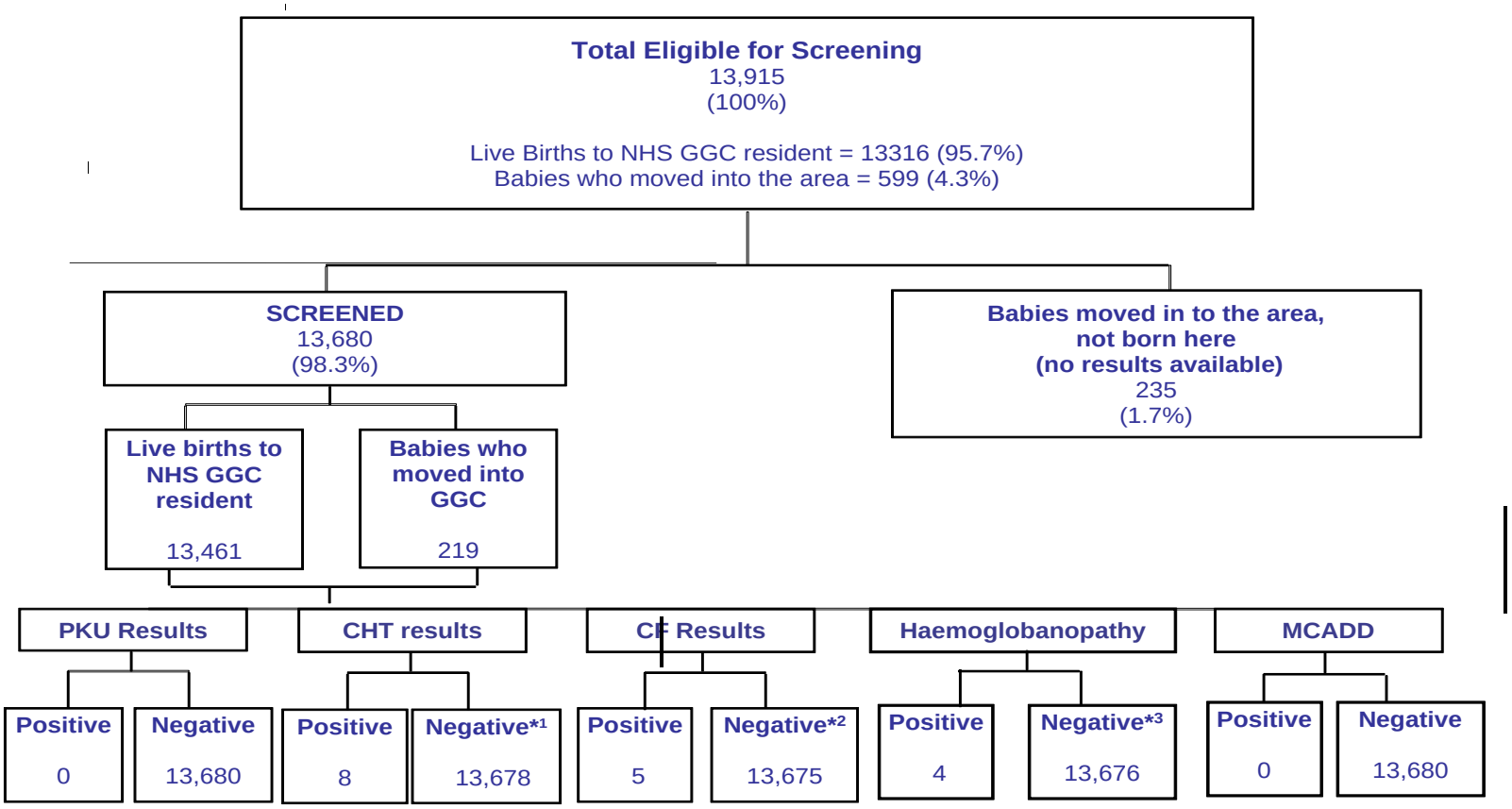


Source: SMR02; ISD Scotland

Figure 5.2 illustrates newborn bloodspot uptake rates and the results of the screening programme from 1 April 2012 to 31 March 2013.

13,680 babies resident in NHS Greater Glasgow and Clyde were screened, that is 98.3% of the total eligible population of 13,915. Results were not available for the 235 (1.7%) babies that moved into the NHSGGC Board area.

Figure 5.2 Summary of NHSGGC Newborn Bloodspot Screening activity : 1st April 2012 to 31 March 2013



Source: Child Health (CH2008); Date extracted: 27th June 2013

Notes:

*1 Total includes 1 verification.

*2 Total includes 11 carriers and 7 late tests

*3 Total includes 86 carriers; 1 verification

There were eight babies with congenital hypothyroidism, five babies with cystic fibrosis. There were four positive cases of sickle cell and 88 babies identified as potential carriers for haemoglobinopathies. All received appropriate management within the timescale of the set NHSQIS standards.

Table 5.1 shows that the percentage uptake rate of bloodspot screening is high across all CH(C)P areas and deprivation categories.

Table 5.1 Percentage uptake of NHSGGC Newborn Bloodspot Screening by CH(C)P and deprivation category
1 April 2012 to 31 March 2013

	Most Deprived				SIMD				Least Deprived			
	1		2		3		4		5		Total	
CHP	No. Screened	% uptake	No. Screened	% uptake	No. Screened	% uptake	No. Screened	% uptake	No. Screened	% uptake	No. Screened	% uptake
East Dunbartonshire	71	100	139	98.582	116	100	163	100	451	98.904	942	99.262
East Renfrewshire	74	100	70	95.89	85	97.701	123	99.194	514	99.228	868	98.861
Glasgow North East	1,535	97.584	229	96.624	177	98.333	142	97.26	53	100	2,140	97.539
Glasgow North West	1,037	98.668	347	98.023	260	95.941	230	94.262	280	95.238	2,157	97.294
Glasgow South	1,367	97.783	610	96.672	483	99.383	268	97.81	156	99.363	2,892	97.901
Inverclyde	416	99.048	105	100	103	99.038	100	100	66	98.507	793	99.249
North Lanarkshire	45	100	22	100	54	100	96	98.969	8	100	225	99.558
Renfrewshire	618	99.038	390	99.237	321	99.074	268	99.259	305	99.349	1,904	99.115
South Lanarkshire	264	98.876	159	99.375	76	100	147	98.658	69	98.571	715	99.03
West Dunbartonshire	422	98.598	315	99.369	182	99.454	82	98.795	35	97.222	1,036	98.949
Total	**5,849**	**98.286**	**2,386**	**98.068**	**1857**	**98.724**	**1,619**	**98.121**	**1,937**	**98.525**	**13,680**	**98.311**

Source: Child Health (CH2008); Date extracted: 27th June 2013

SIMD=Scottish Index of Multiple Deprivation 2009

Note: 32 patients could not be assigned CH(C)P/SIMD due to incomplete/incorrect postcodes but have been included in the overall total.

Table 5.2 shows the breakdown of the ancestry group for babies tested. Data includes babies born in Argyll and Bute. 74% of babies had white UK ancestry, 6.7% had South Asian ancestry and 3.8% had mixed background ancestry.

Table 5.2 NHSGGC Newborn Bloodspot screening – ancestry of the babies tested 2012 - 2013

	Clyde		Glasgow		Total	
Ancestry Group	**N**	**%**	**N**	**%**	**N**	**%**
A African or African Caribbean	28	0.8	352	3.4	380	2.7
B South Asian (Asian)	79	2.3	860	8.2	939	6.7
C South East Asian (Asian)	14	0.4	282	2.7	296	2.1
D Other non-European (Other)	8	0.2	137	1.3	145	1.0
E Southern & Other European (White)	79	2.3	406	3.9	485	3.5
F United Kingdom (White)	2,993	86.1	7,339	70.0	10,332	74.0
G North Europe (White)	13	0.4	120	1.1	133	1.0
H Don't Know	2	0.1	19	0.2	21	0.2
I Decline to Answer	2	0.1	0	0.0	2	0.0
J Any Mixed Background	81	2.3	449	4.3	530	3.8
Z Not Stated	178	5.1	527	5.0	705	5.0
Total	**3,477**		**10,491**		**13,968**	

Table 5.3 illustrates the laboratory outcomes of blood spot tests (data could not be separated for Clyde and Argyll and Bute). In 2012/13, of the 14,424 bloodspot samples received, 14,410 were normal. 176 (1.2%) bloodspot specimens could not be analysed due to insufficient amounts of blood on the bloodspot card and required repeat bloodspot screening tests to be carried out on babies. 172 (1.2%) samples received had taken more than seven days to arrive at the laboratory.

National standards require that 95% of positive cases of congenital hypothyroidism and phenylketonuria start treatment by 14 days of age and of cystic fibrosis by 35 days of age. Therefore, the time from when a test is taken to the time of arrival at the laboratory is important.

Table 5.3: Specimen test outcomes for Greater Glasgow and Argyll and Clyde for period 1 April 2012 and 31 March 2013

Specimen Test - Outcomes	Clyde	Glasgow	Total
Refused all tests	1	4	5
Partial refused	0	0	0
Insufficient blood to perform all tests	38	138	176
Unsatisfactory >14 days in transit	0	1	1
Unsatisfactory Other	4	14	18
Updated info	33	146	179
IRT tested late (total)	1	7	8
IRT tested late (Born in Scotland)	1	6	7
>7 days in transit	22	150	172
Ref PKU	0	0	0
Ref CHT	3	5	8
Ref CF	1	4	5
Ref CF Carrier	2	7	9
Ref MCADD	0	0	0
Ref SCD	0	3	3
Ref SCD Carrier	8	49	57
Ref HbV	0	2	2
Ref HbV Carrier	3	27	30
Normal result	3,582	9,793	14,410
Pre-TF	17	57	74
Sent for SCD DNA	15	23	38
Total Specimens received	**3,599**	**10,825**	**14,424**

Insufficent as % of Total	1.1	1.3	1.2
Unsatisfactory as % of Total	0.11	0.14	0.13
IRT tested late as % of Total	0.03	0.06	0.06
IRT tested last (born in Scotland) as % of Total	0.03	0.06	0.05
>7 days in transit as % of Total	0.6	1.4	1.2

Source: National Newborn Screening Laboratory

Notes

Parental decline - Parents have the option to decline tests for some or all of the conditions screened

Unsatisfactory = specimen damaged or of poor quality

Updated Information = cards that were received with incorrect or missing details

Results are not issued until the relevant information is received

IRT Tested Late = babay was more than 6 weeks of age when specimen was taken. The test for Cystic Fibrosis is not reliable after 6 weeks.

