Public Health Screening Programmes

1 April 2013 to 31 March 2014

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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 2013/14:

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. 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

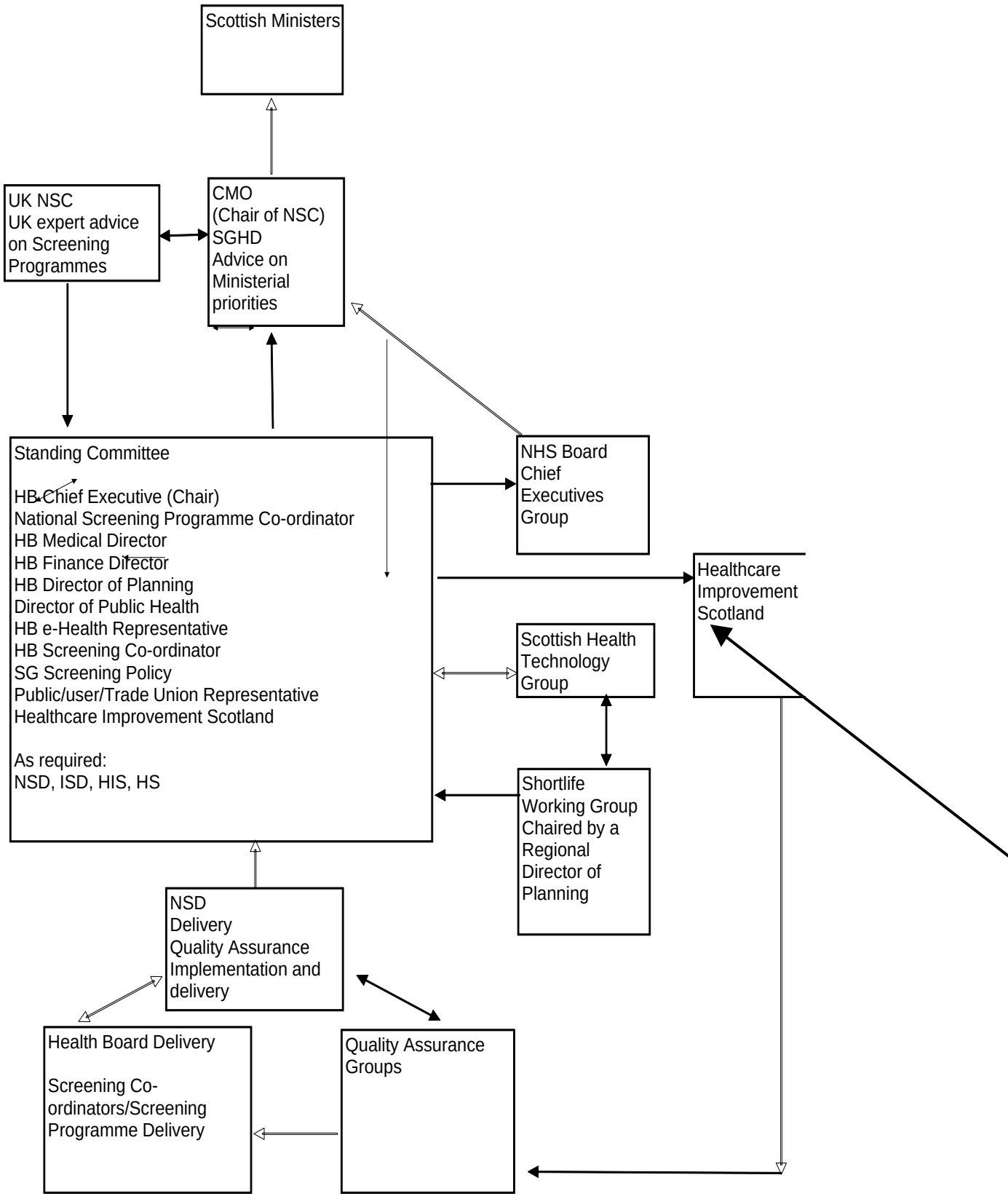
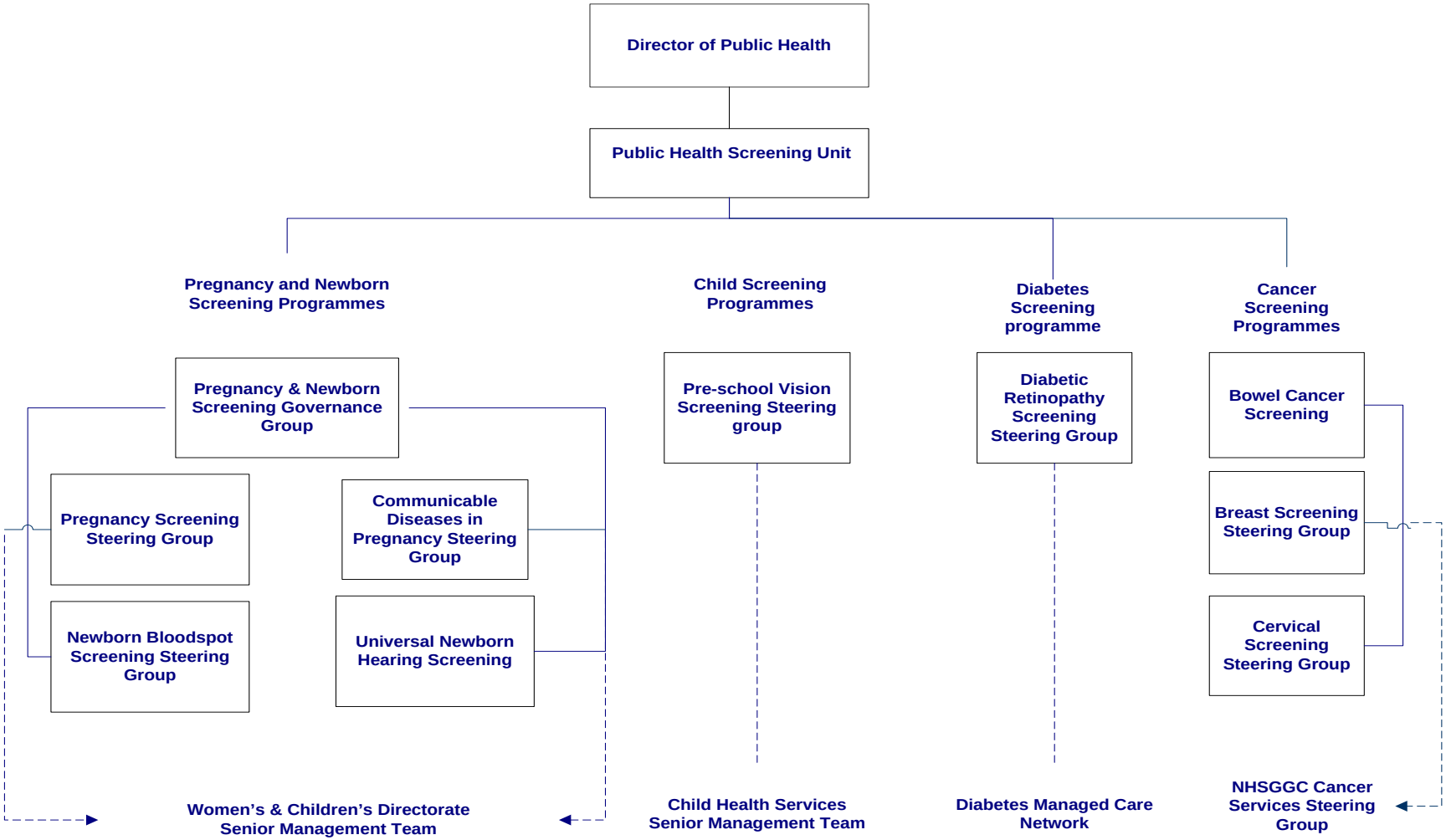


Figure B: Governance arrangements for the NHS Greater Glasgow and Clyde public health screening programmes



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.

This report also includes 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 2013/14 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 2013 to 31 March 2014

Screening programme	Total eligible population	Total number Screened	HIS Target	2013/14 % Uptake[5]
Cervical screening[1]	368,362	261,713	80%	74.0%
Breast screening[2]	143,419	96,214	70%	67.1%
Bowel screening[3]	381,529	196,322	60%	51.5%
Pregnancy screening: Communicable diseases in pregnancy [4]	14,547	13,384	n/a	99.5%
Down's syndrome	14,547	11,274	n/a	77.5%
Haemoglobinopathies	14,547	13,999	n/a	96.2%
Newborn bloodspot Screening	13,322	13,186	n/a	99.0%
Universal newborn hearing screening	13,657	13,215	n/a	96.8%
Pre-school vision screening	13,638	11,728	n/a	85.9%
Diabetic retinopathy Screening	65,265	55,282	80%	84.7%
Abdominal Aortic Aneurysm Screening	5,526	4,486	70%	81.2%

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;, 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 2013 to 31 March 2014

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**.**

- 353,527 women were eligible to be invited to participate in the programme over three years.

- In 2013/2014, the 5.5 year uptake up for NHS Greater Glasgow and Clyde was 74%. This was below the Scotland wide average of 77.3% and the NHS HIS target of 80%.