Ref PKU = babies with high or persistently raised levels of phenylalanine that were referred to paediatricians for further investigations. Some of these may not be confirmed cases of PKU.

Ref CHT = babies with high or persistently raised levels of TSH that were referred to paediatricians for further investigations. Some of these may not be confirmed cases of Congential Hypothyroidism.

Ref CF = babies suspected of having Cystic Fibrosis of babies referred for Sweat testing. Some of these cases may not be confirmed as cases of CF.

Ref Carrier CF = Babies referred as possible carriers of Cystic Fibrosis

Ref MCADD = babies with suspected MCADD referred to paediatricians for further investigations

Ref SCD = babies referred to haematologists with suspected Sickle Cell Disorder

Ref SCD Carrier = babies referred as suspected carriers of Sickle Cell Disorder.

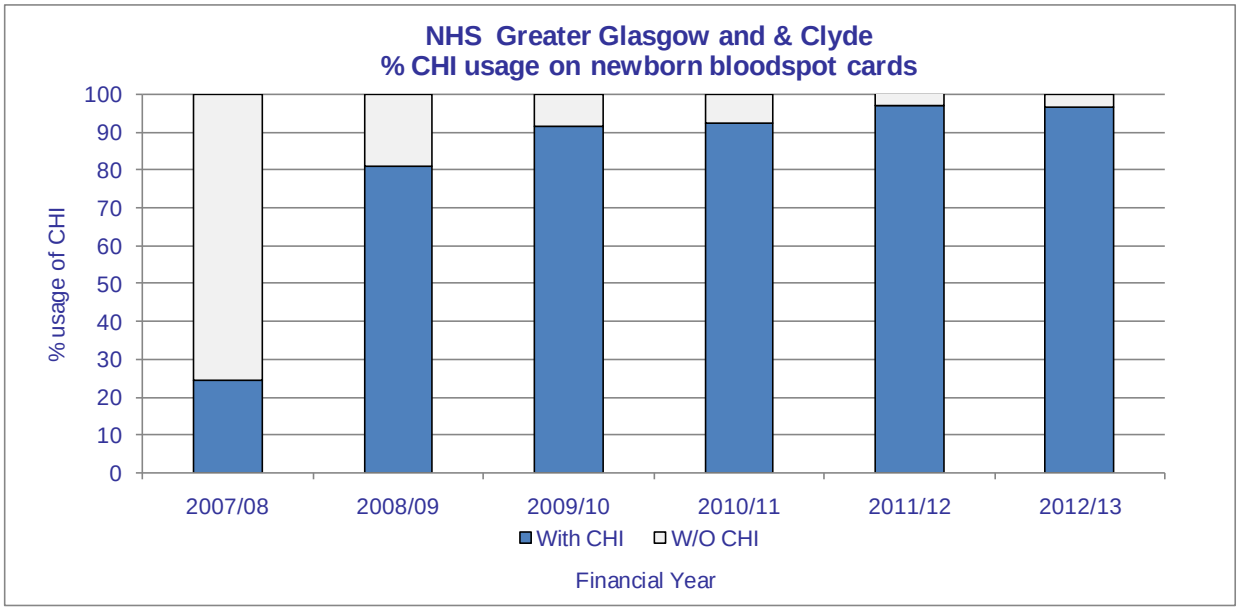
Ref HbV = babies referred to haematologists suspected of having a haemoglobanopathy disorder. These require follow-up for confirmation and some may not be confirmed as cases.

Ref HbV Carrier = babiesr referred as suspected carriers of a haemoglobanopathy disorder. Some of these have unidentified variants and may required follow-up for confirmation.

The use of the patient identifier number (called the Community Health Index (CHI)) on bloodspot cards has remained high.

Figure 5.4 illustrates the proportion of bloodspot cards with and without a CHI number received by the National Newborn Screening Laboratory for babies tested in Greater Glasgow and Argyll and Clyde. There has been a year on year improvement with 98% of cards received with a CHI number in 2012/13 compared to 24% in 2007/08.

Figure 5.4 Percentage of bloodspot screening sample cards received with a Community Health Index number



Delivery of the NHSGGC Universal Newborn Hearing Screening programme

Integration of the Universal Newborn Hearing Screening programme across NHS Greater Glasgow and Clyde was completed in April 2013.

Table 5.4 shows that the percentage uptake rate for the newborn hearing screening is high for all CH(C)P areas.

CH(C)P	Eligible	Screened	% Uptake
East Dunbartonshire	935	909	97
East Renfrewshire	823	809	98
Glasgow North East	2,236	2,154	96
Glasgow North West	2,328	2,243	96
Glasgow South	3,072	2,942	96
Inverclyde	779	766	98
North Lanarkshire[1]	811	802	99
Renfrewshire	1,915	1,899	99
South Lanarkshire[1]	938	924	99
West Dunbartonshire	1,011	979	97
Unassigned[2]	55	48	87
Total	**14,903**	**14,475**	**97**

Source: Scottish Birth Record (SBR) Extracted: July 2013

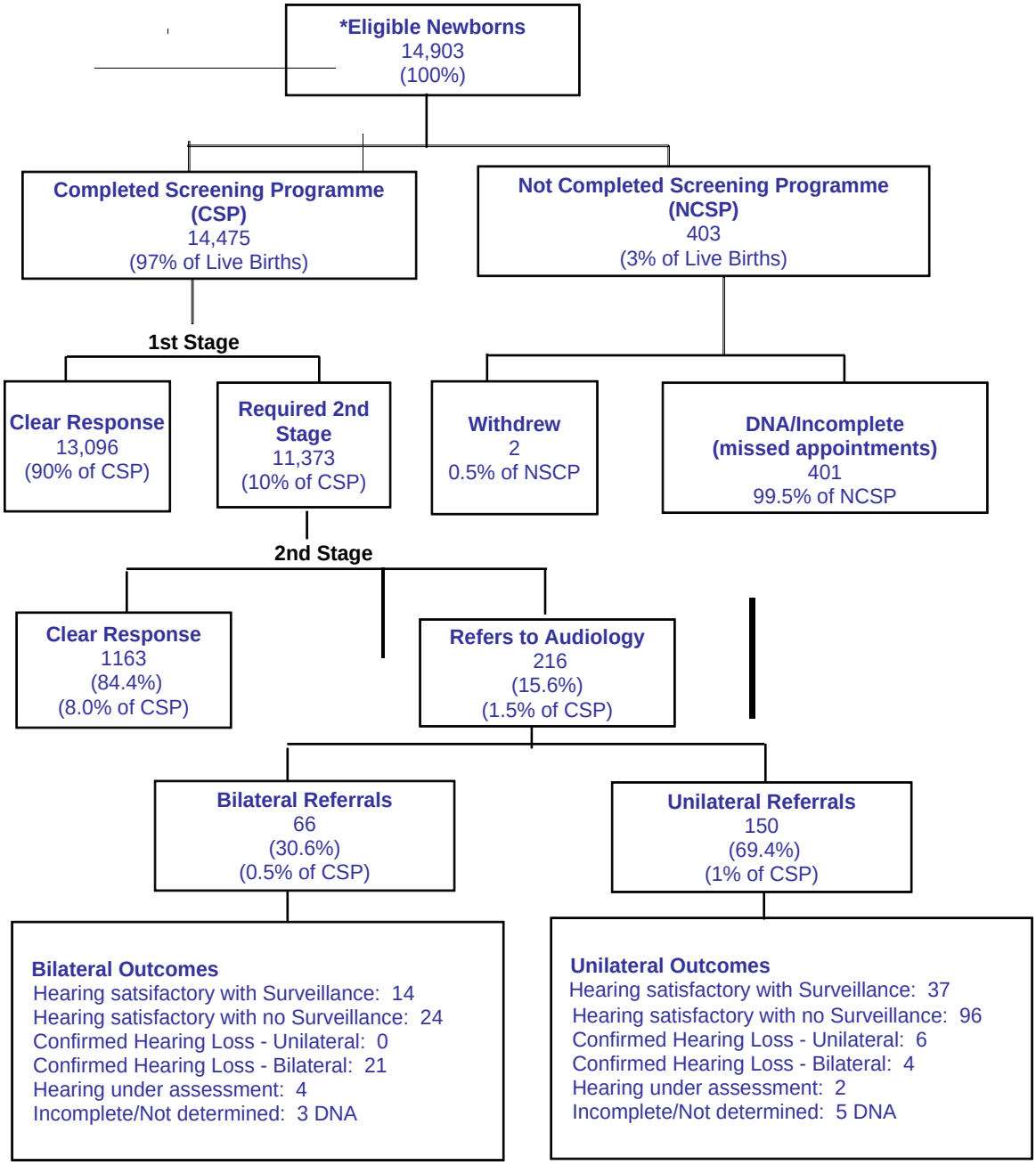
Notes

[1] NHS Greater Glasgow and Clyde residents only

[2] Unable to assign CH(C)P or SIMD due to incompete/incorrect postcodes

Figure 5.5 illustrates the hearing screening activity. Of the 14,903 eligible babies, 14,475 were screened for hearing loss giving an uptake of 97% **(Figure 5.5 and Table 5.4)**.

Figure 5.5 Summary of NHS Greater Glasgow and Clyde Universal Newborn Hearing Screening Programme



Source: Child Health, extracted October 2012

* Note: includes Argyll and Bute babies

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,

Clear Response - is a pass, though some have follow up but majority don't

Outcomes - as agreed with undefined being better wording for the possible hearing loss and incompletes including DNA, deceased and pendings etc.