- This represents an overall 0.6% decrease in uptake since 2012/2013. The lowest uptake of 63.4% was in Glasgow North West sector. East Dunbartonshire, East Renfrewshire, and North and South Lanarkshire exceeded the minimum standard of 80%.

- 63,344 (17.3%) 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 was among the 21 to 24 year olds at 54.6% when only no cervix exclusion was applied. This represents a 2.4% decrease on previous year's uptake of 57%.

- The uptake of cervical screening among women residents in the most deprived areas has decreased by 0.5% from 73.6% in 2012/13 to 73.1% in 2013/14. Uptake for women resident in the most affluent areas has decreased by 1.2% from 79.6% to 78.4% over the same period.

- The total number of smear tests processed in 2013/14 was 98,959 and represents a decrease of 5.3% from the 104,507 smears processed in 2012/13. The decrease in smears is primarily a result of change of screening pathway.

- The overall percentage of unsatisfactory smears was 2.8% and above the Scottish average of 2.7%.

- 10.2% of smears were reported as abnormal in 2013/14 representing a decrease of 3.1% since 2012/13.

- 87.2% of smears processed were reported to be negative; 4.2% were borderline squamous; 4.3% mild dyskaryosis and 1.3% to have moderate to severe dyskaryosis.

- 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.

- 4,473 patients were referred to colposcopy for treatment, 3,558 (79.5 %) were seen within 8 weeks. 128 (2.86%) were seen over the 8 week period. 785 (17.5%) either cancelled or did not attend their appointment.

- In 2013, we reviewed the notes of 71 women who developed invasive cervical cancer and had a pathology diagnosis made in NHS Greater Glasgow and Clyde laboratories.

- 30 of the 71 cases were screen detected**.**

- Over the six years audited, 61 (14.1%) women out of the 432 that developed cancer had never had a smear; 171 (39.7%) had complete smear histories and 195 (45.1%) of women had incomplete smear histories.

- In 2012, 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 92. This gives a standardised incidence rate of 14.7 per 100,000 per population which is higher than that for Scotland at 10.9.

- In 2013, 20 women with a diagnosis of cervical cancer died in NHS Greater Glasgow and Clyde. This gives a standardised rate of 3.3 per 100,000 population equal to the Scotland rate of 3.3 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 95%, and 93.3% for the second dose. This was above the Scottish averages of 93.6% and 91.7% respectively. Uptake for the third dose was 79.9% which was below the Scottish average of 81.4%. Final uptake rates one year later for the S2 routine cohort of girls in 2013/14 will be published in September 2015.

- From April 2016, the age range and frequency of the cervical screening programme will change for routine screening to three years from age 25 and 5 yearly from age 50 – 64. Women on non routine screening will be invited up to the age of 70 years, a change from current arrangement of 68 years.

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.

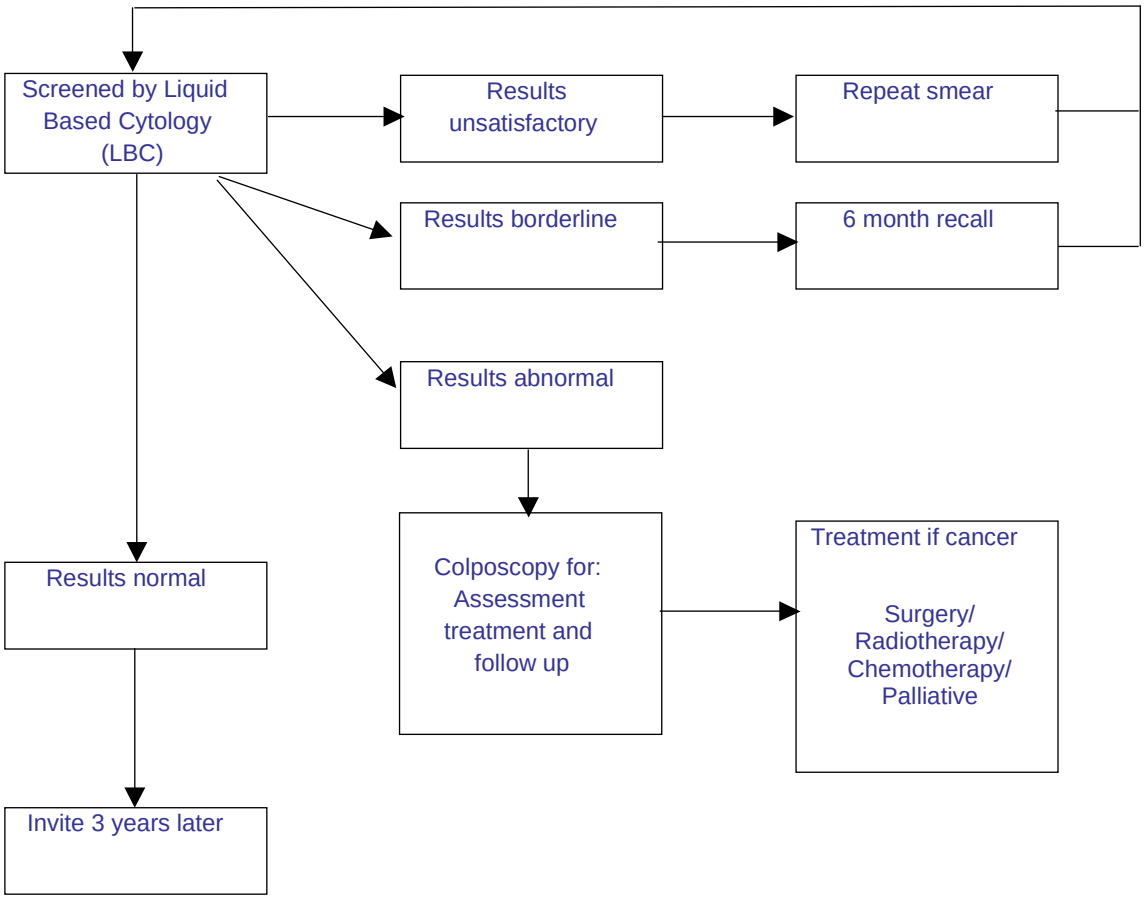
Liquid based cytology (LBC) is a way of preparing cervical samples for examination in the laboratory. The sample is collected using a special device which brushes cells from the neck of the womb. The head of the brush, where the cells are lodged, is broken off into a small glass vial containing preservative 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 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 368,362 women aged 21 to 60 resident in NHS Greater Glasgow and Clyde in the target population. Following the exclusion of those with no cervix, 353,527 women were eligible to be invited to participate in the programme over three years. Approximately 117,842 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 with no cervix (%)	All eligible women based on GMS Payments[4] (N)	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*
2013/14[5]	368,362	353,527	*4.0*	281,103	*23.7*

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

2007/08 - 2013/14 - 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 2013/14 was 74% (see **Table 1.2**). This was below the Scotland wide average of 77.3% and the NHS HIS target of 80%.

This represents an overall 0.6% decrease in uptake since 2012/2013. The lowest uptake of 63.4% 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/ CH(C)P[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	2013/14	2010/11[3]	2011/12	2012/13	2013/14
Glasgow North East	70.4%	72.3%	71.7%	70.9	78.2%	81.7%	81.4%	78.8
Glasgow North West	66.0%	67.5%	65.7%	63.4	74.0%	78.4%	76.2%	72.6
Glasgow South	73.6%	75.1%	74.6%	73.7	80.0%	83.8%	83.3%	80.5
North Lanarkshire[2]	83.4%	83.9%	83.3%	82.7	88.2%	90.7%	89.2%	87.7
South Lanarkshire[2]	80.5%	81.5%	81.6%	80.8	86.2%	88.1%	88.5%	86.0
East Dunbartonshire	81.9%	82.6%	82.2%	81.7	86.5%	89.4%	88.7%	86.7
East Renfrewshire	81.4%	82.2%	82.2%	81.6	86.4%	89.5%	89.2%	86.9
Inverclyde	77.2%	78.0%	78.0%	77.6	82.3%	85.7%	84.8%	82.8
Renfrewshire	78.5%	79.8%	79.5%	78.7	84.2%	87.1%	86.4%	84.1
West Dunbartonshire	77.7%	78.6%	78.3%	77.7	83.5%	86.4%	85.1%	83.4
NHSGGC[4]	**74.5%**	**76.0%**	**75.1%**	**74.0**	**81.1%**	**84.0%**	**83.6%**	**81.0**

Source: Scottish Cervical Call Recall System

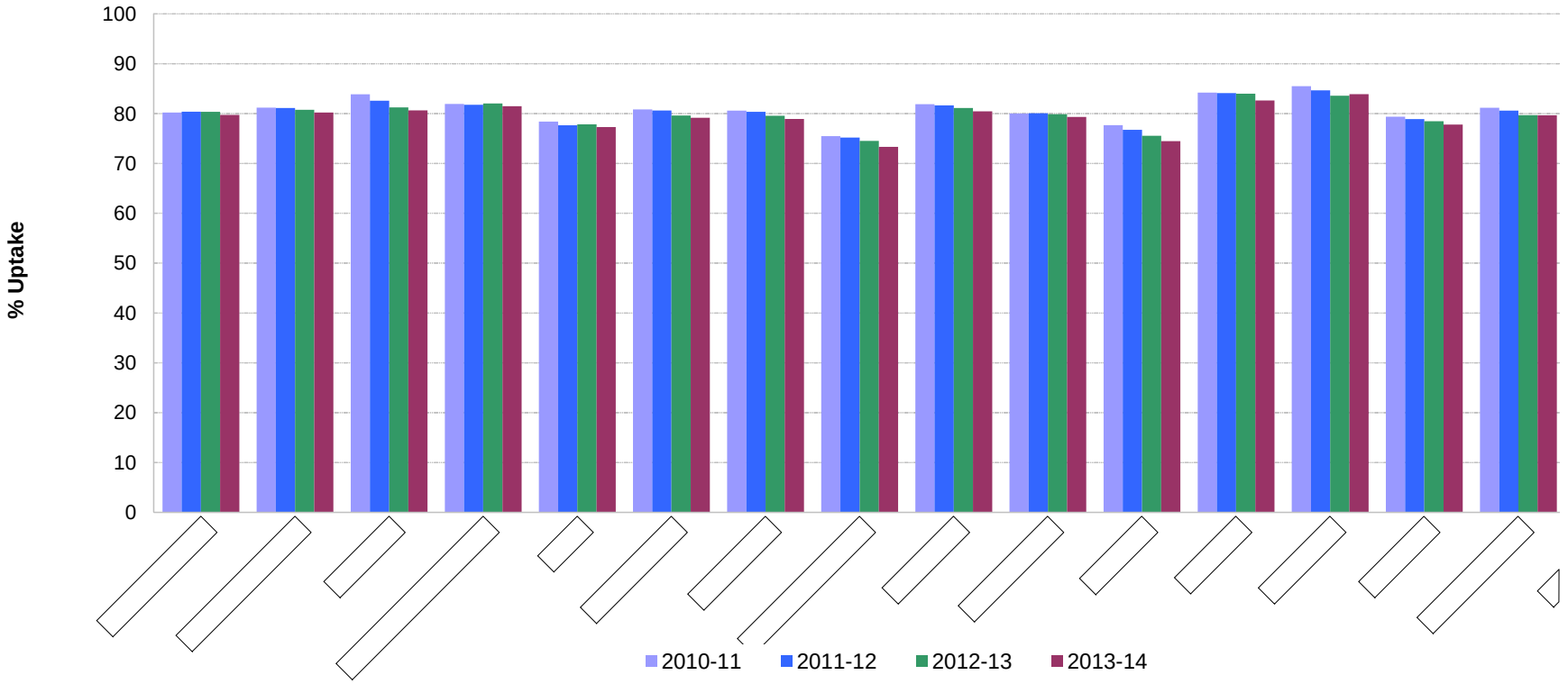
Notes:

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

2 NHSGGC residents only

3 Uptake based on GMS target payments. Excludes women with exclusion categories as defined in the GP contract, implemented in 2004 CHP/CH(C)P

Figure 1.2: Trends in the % uptake of females aged 20-60 with a record of a previous screening test taken within last 5 years by NHS Board of Residence: 1st April 2007 to 31st March 2014



* 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

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 2013/14 being 77.3%.

In NHS Greater Glasgow and Clyde, out of the 353,527 eligible women (excluding women with no cervix), 63,344 (17.3%) 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 and proportion of women excluded from cervical screening programme by exclusion category

Reason for exclusion	No of Women Excluded	% of total eligible population
Pregnancy	2,234	0.6%
Co-Morbidity	23	0.0%
Opted Out	4,442	1.2%
Not Clinically Appropriate	3,234	0.9%
Terminally Ill	11	0.0%
Anatomically Impossible	45	0.0%
No Cervix	14,836	4.0%
No Further Recall	856	0.2%
Suspended	0	0.0%
Defaulter	63,663	17.3%
Transferred out by SCCRs	0	0.0%
Total	**89,344**	**24.3%**

Source: 2013/14 - Scottish Cervical Call Recall System

Table 1.4 shows the percentage of women excluded as defaulters by age group. There has been a year on year increase in the defaulters aged between 21 – 24 and 25 - 29. The table also shows that there was a decrease in the defaulters aged 30 – 49.

Table 1.4 Percentage of women excluded as defaulters by age group

	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
21-24	16.1%	16.6%	16.3%	19.2%	20.6%	21.5%	23.3%
25-29	16.1%	17.1%	16.5%	16.8%	16.2%	16.6%	17.3%
30-39	25.2%	24.5%	24.6%	24.3%	23.4%	23.1%	22.4%
40-49	24.3%	23.9%	24.2%	22.4%	21.8%	20.7%	18.8%
50-60	18.3%	17.8%	18.4%	17.2%	18.0%	18.1%	18.2%

Source: 2013/14 Scottish Cervical Call Recall System

Figure 1.3 Percentage of women excluded as defaulters by age

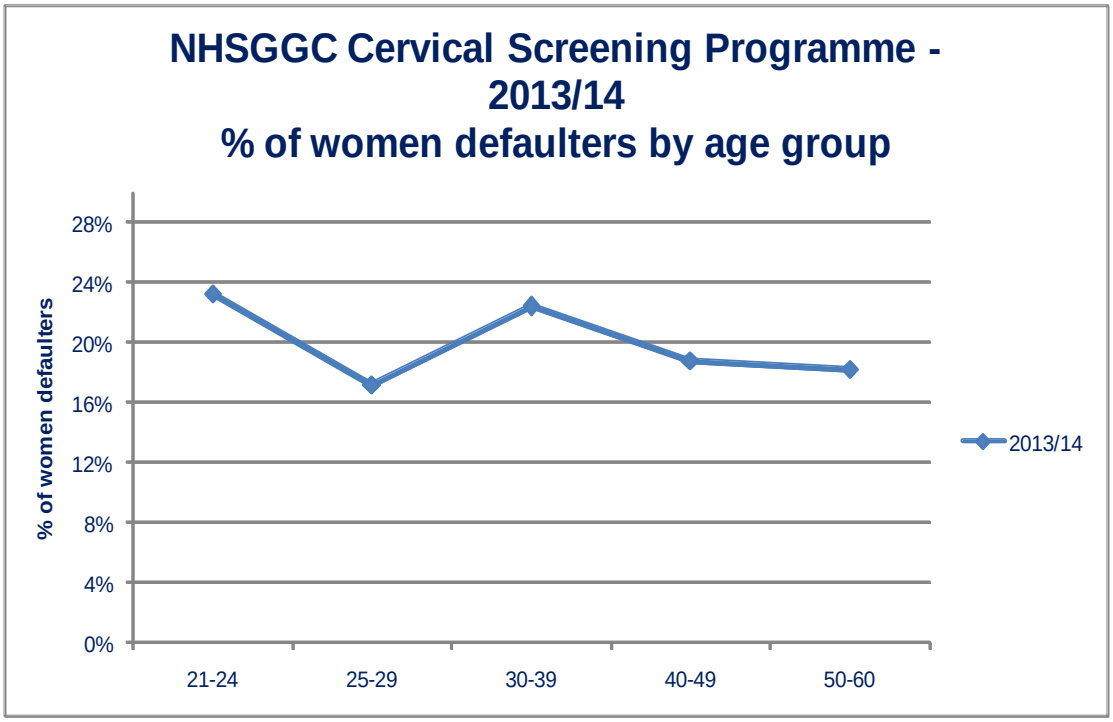


Table 1.5 shows that the cervical screening uptake varied across different age groups. The lowest 5.5 year uptake in 2013/14 was among the 21 to 24 year olds at 54.6% when only no cervix exclusion was applied. This represents a 2.4% decrease on previous year's uptake of 57%. When exclusions allowed for the purpose of GMS target payments were made, overall uptake was 74.4% representing a decrease of 2.3% on previous year's uptake of 76.7%.

Table 1.5 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	41,282	20,431	49.5	22,559	54.6	25,233	17,332	68.7	18,772	74.4
25-29	50,920	28,789	56.5	35,047	68.8	38,274	25,472	66.6	29,224	76.4
30-39	86,890	54,879	63.2	66,958	77.1	70,144	49,799	71.0	57,094	81.4
40-49	88,492	59,023	66.7	71,140	80.4	75,098	55,536	74.0	63,323	84.3
50-60	85,943	54,099	62.9	66,009	76.8	72,354	51,903	71.7	59,177	81.8
Total	**353,527**	**217,221**	**61.4**	**261,713**	**74.0**	**281,103**	**200,042**	**71.2**	**227,590**	**81.0**

Source:- Scottish Cervical Call Recall System(2013/14)

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

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

Table 1.6 shows that the cervical screening uptake rate varied across deprivation categories. The lowest 5.5 year uptake rate in 2013/14 was among women resident in the most deprived neighbourhoods at 73.1% when the no cervix exclusion was applied. Among women residents in the least deprived areas, uptake was higher at 78.4%.

The uptake of cervical screening among women residents in the most deprived areas has decreased by 0.5% from 73.6% in 2012/13 to 73.1% in 2013/14. Uptake for women resident in the most affluent areas has decreased by 1.2% from 79.6% to 78.4% over the same period.