1,163 (8%) babies required a second stage follow up and, of these, 216 (1.5%) babies were referred to audiology. 31 babies were confirmed with a hearing loss (0.2% of the screened population).

403 (3%) babies did not complete the screening programme. These included babies who did not attend for screening, are deceased or have moved away from their current home address or transferred to another Board area.

Information systems

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

- The results of the Bloodspot test are recorded against the individual child's record held within the Scottish Immunisation and Recall System (SIRS) and also in PNBS IT application that supports the failsafe processes for newborn bloodspot screening.

- The Universal Newborn Hearing Screening programme is supported the Scottish Birth Record (SBR) to record hearing screening result.

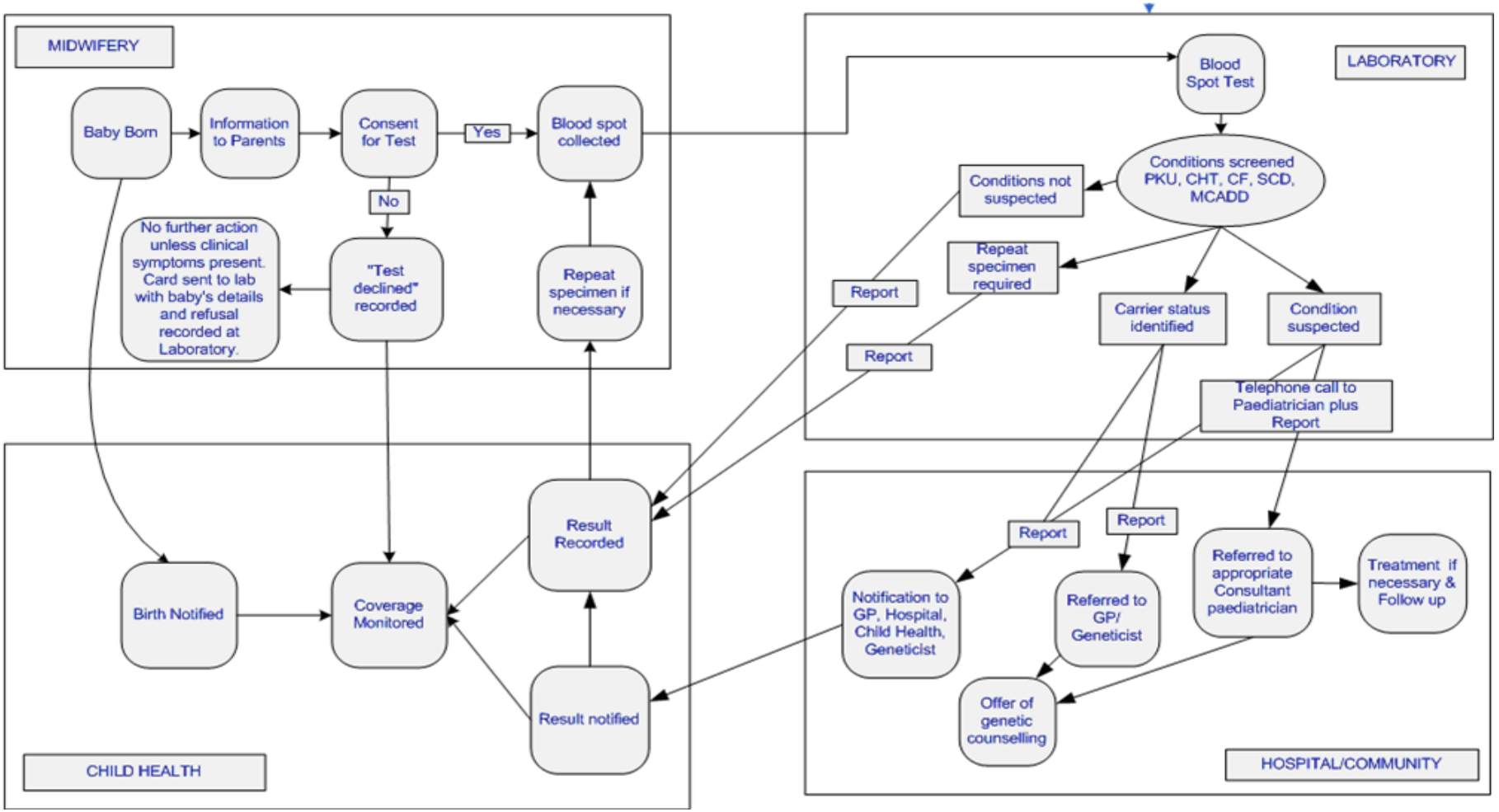
- The Child Health Surveillance Programme Pre-School system (CHSP-PS) is also an important feature of the screening programme, recording screening outcomes and is used as a failsafe to ensure all babies are offered hearing screening.

Challenges and future priorities

- Maintain service performance and ensure that all babies are offered a newborn bloodspot test and hearing test within the targets set by national standards.

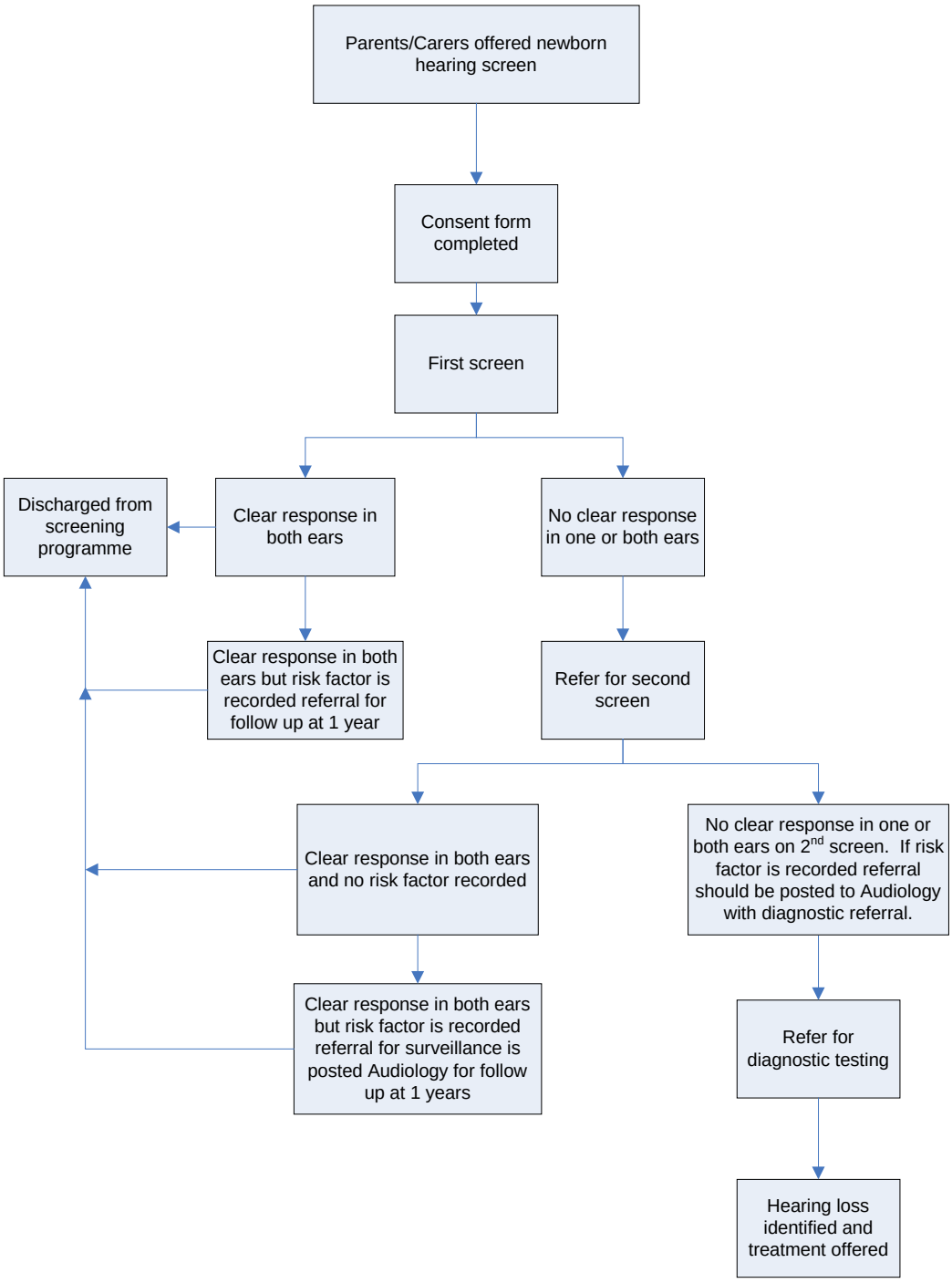
NHSGGC Newborn Bloodspot Screening Pathway

APPENDIX 5.1



APPENDIX 5.2

NHSGGC Universal Newborn Hearing Screening Pathway



APPENDIX 5.3

Members of Newborn Bloodspot Screening Steering Group As at March 2013

Dr Emilia Crighton	Consultant in Public Health Medicine (chair)
Mr Paul Burton	Senior Information Analyst
Mr Bruce Barnett	Assistant General Manager
Mrs Lin Calderwood	HI&T Service Delivery Manager
Mrs Cathy Harkins	Clinical Lead Midwife
Ms Elizabeth Callander	Lead Midwife
Dr Margaret Cartwright	Laboratory Manager
Dr Elizabeth Chalmers	Consultant Paediatric Haematologist
Dr Rosemarie Davidson	Consultant Clinical Geneticist
Dr Anne Devenny	Consultant Paediatrician
Ms Carolyn Dunlop	Senior Paediatric Dietitian
Mrs Catherine Dorrian	Consultant Clinical Scientist
Mr Ian Fergus	Technical Site Manager
Mrs Fiona Gilchrist	Assistant Programme Manager, Screening Dept
Mrs Annie Hair	CHP Children's Services Lead
Mrs Annette Little	Information Analyst
Miss Denise Lyden	Project Officer
Mrs Joan MacKenzie	Laboratory Newborn Screening Co-ordinator
Mrs Marion McNabb	Clinical Lead Midwife
Mrs Julie Mullin	Assistant Programme Manager, Screening Dept
Mrs Diane Paterson	Lead Midwife
Dr Helen McTier	Consultant Neonatologist
Dr Peter Robinson	Consultant in Paediatric Metabolic Medicine
Dr Bernd Schwahn	Consultant in Paediatric Metabolic Medicine
Ms Liz Terrace	Clinical Service Manager
Ms Margaretha van Mourik	Consultant Genetics Counsellor
Mrs Nicola Williamson	Consultant Clinical Scientist

APPENDIX 5.4

Universal Newborn Hearing Screening Programme Steering Group (As at March 2013)

Dr Emilia Crighton	Consultant in Public Health Medicine (Chair)
Mrs Karen Boyle	Newborn Hearing Screening Manager
Mr Jim Bretherton	Clinical Service Manager
Mr Paul Burton	Senior Information Analyst
Ms Elizabeth Callander	Lead Midwife
Mrs Liz Daniels	Clinical Service Manager, Partnerships
Mrs Fiona Gilchrist	Assistant Programme Manager, Screening Dept
Mr James Harrigan	Head of Audiology
Mrs Annette Little	Information Analyst
Miss Denise Lyden	Project Officer
Mrs Lin Calderwood	Screening Service Delivery Manager
Dr Juan Mora	Consultant Audiological Physician
Mrs Julie Mullin	Assistant Programme Manager, Screening Dept
Dr Andrew Powls	Consultant Neonatologist
Mrs Jacqueline Truss	Audiologist Team Leader
Mrs Jan Savage	National Deaf Children's Society
Dr Madeline White	Consultant Neonatologist
Ms Heather Young	National Deaf Children's Society, Family Support

SUMMARY

CHAPTER 6: PRE-SCHOOL VISION SCREENING

- In 2012/13, 13,795 children aged between four to five years old were identified using the Community Health Index System as being eligible for pre-school vision screening. This represents a 4.6% decrease from previous year 2011/12.

- 40% (5,519) of children live in the most deprived areas, with the largest proportion living in the Glasgow area.

- 75.2% (10,378) of children were registered with a nursery. 3,417 (24%) children were not registered with a nursery, 1,950 (57%) were from the Glasgow area**.**

- Of the 13,795 eligible children, 12,010 were screened for a visual abnormality, giving an overall uptake of 87.1%.

- 12,010 children screened, 8,919 (74.3%) had a normal result. . Of the 2,270 (18.9%) children referred for further assessment, 1,069 (23%) were from the most deprived areas.

- Uptake rate for the programme across the CH(C)P areas varied from 82.8% in Glasgow North West to 92.1% in East Renfrewshire. Glasgow North East uptake improved significantly from 74.8% in 2011/12 to 83.2% in 2012/2013.

- The highest proportion of children screened that were referred for further investigation was in Glasgow North East (26%) and Glasgow North West (23.3%) and the lowest was 11.9% in East Renfrewshire.

.

CHAPTER 6: PRE-SCHOOL VISION SCREENING

Background

Vision Screening is routinely offered to all pre-school age children resident in NHS Greater Glasgow and Clyde area.

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

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

Aim of vision screening programme

The aim of the screening programme is to detect reduced visual acuity, the commonest causes of which are amblyopia and refractive error. There is emerging evidence that good screening and treatment result in lower incidence of significant permanent vision loss.

Eligible population

All children resident in the NHS Greater Glasgow and Clyde between four and five years of age are invited to attend screening for reduced vision.

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 2010 and 28 February 2011 were downloaded from CHI and matched against the lists received from nurseries.

The vision screening clinics take place in the nursery setting. The pre-school children that do not attend nursery, or whose nursery is unknown to the screening programme and the children that miss their appointment within the nursery are invited to a hospital Orthoptic clinic to have their vision screened.

A proportion of children require further testing in secondary care following the initial screen. These children are referred for further assessment to a paediatric clinic in an ophthalmology department, though a small number may be referred to a community optometrist. The assessment appointment involves a full eye examination, and allows operators to identify whether the screen test was a false positive and no further action is required, or if the screen test was a true positive to enable the specific disorder to be identified and treated.

Delivery of Pre-School Vision Screening Programme 2012/13

In 2012/13, 13,795 children aged between four to five years old were identified using the Community Health Index System as being eligible for pre-school vision screening. This represents a 4.6% decrease from previous year 2011/12.

Table 6.1 shows that 40% (5,519) of children live in the most deprived areas, with the largest proportion living in the Glasgow area.

Table 6.1 Total number of eligible NHSGGC child residents by CH(C)P area and by deprivation category

	Scottish Index of Multiple Deprivation[1]						
	Most deprived				Least deprived		
Row Labels	**1**	**2**	**3**	**4**	**5**	**Unassigned[2]**	**Total**
East Dunbartonshire CHP	68	190	102	164	626	2	1,152
East Renfrewshire CHCP	111	100	73	174	618		1,076
Glasgow North East	1,296	278	158	160	60	6	1,958
Glasgow North West	1,082	252	220	185	271	6	2,016
Glasgow South	1,287	647	342	300	134	5	2,715
Inverclyde CHP	390	113	113	135	116	2	869
North Lanarkshire CHP	36	30	80	113	6	2	267
Renfrewshire CHP	582	279	415	258	378	8	1,920
South Lanarkshire CHP	244	88	143	182	95	1	753
West Dunbartonshire CHP	423	296	201	102	36	3	1,061
Unassigned[2]						8	8
Total	**5,519**	**2,273**	**1,847**	**1,773**	**2,340**	**43**	**13,795**
% of Total	**40.0**	**16.5**	**13.4**	**12.9**	**17.0**	**0.3**	

Source: Child Health - Pre-School Date Extracted: October 2013

Notes

1 Scottish index of multiple deprivation 2012

2 Unable to assign SIMD due to incomplete or incorrect postcode

Table 6.2 shows that 75.2% (10,378) of children were registered with a nursery. Of the 3,417 (24.8%) children not registered with a nursery, 1,950 (57%) were from Glasgow City CHP sectors. With the introduction of the 30 month assessment in 2013, Health visitors will be asked to identify the reasons for children not attending nursery.

Table 6.2 The number of children eligible for screening, number and percentage registered and not registered with a nursery by CH(C)P

CH(C)P	Children eligible for screening	Registered with a Nursery	% Registered	Not registered with a nursery	% Not Registered
East Dunbartonshire CHP	1,152	935	81.2	217	18.8
East Renfrewshire CHCP	1,076	870	80.9	206	19.1
Glasgow North East	1,958	1,413	72.2	545	27.8
Glasgow North West	2,016	1,425	70.7	591	29.3
Glasgow South	2,715	1,901	70.0	814	30.0
Inverclyde CHP	869	677	77.9	192	22.1
North Lanarkshire CHP	267	204	76.4	63	23.6
Renfrewshire CHP	1,920	1,563	81.4	357	18.6
South Lanarkshire CHP	753	549	72.9	204	27.1
West Dunbartonshire CHP	1,061	835	78.7	226	21.3
Unassigned[1]	8	6	75.0	2	25.0
Total	**13,795**	**10,378**	**75.2**	**3,417**	**24.8**

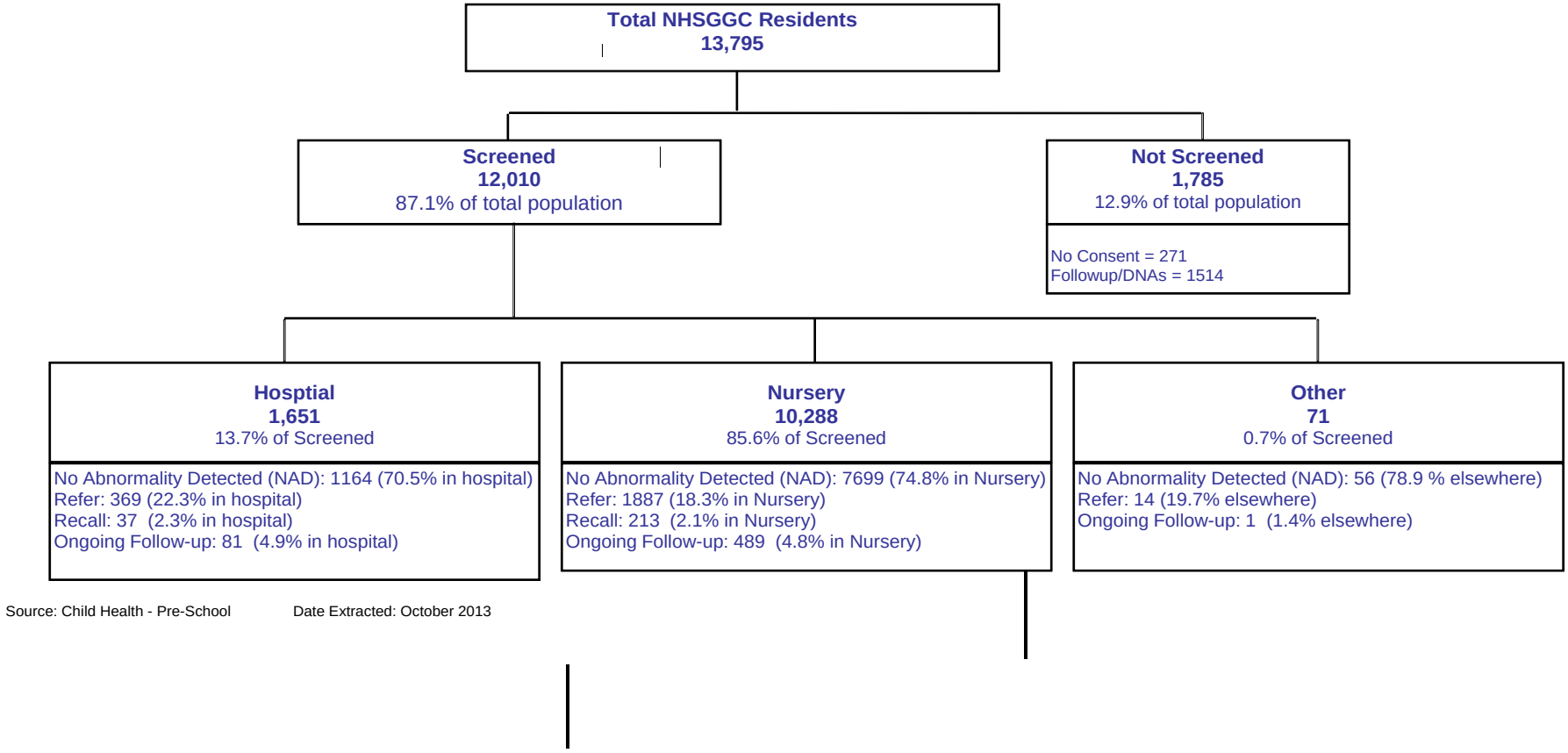
Source: Child Health - Pre-School Date Extracted: 19 September 2013