Table 1.6 NHSGGC Cervical screening uptake by age and deprivation categories

		All Eligible Women (exluding women with No Cervix[1])					All Eligible Women (based on Target GMS Payments[2])				
		Eligible	3.5 yr uptake		5.5 yrs uptake		Eligible	3.5 yr uptake		5.5 yrs uptake	
SIMD[3]		Women	Total	%	Total	%	Women	Total	%	Total	%
Most Deprived	1	124,410	74,131	59.6	90,993	73.1	97,869	67,472	68.9	77,729	79.4
	2	60,819	36,785	60.5	44,713	73.5	48,049	33,801	70.3	38,676	80.5
	3	53,660	32,500	60.6	39,023	72.7	42,475	29,939	70.5	33,976	80.0
	4	50,610	31,003	61.3	36,881	72.9	40,007	28,788	72.0	32,479	81.2
Least Deprived	5	62,214	41,672	67.0	48,760	78.4	51,278	39,029	76.1	43,584	85.0
New/Incomplete postcodes[4]		1,814	1,130	62.3	1,343	74.0	1,425	1,013	71.1	1,146	80.4
Total		**353,527**	**217,221**	**61.4**	**261,713**	**74.0**	**281,103**	**200,042**	**71.2**	**227,590**	**81.0**

Source:- Scottish Cervical Call Recall System(2013/14)

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 2012

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 79.4% representing a decrease of 2.5% from 2012/13 uptake of 81.9%. Highest uptake of 85% was among residents living in least deprived areas and represents a decrease of 2.2% on 2012/13 uptake of 87.2%.

The comparative cervical screening uptake for women with learning disabilities by age group is shown in **Table 1.7**. The 5.5 years uptake for women with no cervix was 24% and represented a decrease of 0.2% from 24.2% on previous year and is lower than the general population. The 5.5 years uptake based on the GMS contract increased by 0.8% from 49.1% in 2012/2013 to 49.9% in 2013/14.

Table 1.7 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	102	15	15	15	15	35	13	37	13	37
25-29	223	47	21	61	27	116	44	38	55	47
30-39	359	75	15	89	15	148	67	45	76	51
40-49	492	97	20	130	26	198	94	47	109	55
50-60	505	81	16	108	21	186	74	40	88	47
Total	**1,681**	**315**	**18.7**	**403**	**24.0**	**683**	**292**	**42.8**	**341**	**49.9**

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

NHSGGC Cytopathology Laboratories Workload

Table 1.8 shows the number of tests performed in Cytopathology laboratories in the NHS Greater Glasgow and Clyde area. An essential criterion of the NHS 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 2013/14 was 98,959 and represents a decrease of 5.3% from the 104,507 smears processed in 2012/13. The decrease in smears is primarily a result of change of screening pathway.

Table 1.8 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**	405,020
2013/14	n/a	n/a	98,959	n/a	**98,959**	384,296

Sources: 2002-2007 Cervical Cytology System (CCS); 2007/14 - 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 1.9 shows the proportion of the total cervical samples sent to each of the cytology laboratories that were reported as unsatisfactory smears in 2013/14. The overall percentage of unsatisfactory smears was 2.8% and above the Scottish average of 2.7%.

Table 1.9 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%
2013/14	n/a	n/a	2.8%	n/a	**2.8%**	2.7%

Sources: 2002-2007 Cervical Cytology System (CCS); 2007/14 - 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 1.10 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 2013/14. Abnormal smears results include: borderline, mild, moderate and severe dyskaryosis, severe dyskaryosis/invasive, glandular abnormality and adenocarcinoma. 10.2% of smears were reported as abnormal in 2013/14 representing a decrease of 3.1% since 2012/13.

Table 1.10 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**	**STOB**	**VIC**	**NHSGGC**	**Scotland**
2000/01	7.8%	8.6%	10.2%	11.2%	10.1%	8.5%	**9.4%**	8.0%
2001/02	7.2%	7.4%	7.8%	12.4%	16.5%	8.5%	**9.5%**	8.3%
2002/03	7.0%	8.3%	5.7%	10.0%	n/a	n/a	**8.1%**	7.3%
2003/04	7.6%	10.2%	5.2%	10.3%	n/a	n/a	**8.5%**	7.2%
2004/05	7.8%	7.4%	6.0%	9.8%	n/a	n/a	**8.2%**	7.2%
2005/06	7.6%	n/a	6.7%	10.7%	n/a	n/a	**8.7%**	7.4%
2006/07	8.2%	n/a	7.6%	10.2%	n/a	n/a	**8.9%**	7.6%
2007/08	8.5%	n/a	7.1%	11.1%	n/a	n/a	**9.3%**	7.7%
2008/09	9.6%	n/a	8.5%	10.9%	n/a	n/a	**9.9%**	8.4%
2009/10	8.9%	n/a	9.3%	11.8%	n/a	n/a	**10.3%**	8.7%
2010/11	9.8%	n/a	8.1%	13.2%	n/a	n/a	**10.8%**	9.4%
2011/12	8.8%	n/a	8.2%	13.8%	n/a	n/a	**10.8%**	9.1%
2012/13	n/a	n/a	13.3%	n/a	n/a	n/a	**13.3%**	9.7%
2013/14	n/a	n/a	10.2%	n/a	n/a	n/a	**10.2%**	9.4%

*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

STOB stopped reporting smears taken as at quarter ending 30th June 2001

VIC stopped reporting smears taken as at quarter ending 30th September 2001

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

Scotland figures from ISD Website

Table 1.11 shows the detailed breakdown of smear results profile reported by NHSGGC laboratories.

Of the 98,959 smears tests received by the laboratories, 96,172 (97.1%) were processed. 87.2% of smears processed were reported to be negative; 4.2% were borderline squamous; 4.3% mild dyskaryosis and 1.3% to have moderate to severe dyskaryosis. Appendix 1.1 shows the management and follow up advice for cytology results.

Table 1.11 Result profiles by age band: 1 April 2013 to 31 March 2014 (compiled from quarterly reports)
All NHS Greater Glasgow and Clyde Laboratories

Age Band	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 - 60	%Satisfactory	Cumulative%
Unsatisfactory	16	308	359	372	297	303	369	326	332	98	7	2,787			2,726		
%Total	**2.9**	**2.1**	**2.5**	**2.8**	**2.7**	**2.6**	**2.9**	**3.0**	**4.0**	**5.5**	**4.6**	**2.8**			**2.8**		
Negative	452	11,313	11,500	11,434	9,871	10,752	11,437	9,996	7,764	1,635	126	86,280	87.2	87.2	85,243	87.2	87.2
Borderline change in squamous cells	47	1,267	872	542	343	346	373	210	96	29	7	4,132	4.2	91.4	4,060	4.2	91.4
Borderline change in endocervical cells	-	5	17	10	13	7	8	7	2	-	-	69	0.1	91.4	69	0.1	91.5
Low grade dyskaryosis	39	1,426	968	582	370	321	296	171	88	29	8	4,298	4.3	95.8	4,234	4.3	95.8
High grade dyskaryosis (moderate)	5	191	241	141	85	61	45	30	16	2	3	820	0.8	96.6	810	0.8	96.6
High grade dyskaryosis (severe)	2	67	153	114	59	47	31	21	11	1	1	507	0.5	97.1	504	0.5	97.1
High grade dyskaryosis invasive	-	2	3	4	3	4	2	4	-	2	-	24	0.0	97.1	22	0.0	97.2
Glandular Abnormality	-	5	12	5	3	3	1	3	4	-	-	36	0.0	97.2	36	0.0	97.2
Endocervical Adenocarcinoma	-	-	1	-	-	-	-	-	-	-	-	1	0.0	97.2	1	0.0	97.2
Endometrial or other malignancy	-	-	-	-	-	-	2	2	1	-	-	5	0.0	97.2	5	0.0	97.2
Total including unsatisfactory results	**561**	**14,584**	**14,126**	**13,204**	**11,044**	**11,844**	**12,564**	**10,770**	**8,314**	**1,796**	**152**	**98,959**			**97,710**		
Total excluding unsatisfactory results	**545**	**14,276**	**13,767**	**12,832**	**10,747**	**11,541**	**12,195**	**10,444**	**7,982**	**1,698**	**145**	**96,172**			**94,984**		

	All Ages	20-60
Abnormal	9,892	9,741
% abnormal	10.2	10.2

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
2 Smear counts for the orginating lab
3 Date received into the lab is the qualification date - report wont run until all smears completed for reporting period. Date authorised may be at the end of reporting period.

Table 1.12 shows the activity data across NHSGGC colposcopy service. In 2013/14, there were 11,575 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 1.12 NHSGGC Colposcopy Service workload 1 April 2013 to 31 March 2014

Attendance Status	New Outpatients	Return/ Follow Up Outpatients	Inpatients	Total Episodes
Patient was Seen (Attended)	4,045	4,175	38	8,258
Cancelled by Patient	317	649	0	966
Cancelled by Clinic or Hospital	18	151	0	169
Patient attended but was not seen	3	8	0	11
Patient Did Not Attend	685	1,486	0	2,171
Total	**5,068**	**6,469**	**38**	**11,575**

Source: National Colposcopy Clinical Audit System (Extracted August 2014)

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 1.13 illustrates that 79.5% of patients were seen within 4 weeks; 16.4% were seen within 8 weeks and 3.7% were seen more than 8 weeks. Delays in referral to first appointment may also include patient induced delays.