Notes

1 Unable to assign SIMD due to incomplete or incorrect postcode

Figure 6.1 illustrates the activity for the service in NHS Greater Glasgow and Clyde for the school year 2012. Of the 13,795 eligible children, 12,010 were screened for a visual abnormality, giving an overall uptake of 87.1%. 2,270 (18.9%) children were referred for further assessment (**Figure 6.1**).

Figure 6.1 Summary of NHSGGC Pre-school Vision Screening Activity



Source: Child Health - Pre-School Date Extracted: October 2013

Table 6.3 shows that, of the 12,010 children screened, 8,919 (74.3%) had a normal result. Of the 2,270 (18.9%) children referred for further assessment, 1,069 (23%) were from the most deprived areas. 250 (2.1%) children were recalled back to be screened due to technical difficulties screening the children's vision during their first screen. 571 (4.8%) children are currently under follow up by ophthalmology service

Table 6.3 Pre-school vision screening uptake and outcomes by deprivation category

:

SIMD	Number of Children Screened	No Abnormality Detected (NAD)	% NAD	Referred	% Referred	Recall	% Recall	Ongoing Follow up	%Ongoing Follow up
1	4,656	3,209	68.9	1,069	23.0	124	2.7	254	5.5
2	1,972	1,450	73.5	391	19.8	46	2.3	85	4.3
3	1,607	1,241	77.2	259	16.1	22	1.4	85	5.3
4	1,577	1,248	79.1	235	14.9	30	1.9	64	4.1
5	2,159	1,748	81.0	304	14.1	26	1.2	81	3.8
Unassigned[1]	39	23	59.0	12	30.8	2	5.1	2	5.1
Total	**12,010**	**8,919**	**74.3**	**2,270**	**18.9**	**250**	**2.1**	**571**	**4.8**

Source: Child Health - Pre-School Date Extracted: October 2013

Notes

1 Unable to assign SIMD due to incomplete or incorrect postcode

Table 6.4 shows the uptake rate for the programme across the CH(C)P areas varied from 82.8% in Glasgow North West to 92.1% in East Renfrewshire. Glasgow North East uptake improved significantly from 74.8% in 2011/12 to 83.2% in 2012/2013.

The highest proportion of children screened that were referred for further investigation was in Glasgow North East (26%) and Glasgow North West (23.3%) and the lowest was 11.9% in East Renfrewshire.

Table 6.4 Uptake and outcome of pre-school vision screening programme across NHS Greater Glasgow and Clyde by CH(C)P area

CH(C)P	Total Population	Total number of children screened	Total number of children not screened	Uptake %	No Abnormality Detected (NAD) of those screened %	Referred of those screened %	Recalled of those screened %	Ongoing Follow-up of those screened %
East Dunbartonshire CHP	1,152	1,057	95	91.8	74.7	18.5	2.4	4.4
East Renfrewshire CHCP	1,076	988	88	91.8	83.6	11.9	0.8	3.6
Glasgow North East	1,958	1,630	328	83.2	65.9	26.0	3.1	5.1
Glasgow North West	2,016	1,670	346	82.8	68.2	23.3	3.2	5.3
Glasgow South	2,715	2,271	444	83.6	74.9	18.7	2.9	3.5
Inverclyde CHP	869	785	84	90.3	74.9	18.6	0.3	6.2
North Lanarkshire CHP	267	238	29	89.1	76.5	18.1	0.8	4.6
Renfrewshire CHP	1,920	1,769	151	92.1	78.6	14.6	0.8	6.0
South Lanarkshire CHP	753	647	106	85.9	78.7	16.2	1.9	3.2
West Dunbartonshire CHP	1,061	948	113	89.3	75.5	17.5	1.6	5.4
Unassigned 1	8	7	1	87.5	42.9	28.6	28.6	0.0
Total	**13,795**	**12,010**	**1,785**	**87.1**	**74.3**	**18.9**	**2.1**	**4.8**

Source: Child Health - Pre-School Date Extracted: October 2013

Notes

1 Unable to assign SIMD due to incomplete or incorrect postcode

Information systems

Child Health Surveillance System (CHS-P) currently supports the delivery of the programme across NHS Greater Glasgow and Clyde.

Challenges and future priorities

- Ensure the co-operation of all nurseries to allow screening to take place.
- Increase the proportion of children attending nursery.
- Work with Education to understand taking up nursery places and how to improve this.

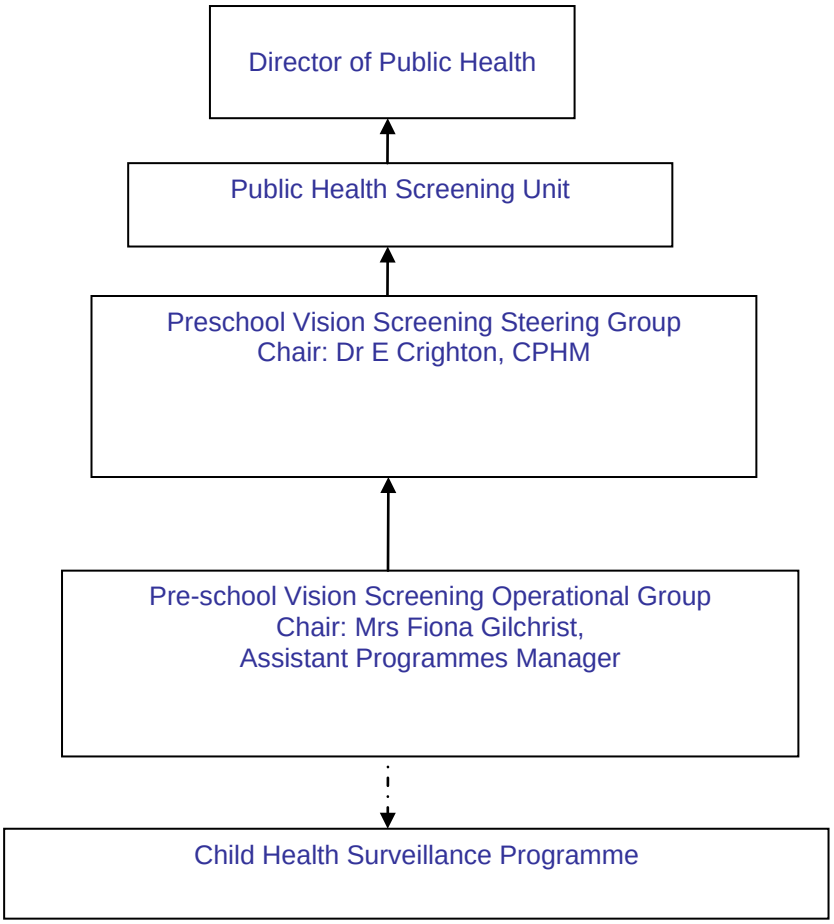
Appendix 6.1

Members of Pre-school Vision Screening Steering Group (As at March 2013)

Dr Emilia Crighton	Consultant in Public Health Medicine (Chair)
Mrs Angela Carson	Head of Optometry
Mr Jim Bretherton	Clinical Service Manager
Mrs Maggie Darroch	Optometrist
Mrs Fiona Gilchrist	Assistant Programme Manager, Screening Dept
Ms Nicola McElvanney	Chair Area Optometry Committee
Mrs Rachel McKay	Head Orthoptist
Ms Carolyn MacLellan	Head Orthoptist
Mrs Annette Little	Information Analyst
Miss Denise Lyden	Project Officer
Mrs Lin Calderwood	Screening Service Delivery Manager
Mrs Diane Russell	Head Orthoptist
Mrs Elaine Salina	Principal Optometrist

Appendix 6.2

Reporting Structure:
Pre-School Vision Screening Steering Group



Key:

_____ Direct Reports

- - - - - - - Network Links

SUMMARY

CHAPTER 7: DIABETIC RETINOPATHY SCREENING

- There were 63,094 NHS Greater Glasgow and Clyde residents with a diagnosis of diabetes in 2012/13**,** representing an increase of 4.1% from 2011/12.

- The prevalence of diabetes among NHS Greater Glasgow and Clyde adult residents has gradually increased from 4.3% in 2007/08 to 5.5% in 2012/13.

- 53,502 (84.8%) were eligible for screening. Of those, 87.8% (46,988) were screened. This means that 74.4% of total diabetic population in NHS GGC were screened in 2012/13.

- Of the total number of residents screened (46,988), 1,223 were referred to Ophthalmology for further investigation.

- 25,965 (40.7%) are known to be resident in the most deprived areas compared to 8,956 (14.1%) who live in the least deprived areas. The largest proportion of people with diabetes was among the 50 – 79 year olds. This represents 69.4% (43,768) of the total population with diabetes.

CHAPTER 7: 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 in a 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.

Aim of screening programme

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

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

Eligible population

All people with diabetes aged 12 and over who are resident in the NHS Greater Glasgow and Clyde area are eligible for Diabetic Retinopathy Screening.

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

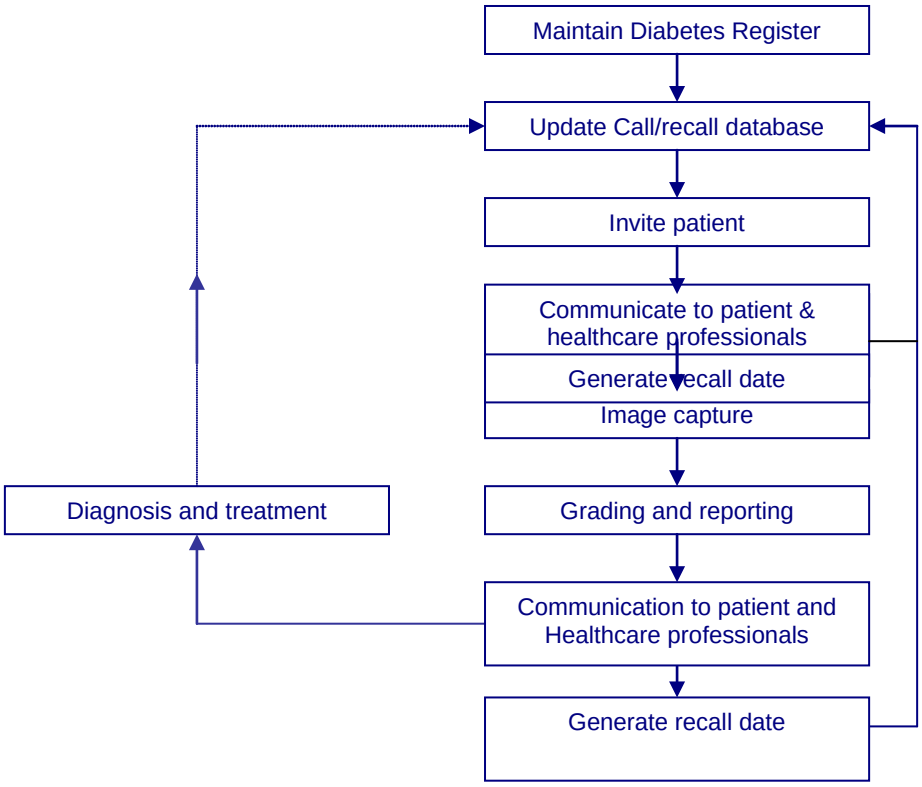
The screening programme takes place in a variety of settings. This can either be at a fixed site or within a mobile screening unit, which visits health centres and other locations around the area. Across Greater Glasgow and Clyde there were six fixed site locations and four mobile screening units.

The service also provides a slit lamp service from their fixed sites for patients who are not suitable for retinal photography.

Screening Pathway

To reduce diabetes related blindness in general population by identifying and treating sight threatening diabetic retinopathy.

Figure 7.1 illustrates the Diabetic Retinopathy screening pathway



Delivery of NHSGGC Diabetic Retinopathy Screening Programme

Table 7.1 shows the year on year increase in the number of people diagnosed with diabetes over a six year period from 2007/08 to 2012/13. There were 63,094 NHS Greater Glasgow and Clyde residents with a diagnosis of diabetes in 2012/13**,** representing an increase of 4.1% from 2011/12. The table also shows that the prevalence of diabetes among NHS Greater Glasgow and Clyde adult residents has gradually increased from 4.3% in 2007/08 to 5.5% in 2012/13.

Table 7.1 Number of NHSGGC residents with diabetes, type of diabetes and prevalence from 2007/2008 to 2011/2012

Year	Total Population[1]	Type 1 Diabetes Mellitus	Type 2 Diabetes Mellitus	Other Diabetes Mellitus	Unspecified[2]	Total Diabetic Population	Prevalance %
2007/2008	1,123,080	5,630	41,622	616	492	48,360	**4.3**
2008/2009	1,140,434	5,924	45,222	993	422	52,561	**4.6**
2009/2010	1,146,795	6,417	47,916	679	820	55,832	**4.9**
2010/2011	1,147,994	6,205	49,725	697	1,088	57,715	**5.0**
2011/2012	1,161,195	6,333	52,349	820	1,016	60,578	**5.2**
2012/2013	1,140,039	6,456	53,750	1,011	2,583	63,094	**5.5**

Source: SOARIAN

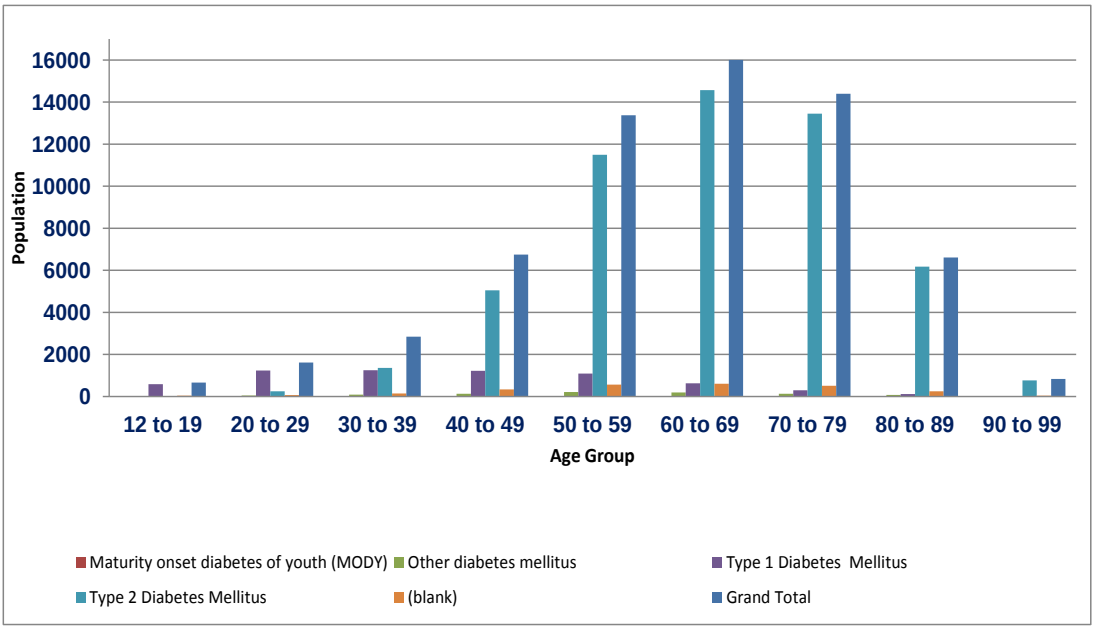
[1] Total Population aged over 12 years old (Source CHI - Jan08, Jan09, Jan10, Jan11, Jun12, Aug12)

[2] Unspecified: No type of Diabetes recorded

The number of patients with diabetes increases with age and peaks between 60-69 years.

Figure 7.2 shows that the majority of people with diabetes who are under 30 years old have Type 1 diabetes. With increasing age the burden of disease is due to Type 2 diabetes. The public health importance of this is that type 2 diabetes is largely preventable and is associated with lifestyle factors such as diet, exercise and obesity.

Figure 7.2 Classification of diabetes for the total NHSGGC diabetic population by age group



Source: Soarian, extracted August 2012

Table 7.2 shows the prevalence and type of diabetes by CH(C)P.

Table 7.2 Number of patients with diabetes in NHS Greater Glasgow and Clyde by type of diabetes and CH(C)P

CHP	Total Population[1]	Type 1 Diabetes Mellitus	Type 2 Diabetes Mellitus	Other Diabetes Mellitus	Unspecified[2]	Total Diabetic Population	Prevalance %
East Dunbartonshire	96,795	525	4,178	62	131	4,896	5.1%
East Renfrewshire	80,718	468	3,426	59	201	4,154	5.1%
Glasgow North East	170,824	945	8,503	198	192	9,838	5.8%
Glasgow North West	198,446	1,002	7,683	163	233	9,081	4.6%
Glasgow South	209,412	1,203	10,912	211	208	12,534	6.0%
Inverclyde	71,857	430	3,537	72	406	4,445	6.2%
North Lanarkshire[3]	17,256	107	845	11	19	982	5.7%
Renfrewshire	158,048	898	7,305	98	882	9,183	5.8%
South Lanarkshire[3]	54,037	321	2,625	24	44	3,014	5.6%
West Dunbartonshire	82,642	510	4,080	55	240	4,885	5.9%
Unassigned[4]	n/a	15	42	12	12	81	
NHSGGC Total	**1,140,039**	**6,424**	**53,137**	**965**	**2,568**	**63,094**	**5.5%**

Source: DRS, Soarian Date Extracted: September 2013

Notes:

1 Total population over 12 years old (CHI, August 2013)

2 Unspecified: No type of Diabetes recorded

3 NHSGGC residents only

4 Unassigned: Incomplete or incorrect postcodes - unable to assign CHP

Table 7.3 shows the distribution of the population with diabetes across deprivation categories and by age group. Of the total population with diabetes in NHS GGC, 25,965 (40.7%) are known to be resident in the most deprived areas compared to 8,956 (14.1%) who live in the least deprived areas. The largest proportion of people with diabetes was among the 50 – 79 year olds. This represents 69.4% (43,768) of the total population with diabetes.