Table 1.13 NHSGGC waiting times from referral to colposcopy appointment

New Outpatients by Attendance Status	Time Waited from Referral to First Appointment			Total New Referrals
	Less than or equal to 4 weeks	Greater than 4 weeks and <= 8 weeks	Greater than 8 weeks	
Patient was Seen (Attended)	2971	587	128	
Cancelled by Patient	200	48	9	
Patient attended but was not seen	1	1	0	
Patient Did Not Attend	401	98	29	
New Referrals	3573	734	166	4473

Source: National Colposcopy Clinical Audit System (extracted August 2014)

Table 1.14 NHSGGC Colposcopy benchmarking standards for 2013/2014

	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	12960	9468	89.0	2.4	98.1	84.3	92.4	6.9
Greater Glasgow & Clyde	**4045**	**2587**	**88.1**	**2.3**	**98.1**	**81.1**	**93.2**	**5.8**
Glasgow Royal Infirmary	4	4	50.0	0.0	100.0	0.0	0.0	0.0
Inverclyde Royal Hospital	290	202	82.8	4.2	98.3	77.5	93.9	3.6
New Victoria Hospital	1329	649	87.2	2.2	96.3	77.9	94.8	7.7
Royal Alexandra Hospital	425	364	89.8	0.7	98.1	73.3	89.9	6.0
Sandyford Initiative	207	73	94.7	4.4	99.0	88.9	93.5	7.9
Stobhill Hospital	1676	1205	87.5	2.6	98.6	84.7	93.3	5.1
Vale of Leven District General Hospital	114	90	100.0	3.0	99.5	0.0	100.0	1.8
Western Infirmary	0	0	0.0	0.0	0.0	0.0	0.0	0.0

Source: National Colposcopy Clinical Audit System (Extracted: August 2014)

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 1.14.** 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.

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 2013, we reviewed the notes of 71 women who developed invasive cervical cancer and had a pathology diagnosis made in NHS Greater Glasgow and Clyde laboratories.

Table 1.15 shows numbers and the distribution of women's age at diagnosis for years 2008 to 2013. The largest number of cervical cancers occurred in women aged between 30 and 49 years.

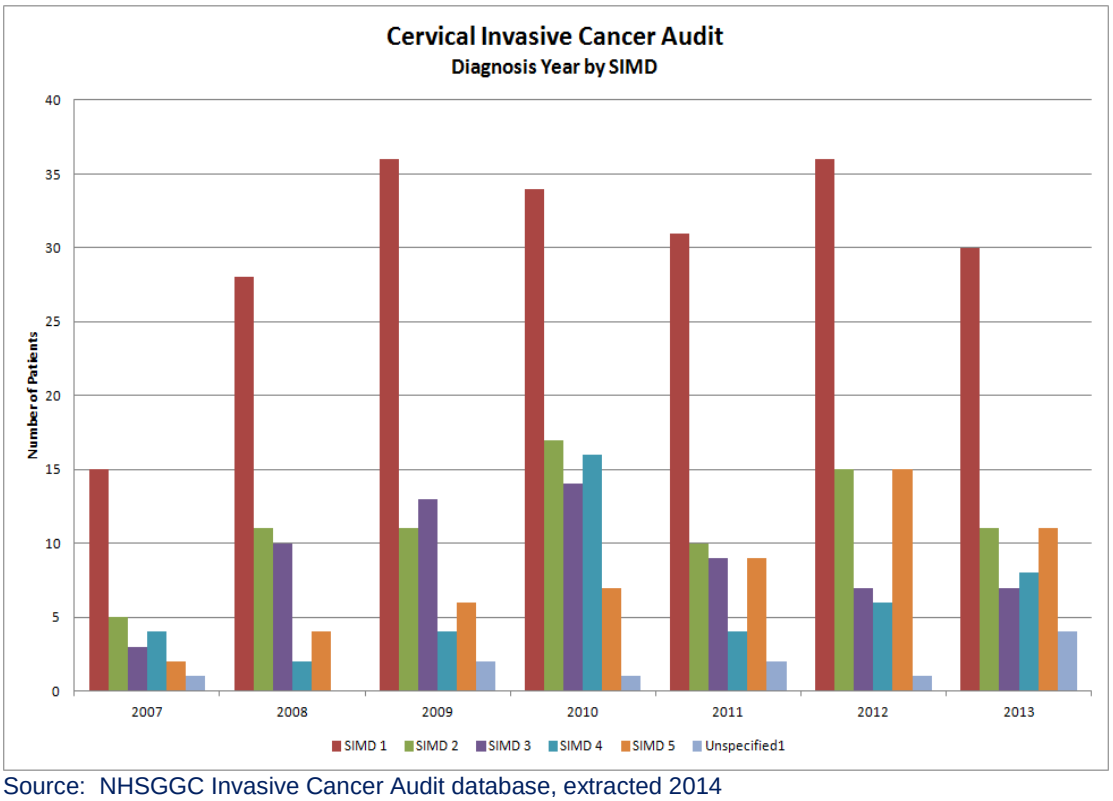
Table 1.15 Number of NHSGGC residents with invasive cervical cancers by age at diagnosis and year of diagnosis

Age at Diagnosis	Year of Diagnosis						
	2008	2009	2010	2011	2012	2013	Total
20-29	8	7	10	7	12	5	49
30-39	19	15	26	17	29	24	130
40-49	11	23	27	11	18	18	108
50-59	10	8	8	11	7	10	54
60-69	3	8	5	8	7	2	33
70-79	2	6	10	8	5	5	36
80+	2	4	3	3	2	4	18
Unknown	0	1	0	0	0	3	4
Total	**55**	**72**	**89**	**65**	**80**	**71**	**432**

Source: NHSGGC Invasive Cancer Audit database

Figure 1.4 shows the distribution of cervical cancers by SIMD for the period 2007 to 2013. The highest proportion of cervical cancers occurred in women living in the least deprived areas.

Figure 1.4 distribution of cervical cancers diagnosed by deprivation area from 2007 to 2013



Source: NHSGGC Invasive Cancer Audit database, extracted 2014

Table 1.16 shows the distribution of clinical stage at diagnosis over a six year period from 2008 to 2013.

Table 1.16 Number of women with invasive cervical cancers by clinical stage and by year of diagnosis

Clinical stage of diagnosis	2008	2009	2010	2011	2012	2013	Total
1a1, 1a2 or 1b	29	41	40	29	48	42	**229**
2 or greater (spread outwith cervix)	26	28	43	35	31	24	**187**
No Details	0	3	6	1	1	5	**16**
Total	**55**	**72**	**89**	**65**	**80**	**71**	**432**

Source: NHSGGC Invasive Cancer Audit

Table 1.17 shows that, in 2013, 30 of the 71 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 1.17 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	2013	Total
Screen Detected	26	28	32	21	43	30	**180**
Symptomatic	17	16	32	22	36	36	**159**
Incidental Finding	0	0	0	0	1	2	**3**
No Details	12	28	25	22	0	3	**90**
Total	**55**	**72**	**89**	**65**	**80**	**71**	**432**

Table 1.18 shows that, in 2013, 27 women of 71 women had a complete smear history compared to 34 women who had incomplete smear histories.

Table 1.18 Smear histories of women with invasive cervical cancer

Smear History	Year of diagnosis						
	2008	2009	2010	2011	2012	2013	Total
Complete	26	27	31	26	34	27	**171**
Incomplete	24	29	45	25	38	34	**195**
Not Applicable	5	16	12	14	7	7	**61**
Unknown			1	0	1	3	**5**
Total	**55**	**72**	**89**	**65**	**80**	**71**	**432**

Source: NHSGGC Invasive Cancer Audit Database

* Apart from index smear ie the abnormal smear causing referral

Over the six years audited, 61 (14.1%) women out of the 432 that developed cancer had never had a smear; 171 (39.7%) had complete smear histories and 195 (45.1%) of women had incomplete smear histories.

Table 1.19 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 1.19 Follow up status of the women with invasive cervical cancer

	Year diagnosis						
Status	**2008**	**2009**	**2010**	**2011**	**2012**	**2013$_p$**	**Total**
Death	2	0	6	8	6	2	24
Early recall	0	0	0	0	2	0	2
Lost to colposcopy service	1	0	1	0	1	1	4
On follow up at colposcopy	14	20	25	10	27	17	113
On follow up at oncology/Beatson	37	48	51	41	43	46	266
Routine Call/Recall						1	1
Unknown	1	4	6	6	1	4	22
Grand Total	**55**	**72**	**89**	**65**	**80**	**71**	**432**

Source: NHSGGC Invasive Cancer Audit database
p = provisional data

The audit demonstrated the positive impact the introduction of SCCRS had on call/recall with full histories being available since 2007.

Very few women included in the audit took up appointments according to the recommendation management despite invites being sent. The review smear will be recorded from 2012 to calculate the false negative reporting rate.

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

In 2012, 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 92 (see **Table 1.20**). This gives a standardised incidence rate of 14.7 per 100,000 per population which is higher than that for Scotland at 10.9.

Figure 1.5 illustrates that the standardised incidence and mortality rates for cervical cancer for NHS Greater Glasgow and Clyde and Scotland.

In 2013, 20 women with a diagnosis of cervical cancer died in NHS Greater Glasgow and Clyde. This gives a standardised rate of 3.3 per 100,000 population equal to the Scotland rate of 3.3 per 100,000.