Table 7.3 Number of people with diabetes by age group and deprivation categories

	Most Deprived				Least Deprived			
Age Group	1	2	3	4	5	Unassigned	Total	Most Deprived (SIMD=1)
12 to 19	228	126	87	94	119	5	659	34.6%
20 to 29	627	267	263	216	230	9	1,612	38.9%
30 to 39	1,249	580	396	316	291	15	2,847	43.9%
40 to 49	3,089	1,323	890	732	683	30	6,747	45.8%
50 to 59	5,600	2,503	1,856	1,590	1,766	55	13,370	41.9%
60 to 69	6,288	2,985	2,153	2,064	2,460	52	16,002	39.3%
70 to 79	5,831	2,768	1,976	1,666	2,126	29	14,396	40.5%
80 to 89	2,478	1,269	926	792	1,127	15	6,607	37.5%
90 to 99	298	153	127	106	150	2	836	35.6%
100+	7	1	4	1	4	1	18	38.9%
Total	**25,695**	**11,975**	**8,678**	**7,577**	**8,956**	**213**	**63,094**	**40.7%**
% Total	**40.7%**	**19.0%**	**13.8%**	**12.0%**	**14.2%**			

Source: DRS, Sorian Date Extracted: September 2013

Notes:

Unassigned SIMD: Postcode incompleted or only partially recorded - unable to assign SIMD

Age calculated as at financial year end (ie 31/03/2013)

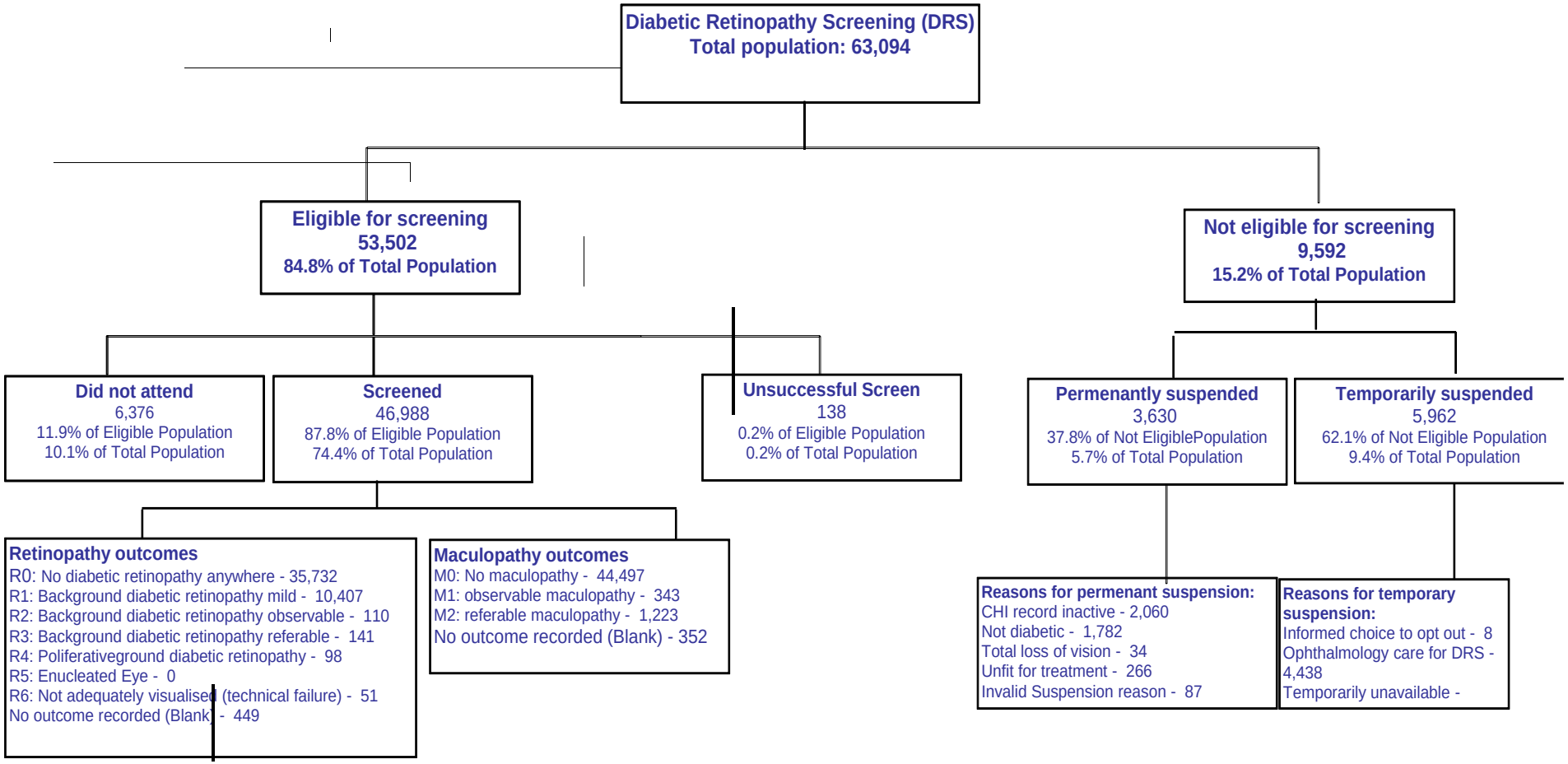
Figure 7.3 illustrates the summary of the NHS Greater Glasgow and Clyde Diabetic Retinopathy Screening programme for the period 1 April 2012 to 31 March 2013.

Of the 63,094 patients with diabetes, 53,502 (84.8%) were eligible for screening. Of those, 87.8% (46,988) were screened. This means that 74.4% of total diabetic population in NHS GGC were screened in 2012/13.

9,592 (15.2%) people were not eligible for screening because they were either permanently or temporarily suspended from the programme. The main reason for suspension from screening was ongoing ophthalmology care following attendance in diabetic retinopathy screening.

Of the total number of residents screened (46,988), 1,223 were referred to Ophthalmology for further investigation.

Figure 7.3 Summary uptake and results of NHS Greater Glasgow and Clyde Diabetic Retinopathy Screening Programme for period 1 April 2010 to 31 March 2011



Source: DRS, Soarian Date Extracted: September 2013

The minimum national standard for uptake for diabetic retinopathy screening is 80%. **Table 7.4** shows the uptake rates of diabetic retinopathy screening programme by Community Health (and Care) Partnership areas and that all areas exceeded the minimum standard.

Table 7.4 NHSGGC Diabetic Retinopathy Screening programme uptake for NHSGGC residents by CH(C)P area

CHP	Total Population	Eligible Population	Screened	Uptake
East Dunbartonshire	4,896	4,113	3,820	92.9%
East Renfrewshire	4,154	3,515	3,224	91.7%
Glasgow North East	9,838	8,487	7,245	85.4%
Glasgow North West	9,081	7,591	6,501	85.6%
Glasgow South	12,534	10,469	9,037	86.3%
Inverclyde	4,445	3,726	3,302	88.6%
North Lanarkshire[1]	982	873	769	88.1%
Renfrewshire	9,183	7,873	7,047	89.5%
South Lanarkshire[1]	3,014	2,604	2,357	90.5%
West Dunbartonshire	4,885	4,215	3,657	86.8%
Unassigned[2]	82	35	28	80.0%
NHSGGC Total	**63,094**	**53,502**	**46,988**	**87.8%**

Source: DRS, Sorian Data Extracted: September 2013

Notes

1 NHSGGC residents only

2 Unassigned: Incomplete or incorrect postcodes - unable to assign CHP

Staff Training

Fifteen screening and administrative staff had signed up to complete the City & Guilds Joint Education Work accreditation programme in 2012 equating to 4 national screening Diplomas, 10 national retinal screening certificated units and 1 single unit . A further 11 who are registered for the qualifications are scheduled to complete the programme during 2014/15 .

Information systems

There are two main information systems used in the provision of Diabetic Retinopathy Screening.

SOARIAN provides the call/recall, image capture, grading, quality assurance and result delivery.

SCI-DC is an essential component for effective Diabetic Retinopathy Screening. It provides both the diabetes population register for the DRS call/recall and feedback the results of the Diabetic Retinopathy Screening to clinical staff involved in the care of patients with diabetes.

During 2012, DRS programme piloted the use of autograder software that met the modified cost savings and performance as predicted. Locally we have supported the implementation of the autograder and have recommended to the Director of Finance that the continued use of the autograder is funded. No decision has yet been made by the Directors of Finance nationally.

Challenges and future priorities

- It is anticipated that the number of people with diabetes will continue to increase that would require additional service capacity in the future. At present the current prevalence of diabetes for NHSGGC adult residents is 5.5%.

- Work will continue to try and increase the number of people taking up appointments.

- Develop and implement OCT to assess referable maculopathy better within the screening service.

Appendix 7.1

Members of Diabetic Retinopathy Screening Steering Group (As at March 2013)

Dr Emilia Crighton	Consultant in Public Health Medicine (chair)
Mrs Donna Athanasopolous	PERL Resources Co-ordinator
Mrs Eileen Ferguson	Lay Member
Mr James Ferguson	Lay Member
Mrs Fiona Gilchrist	Assistant Programme Manager, Screening Dept
Mr Carsten Mandt	Co-ordinator for MCN for Diabetes
Mrs Fiona Heggie	Clinical Nurse Co-ordinator, Retinal Screening
Mrs Annette Little	Information Analyst
Miss Denise Lyden	Project Officer
Mrs Lin Calderwood	HI&TScreening Service Delivery Manager
Miss Nicola McElvanney	AOC Chair
Mr Eddie McVey	Optometric Advisor
Ms Patricia Morrison	DRS Manager
Mrs Elizabeth Rennie	Programme Manager, Screening Dept
Ms Karen Ross	MCN & CDM Planning Manager
Mr David Sawers	DRS Service Manager
Dr William Wykes	Consultant Ophthalmologist

CHAPTER 8: ABDOMINAL AORTIC ANEURYSM SCREENING

Abdominal aortic aneurysm (AAA) screening was implemented across NHS greater Glasgow and Clyde in February 2013.

Background

An abdominal aortic aneurysm is a dilatation of the aorta within the abdomen, where the aortic diameter is 3.0 cm or more. Aneuryms are strongly linked to increasing age, hypertension, smoking, other vascular disease and a positive family history AAA (Vadulkari, 2000).

Studies found that approximately 7% of men aged 65 were found to have an aneurysm and was less common in men and women under aged 65 years (Vadulkari et al., 2000; Ashton et al., 2000).

When an aneurysm ruptures less than half of patients will reach hospital alive and when an operation is possible mortality is as high as 85%.

Aim of the screening programme

The aim of AAA screening is the early detection and elective repair of asymptomatic AAA in order to prevent spontaneous rupture. AAA screening is associated with a 40% reduction in mortality in men.

Eligible population and screening test

All men aged 65 years who are resident in NHS Greater Glasgow and Clyde are invited to attend for a single abdominal ultrasound scan. Men aged over 65 years of age will be able to self-refer to the programme. Screening takes place in Victoria ACAD, Stobhill ACAD, Inverclyde Royal Hospital and Vale of Leven Hospital.

Table 8.1 shows the estimated eligible screening population from 2013 to 2021.

Table 8.1 Eligible 65 year old male population

2013	2014	2015	2016	2017	2018	2019	2020	2021
6110	5815	5691	5671	5570	5907	5858	6191	6398

Source: National Services Division business case (2008)

Screening pathway

Individuals whose aortic diameter is less than 3.0 cm are discharged. Patients with a positive result from screening (AAA dimensions between 3.0 and 5.4 cm) will be offered interval surveillance scanning and treatment. Men with clinically significant AAA (over 5.5 cm) will be referred to secondary care for assessment **(Appendix 8.1).**

Patients with an abdominal aortic aneurysm over 5.4 cm are assessed in vascular surgical outpatient clinics to assess willingness and fitness for either surgery or for referral to interventional radiological services for assessment for endovascular aneurysm repair (EVAR). There is a dedicated multidisciplinary team for aneurysm patients (both screened and unscreened). Some patients will not go on to have an intervention, mainly due to fitness for surgery or a preference for no intervention after consultation and assessment.

Service delivery – interim report

From 1 February 2013 to 31 March 2013**,** 124 male residents aged 65 in NHS Greater Glasgow and Clyde were invited to participate in the AAA Screening programme. Of the total invited, 89 (71.8%%) took up screening.

Table: 8.2 NHS Greater Glasgow and Clyde AAA Screening activity 1 February 2013 – 31 March 2013

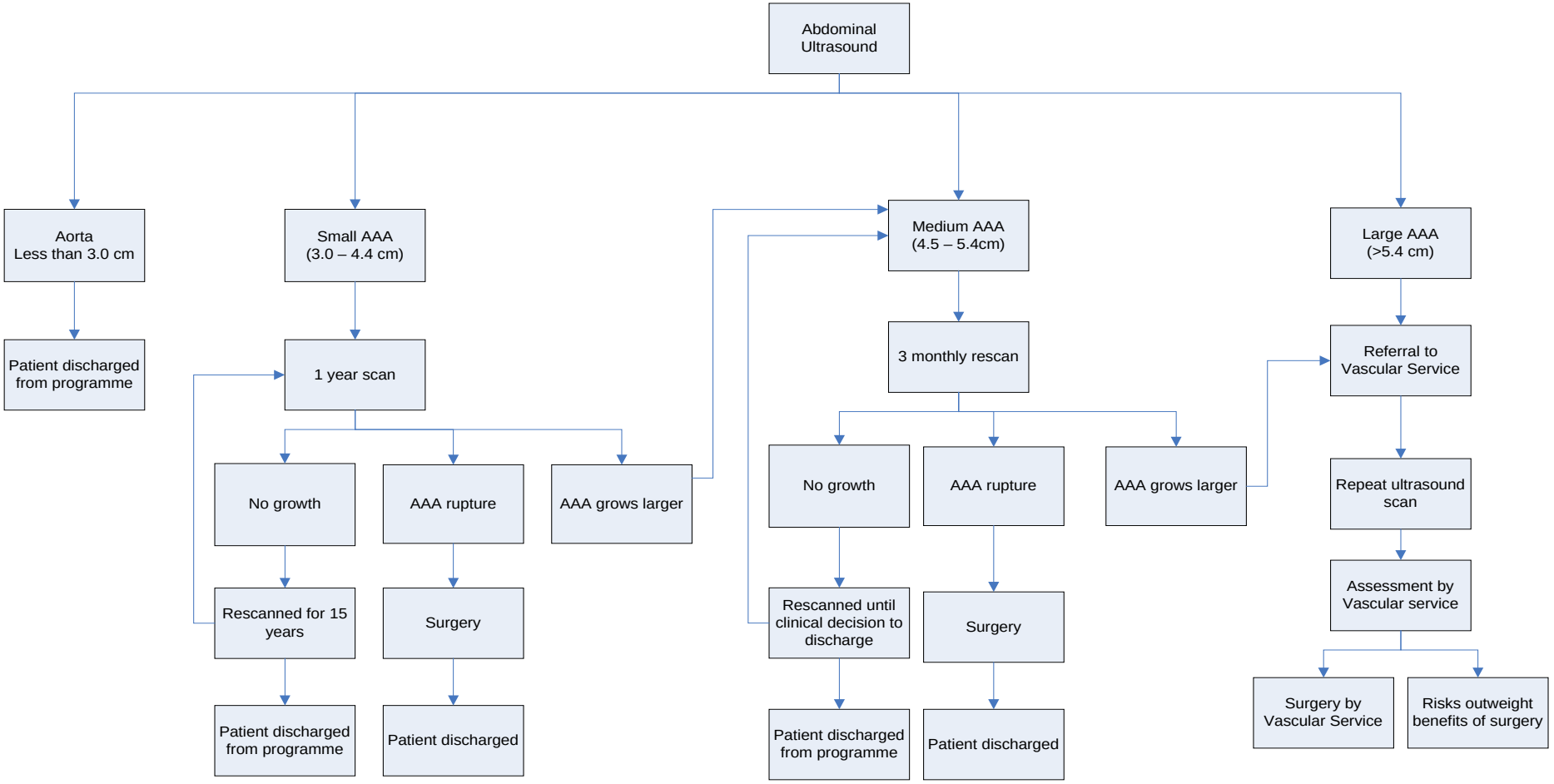
Allocated	124
Attended	89
Did Not Attend	35
% Uptake	71.8
% Did Not Attend	28.2

Challenges

8,396 men will be ready for screening over 2013/14. This represents a variance of 27% (2,286) on the previous business case estimate of 6,110. Increasing clinic capacity to ensure all eligible residents are offered screening will be the main challenge.

APPENDIX 8.1

Positive Abdominal Aortic Aneurysm Screening Pathway



APPENDIX 8.2

Members of Abdominal Aortic Aneurysm Screening Implementation Group (as at March 2012)

Dr Emilia Crighton, Consultant in Public Health Medicine (Chair)
Dr Sandy Binning, Clinical Director, Critical Care
Mrs Kate Blacklock, Health Records Site Manager
Mr Paul Burton, Senior Information Analyst
Mrs Lin Calderwood, HI&T Service Delivery Manager
Mrs Jacquie Campbell, General Manager, Theatres, Anaesthetics & Critical Care
Mrs Marie Devine, Radiographer
Dr Richard Edwards, Consultant Radiologist
Dr Nick Pace, Clinical Director, Theatres and Anaesthesia
Ms Marilyn Horne, Acting Health Records Services Manager
Ms Denise Lyden, Project Officer
Ms Aileen MacLennan, Director, Diagnostics
Mrs Janette Fraser, NHS Forth Valley
Mrs Karen McClure, NHS Forth Valley
Mrs Susan McFadyen, General Manager, General Surgery, Urology, Endoscopy
Mrs Frith Noble, Sonographer, Diagnostics
Mrs Elizabeth Rennie, Programme Manager, Screening Department
Mrs Lynn Ross, General Manager, Diagnostics
Mr Wesley Stuart, Consultant Vascular Surgeon
Mr George Welch, Lead Clinician

REFERENCES

Mansouri, D., McIlveen, E., McMillan, D.C., Morrison, D., Crighton, E.M., Horgan, P.G. (2013) Interval versus screen-detected colorectal cancer: Comparison of host and tumour prognostic factors and outcome

Mansouri, D., McMillan, D.C., Morrison, D., Crighton, E.M., Horgan, P.M. (2013) Efficacy of a populated based colorectal cancer screening programme and analysis of outcomes in screen detected and non screen detected tumours.

Simpson, L and Robins, J (2013) A review Review of the data relating to the process of screening and detection of Trisomy 21

Campbell, H (2012) Vardulaki KA, Walker NM, Day NE, Duffy SW, Ashton HA, Scott, RAP (2000) Quantifying the risks of hypertension, age, sex and smoking in patients with abdominal aortic aneurysm. British Journal of Surgery 87: 195-200.

Ashton HA, Buxton MJ, Day NE, Kim LG, Marteau TM, Scott RAP et al (2000). Multicentre Aneurysm Screening Study Group. The Multicentre Aneurysm Screening Study (MASS) into the effect of abdominal aortic aneurysm screening on mortality in men: a randomised controlled trial. Lancet 360 (9345): 1531-9.

Hallin A, Bergqvist D, Holmberg L. Literature review of surgical management of abdominal aortic aneurysm. (2001) European Journal of Vascular and Endovascular Surgery; 22 (3): 197-204.

National Services Division (2008) Abdominal Aortic Aneurysm Screening Programme Business case.

ACKNOWLEDGEMENTS

This annual report was prepared by Dr Emilia Crighton, Consultant in Public Health Medicine and Denise Lyden, Project Officer Public Health Screening Unit in collaboration with colleagues across NHS Greater Glasgow and Clyde.

Special thanks are conveyed to Annette Little, Information Analyst, Paul Burton, Information Analyst, Hilary Jordan, Information Analyst, Dr Jim Robins, Consultant Obstetrician, Dr David Mansouri, Research Fellow, University of Glasgow, Linda Simpson, Medical Student, Louise Brown, Principal Scientist, and Joan McKenzie, Laboratory Newborn Screening Co-ordinator, and Lorna Crawford, Principal Scientist, Cytogenetics.

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

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