Table 1.20 Cervical Cancer Registrations and Deaths 1997 - 2013

Scotland

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Registration																	
Number	359	369	313	302	309	292	267	284	298	292	293	314	328	332	317	295	
EASR	13.9	14.3	12.0	11.5	11.8	11.1	10.2	10.9	11.2	10.9	11.1	11.8	12.2	12.3	11.7	10.9	
- Lower 95% CI	*12.5*	*12.9*	*10.7*	*10.3*	*10.6*	*9.9*	*9.0*	*9.7*	*9.9*	*9.7*	*9.8*	*10.5*	*10.9*	*11.0*	*10.4*	9.7	
- Upper 95% CI	*15.4*	*15.8*	*13.4*	*12.9*	*13.2*	*12.5*	*11.4*	*12.2*	*12.5*	*12.2*	*12.4*	*13.1*	*13.6*	*13.6*	*13.0*	12.1	
Deaths																	
Number	144	145	122	117	113	100	120	102	127	92	105	102	107	99	108	112	91
EASR	5.9	5.8	4.9	4.7	4.5	3.9	4.7	4.0	4.9	3.5	4.0	3.8	4.0	3.7	3.9	4.1	3.3
- Lower 95% CI	*4.9*	*4.9*	*4.1*	*3.9*	*3.7*	*3.2*	*3.9*	*3.2*	*4.1*	*2.9*	*3.3*	*3.1*	*3.3*	*3.0*	*3.2*	*3.4*	*2.7*
- Upper 95% CI	*6.9*	*6.8*	*5.8*	*5.6*	*5.3*	*4.7*	*5.6*	*4.8*	*5.7*	*4.3*	*4.8*	*4.6*	*4.8*	*4.4*	*4.7*	*4.9*	*4.1*

Greater Glasgow & Clyde

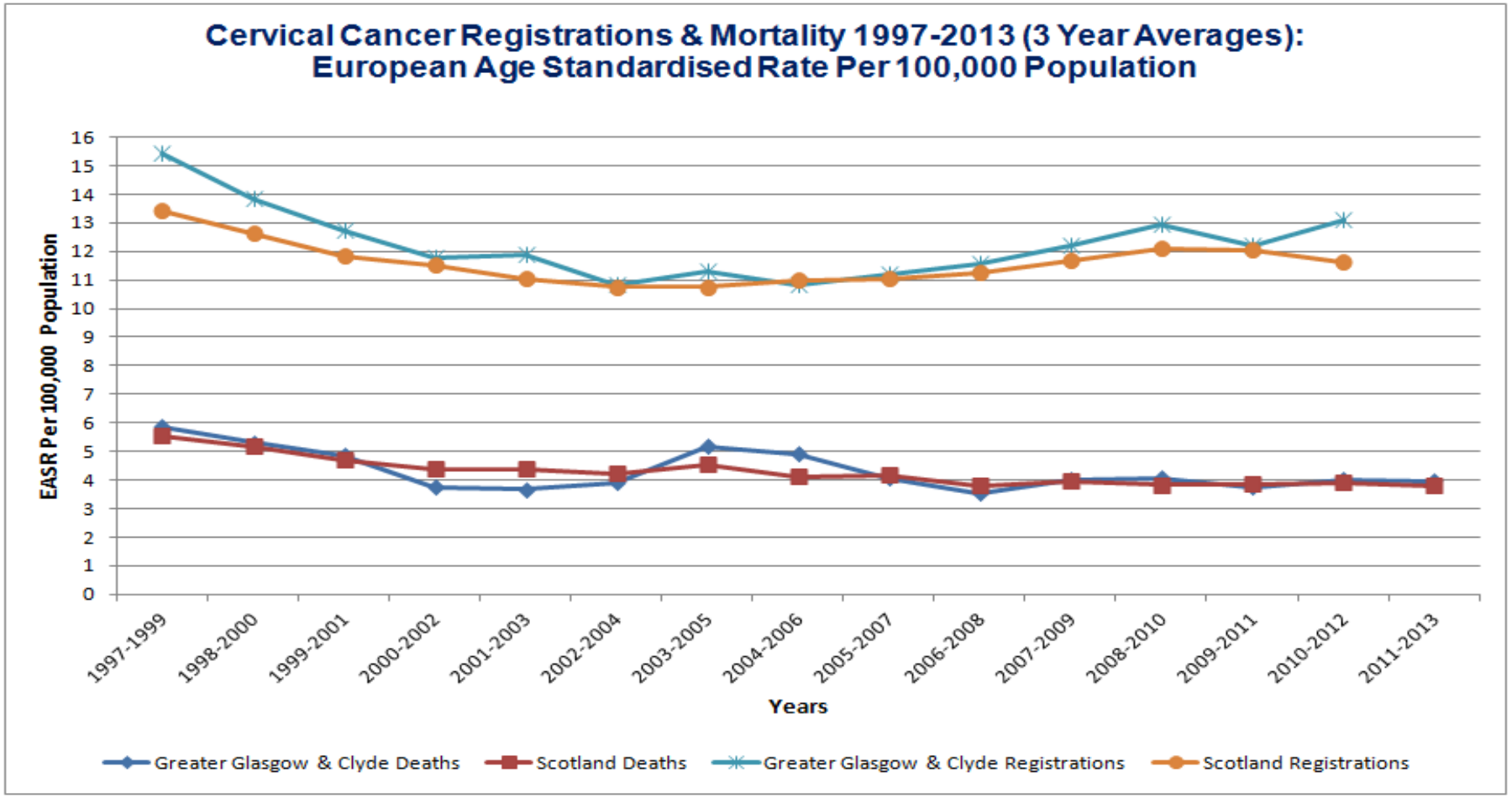
	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Registration																	
Number	96	109	79	71	88	63	70	68	70	62	76	77	75	90	64	92	
EASR	16.0	17.6	12.7	11.2	14.3	9.9	11.5	11.1	11.3	10.0	12.2	12.4	11.9	14.5	10.2	14.7	
- Lower 95% CI	*12.9*	*14.4*	*10.0*	*8.7*	*11.4*	*7.6*	*8.9*	*8.6*	*8.8*	*7.7*	*9.6*	*9.8*	*9.3*	*11.6*	*7.8*	11.8	
- Upper 95% CI	*19.4*	*21.0*	*15.7*	*14.0*	*17.4*	*12.5*	*14.3*	*14.0*	*14.1*	*12.7*	*15.1*	*15.4*	*14.7*	*17.6*	*12.9*	17.9	
Deaths																	
Number	32	37	33	23	30	14	22	33	36	17	19	27	26	20	22	32	20
EASR	5.5	6.3	5.7	3.9	5.0	2.3	3.7	5.8	6.0	2.9	3.3	4.5	4.4	3.3	3.5	5.1	3.3
- Lower 95% CI	*3.8*	*4.4*	*3.9*	*2.4*	*3.4*	*x*	*2.3*	*4.0*	*4.2*	*x*	*x*	*2.9*	*2.8*	*2.0*	*2.2*	*3.5*	2.0
- Upper 95% CI	*7.6*	*8.5*	*7.8*	*5.6*	*7.0*	*x*	*5.4*	*7.9*	*8.1*	*x*	*x*	*6.3*	*6.2*	*5.0*	*5.1*	*7.1*	4.9

Cervical Cancer (ICD10 C53)

Deaths EASR: age-standardised incidence rate per 100,000 person-years at risk (European standard population) Source: National Records of Scotland (NRS) Data extracted: November 2014

Registra EASR: age-standardised incidence rate per 100,000 person-years at risk (European standard population) Source: Scottish Cancer Registry, ISD Data extracted: March 2014

Figure: 1.5 Cervical cancer registrations and deaths for NHS Greater Glasgow and Clyde and Scotland



Source: Scottish Cancer Registry, March 2013; National Records Scotland, March 2014

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 1.21 shows the interim uptake rates for S2 routine cohort by the end of the school year by CHP for school year 2013/14.

Overall uptake across NHSGGC for the first dose of the HPV vaccination was 95%, and 93.3% for the second dose. This was above the Scottish averages of 93.6% and 91.7% respectively. Uptake for the third dose was 79.9% which was below the Scottish average of 81.4%. Final uptake rates one year later for the S2 routine cohort of girls in 2013/14 will be published in September 2015.

Change to age range and frequency

From April 2016, the age range and frequency of the cervical screening programme will change for routine screening to three years from age 25 and 5 yearly from age 50 – 64. Women on non routine screening will be invited up to the age of 70 years, a change from current arrangement of 68 years.

Table 1.21: Annual HPV immunisation uptake rates by the end of the school year for the S2 routine cohort in school year 2013/14[1]; by Community Health Partnership (CHP) of residence

CHP/CH(C)P	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	538	512	95.2	506	94.1	452	84.0
East Renfrewshire	532	508	95.5	506	95.1	452	85.0
Glasgow City[4]	2,757	2,606	94.5	2,542	92.2	2,074	75.2
Inverclyde	431	407	94.4	401	93.0	389	90.3
Renfrewshire	907	867	95.6	853	94.0	723	79.7
West Dunbartonshire	449	433	96.4	429	95.5	363	80.8
NHSGGC Total	**5,707**	**5,424**	**95.0**	**5,325**	**93.3**	**4,523**	**79.3**
Scotland	**26,606**	**24,910**	**93.6**	**24,387**	**91.7**	**21,665**	**81.4**
Glasgow City CHP sectors[5]:							
Glasgow North East	837	812	97.0	788	94.1	640	76.5
Glasgow North West	783	738	94.3	731	93.4	613	78.3
Glasgow South	1,137	1,056	92.9	1,023	90.0	821	72.2

Source: CHSP School (May 2014)/SIRS (August 2014)

1. Uptake rates are based on immunisations recorded on SIRS as at 11 August 2014. Final uptake rates for these girls one year later will be published in September 2015.
2. The cohort relates to girls recorded on CHSP School in class year S2 as at 12 May 2014. These girls were in the second year of secondary school during school year 2013/14 and were around 12 to 13 years of age.
3. CHP is derived from the child's home postcode. There are a small number of records which do not have a postcode recorded or where there is no mapping to CHP.

Health Improvement

NHSGGC Cervical Screening Social Marketing Group was established to develop and implement a campaign to increase cervical screening uptake across the Board.

The group adopted social marketing techniques as there was growing evidence that these can be successful in building public awareness and changing behaviour at an individual or societal level. (Department of Public Health, HM Government, UK 2004, cited in Stead et al, 2007)

The essential benchmarks for the campaign are:

1. Behaviour change goal
2. Consumer research to inform intervention
3. Segmentation of audience and targeted interventions to the different groups
4. Marketing mix – 6 P's (product/service; price (cost/time to the individual); place; promotion and communication; person; policy
5. Exchange – what would motivate people to change their behaviour
6. Competition forces that need to be addressed

Source: adapted from McDermott et al., 2005a cited in Stead et al., 2007, p129

Key findings from NHSGGC's research identified that low uptake of cervical screening was among the younger age group of 20 – 35 year olds. Consumer profiling of a sample group of 25-30 year olds in Glasgow North West identified that 57.9% were classed as urban educated – these being students or young professionals starting out in their career. 25% of women were identified as hard pressed, with low income living in high rise flats or council flats. 13% could not be classified due to partial or missing postcodes and 3% represented women that were comfortably well off.

Barriers to cervical screening generally evoked negative attitudes such the belief that smear tests were sore; some felt that it would be embarrassing. If prepared this may help overcome their anxiety and others feared the outcome of an abnormal result.

Key influencers were mothers, GPs and friends and preferred communication channels were social media, TV and radio. Posters were considered useful for raising awareness but would not motivate them to act.

Based on focus group findings, changes were made in 2012 to improve the cervical screening programme by implementing a policy for reducing the unsatisfactory smear rates and regular training programme for smear takers.

A marketing campaign targeted at 20-35 year olds was launched in March 2014 and included public relations, radio advertising, social media and posters and videos posted on solus screens across practices, hospital sites, libraries and local authorities. The campaign was also shared with other organisations across Scotland.

Existing evidence shows that social marketing campaigns require co-ordinated approaches sustained over time to create any change – it requires "long term strategic investment not measured in years but decades" (Stead et al., 2006, p192 cited in Henley et al., 2011, p704).

Since a one off campaign can only reap short term gain, the campaign will be rerun in January and September 2015.

The group will continue to develop targeted interventions to influence and maintain observed gains.

Other health improvement initiatives

The Cancer and Health Improvement Working Group developed an action plan for 2013-14 and included awareness sessions with young women to address barriers to screening; outreach work with Roma Communities that resulted in 40% of the 41 women going for a smear test.

Challenges and future priorities

- To continue efforts to improve uptake of cervical screening and attendance at colposcopy clinics using social marketing tools, health improvement teams and engaging with community groups.

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

- Re-run of cervical screening 'Smear' marketing campaign in January 2015.

- To evaluate the marketing campaign and provide a report by July 2015.

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)

Management and follow up for cytology results: Post Total Hysterectomy prior local test of cure implementation

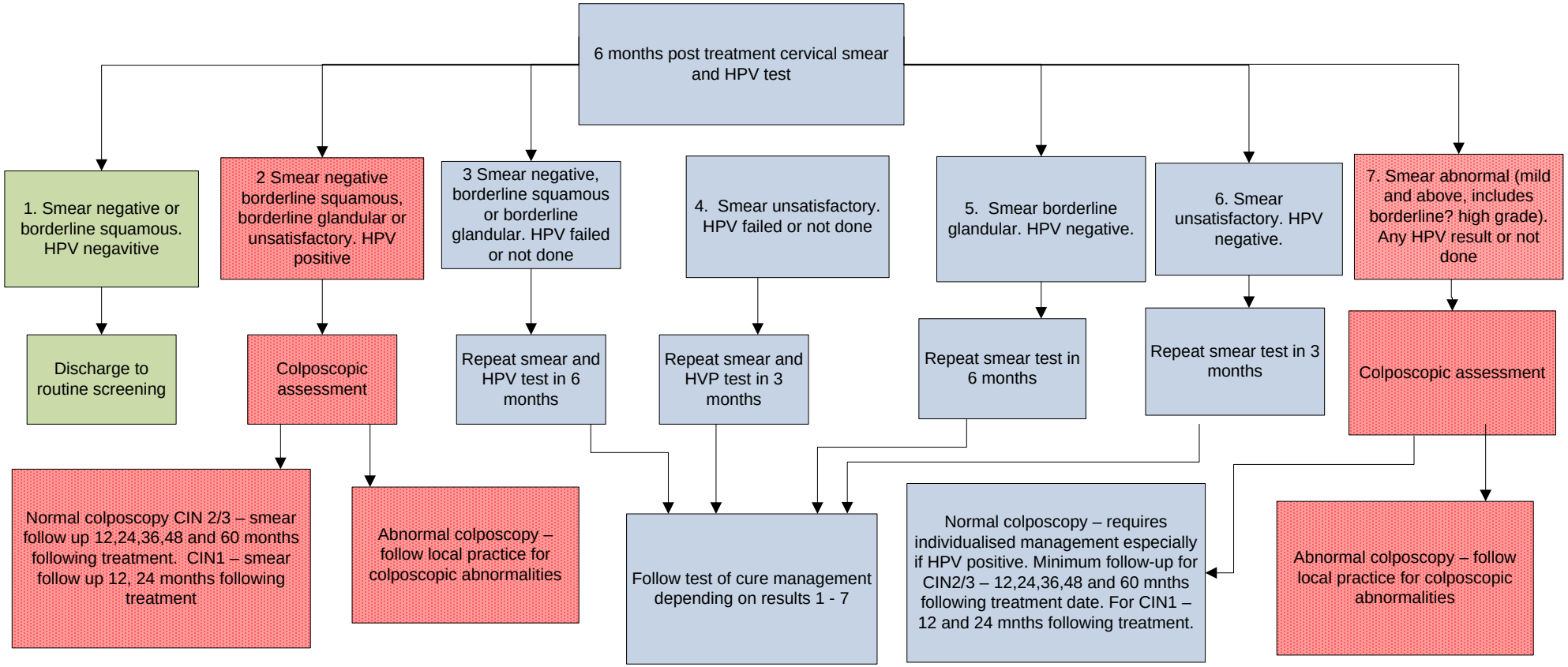
On routine recall No CIN/CGIN in hysterectomy	No further recall
On non-routine recall No CIN/CGIN in hysterectomy	No further recall
CIN/CGIN in hysterectomy completely excised	Vault smears at 6 and 18 months. If negative, no further recall
Low grade CIN/CGIN in hysterectomy incompletely excised	Vault smears at 6, 12 and 24 months. If negative, no further recall
High grade CIN/CGIN in hysterectomy incompletely excised	Vault smears at 6 and 12 months, and then annual vault smears to 5 years. If negative, no further recall.

Management and follow up for cytology results: Post Total Hysterectomy after local test of cure implementation

On routine recall No CIN/CGIN in hysterectomy	No further recall
On non-routine recall No CIN/CGIN in hysterectomy	No further recall
CIN in hysterectomy	Vault smear and HPV Test at 6 months. If both negative, no further recall
CGIN in hysterectomy. Completely excised	Vault smears at 6 and 18 months. If negative, no further recall
Low grade CGIN in hysterectomy incompletely excised	Vault smears at 6, 12 and 24 months. If negative, no further recall
High grade CGIN in hysterectomy incompletely excised	Vault smears at 6 and 12 months, and then annual vault smears to 5 years. If negative, no further recall

CIN = cervical intraepithelial neoplasia
CGIN = cervical glandular intraepithelial neoplasia

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 2014)

Dr Emilia Crighton	Consultant in Public Health Medicine (Chair)
Dr Margaret Burgoyne	Head of Service, Pathology
Dr Kevin Burton	Consultant Gynaecologist
Mrs Lin Calderwood	HI&T Service Delivery Manager
Ms Claire Donaghy	Health Improvement Senior (Cancer)
Mr Chris Garbutt	Health Records Senior Supervisor
Mrs Fiona Gilchrist	Assistant Programme Manager, Screening Dept
Dr Tamsin Groom	Consultant in Sexual and Reproductive Health Medicine
Mrs Kathy Kenmuir	Primary Care Support Nurse Advisor (acting)
Dr Margaret Laing	Staff Grade in Cytology/Colposcopy
Mrs Annette Little	Information Analyst
Miss Denise Lyden	Project Officer
Mrs Michelle McLachlan	General Manager, Women's & Children's
Ms Jane McNiven	Practice Manager
Dr Alan Mitchell	Clinical Director Renfrewshire CHP
Mrs Eilidh O'Neill	Health Visitor, West Dunbartonshire CHP
Mrs Christine Paterson	Primary Care Support Nurse
Mr Graham Reid	Specialty Manager, Cytology
Mrs Elizabeth Rennie	Programme Manager, Screening Dept
Dr Saima Shah	Medical Officer in Addictions

SUMMARY

CHAPTER 2: BREAST SCREENING

This report represents interim screening round data from 1 April 2009 to 31 March 2014

- 143,419 women registered with a practice in NHS Greater Glasgow and Clyde area were invited to attend breast screening over three years.

- 96,214 (67.1%) women attended breast screening during the previous three years. This represents a decrease of 3% since 2006/09 when uptake was 70.1%. The minimum standard is 70%. There were 617 (0.4%) women who were diagnosed with breast cancer following screening.

- The uptake for the three year rounds 2004/07 to 2009/12 remained slightly above the minimum standard of 70% at 71%, compared to the Scottish average of 74%. In the three year round 2009/2012, uptake decreased to 69.8% in NHS Greater Glasgow and Clyde and in 2010/2013 decreased to a further 68.8%.

- In 2012, the number of new breast cancers registered in NHS Greater Glasgow and Clyde was 1,082 This gives a standardised incidence rate of 178.1 per 100,000 per population which is higher than that for Scotland (167.9).

- Simple lifestyle changes by exercising, maintaining a healthy weight and reducing alcohol intake can reduce the risk of breast cancer.

- In 2013, there were 200 deaths from breast cancer, giving a standardised rate of 32.3 per 100,000 population. This is slightly lower than that for Scotland (36.4).

- During 2009 to 2012, 4,145 breast cancers were detected. Of the eligible women, 1,182 (52.8%) were detected through the breast screening programme and 1,055 (47.2%) breast cancers were symptomatic presentations.

- Of the 4,145, 507 (12.2%) were potential interval cancers; 1,250 (30.2%) were screen detected and 2,388 (57.6%) were symptomatic.

- A telephone/text reminder service will be piloted to encourage women to attend their screening appointment.

CHAPTER 2: BREAST SCREENING

Background

Breast cancer is the most common cancer in women in Scotland. Incidence rates continue to rise with a 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 2011 to 31 March 2014.

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.

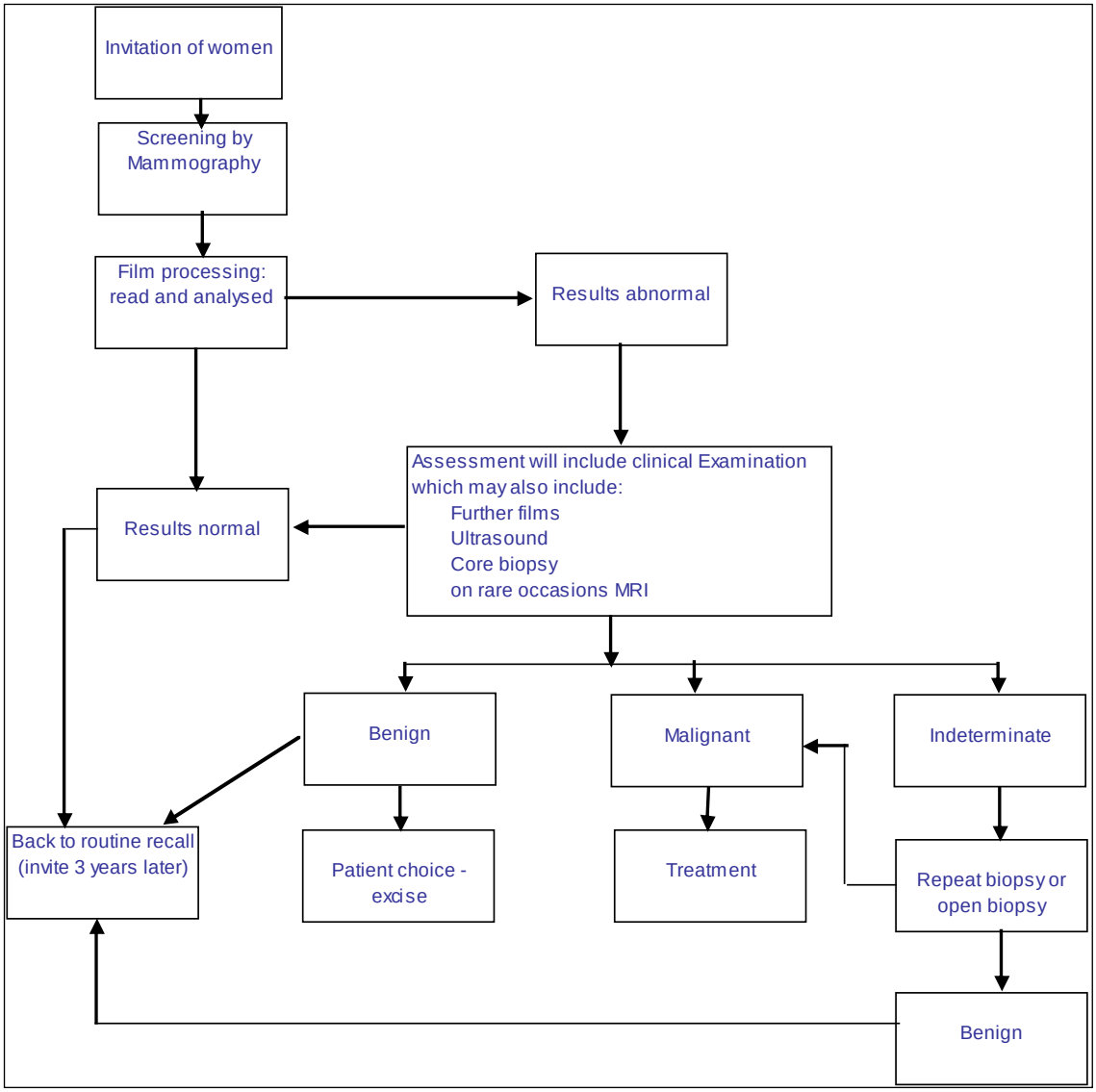
If a woman is found to have cancer, she is referred to a consultant surgeon to discuss the options available to her. This usually involves surgery: a lumpectomy where just the lump and a small amount of surrounding tissue is removed or a mastectomy where the whole breast is removed. Surgery is likely 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 1.2 illustrates the breast screening pathway.

Figure 2.1 Screening pathway



Delivery of NHSGGC Breast Screening Programme

During 2011/2014, there were 162,365 women resident across the area of Greater Glasgow and Clyde (**Table 2.1**).

Table 2.1 Total number of NHSGGC women residents split by age band and CH(C)P

CHP/CH(C)P	Total female population - 3 year round					Total Population per year[2]
	50-54	55-59	60-64	65-70	50-70	
East Dunbartonshire	4,596	4,145	3,633	4,168	16,542	5,514
East Renfrewshire	3,819	3,372	2,818	3,215	13,224	4,408
Glasgow North East	6,951	5,807	4,410	4,711	21,879	7,293
Glasgow North West	6,898	5,813	4,583	4,761	22,055	7,352
Glasgow South	8,621	7,474	5,595	5,746	27,436	9,145
Inverclyde	3,444	2,858	2,527	2,796	11,625	3,875
North Lanarkshire [1]	864	655	624	684	2,827	942
Renfrewshire	7,295	6,207	5,451	6,095	25,048	8,349
South Lanarkshire [1]	2,416	2,270	1,932	1,933	8,551	2,850
West Dunbartonshire	3,808	3,435	2,841	3,094	13,178	4,393
NHSGGC	**48,712**	**42,036**	**34,414**	**37,203**	**162,365**	**54,122**

Source: CHI - Extracted August 2014

Note:

[1] NHS Greater Glasgow and Clyde only

[2] Total female 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 area. 143,419 women registered with a practice in NHS Greater Glasgow and Clyde area were invited to attend breast screening over three years.

Table 2.2 NHSGGC Breast Screening Programme interim activity data for 2011-2014 by CH(C)P area

CHP/CH(C)P	Number invited[1]	Number attended[1]	Attended of those invited %	Number Cancers Detected[1]	Cancers of those Invited %	Cancers of those Attended %
East Dunbartonshire	9,178	6,969	75.9	50	0.5	0.7
East Renfrewshire	10,775	8,291	76.9	55	0.5	0.7
Glasgow North East	21,073	12,983	61.6	107	0.5	0.8
Glasgow North West	22,028	13,702	62.2	98	0.4	0.7
Glasgow South	25,877	15,994	61.8	109	0.4	0.7
Inverclyde	11,655	7,753	66.5	32	0.3	0.4
North Lanarkshire	2,540	1,794	70.6	18	0.7	1.0
Renfrewshire	20,258	14,946	73.8	56	0.3	0.4
South Lanarkshire	7,048	4,882	69.3	41	0.6	0.8
West Dunbartonshire	12,987	8,900	68.5	51	0.4	0.6
Total	**143,419**	**96,214**	**67.1**	**617**	**0.4**	**0.6**

[1] - Rolling Period - 1 April 2011 to 31st March 2014; Source: West of Scotland Breast Screening Data

Current Screening Round commencement dates:

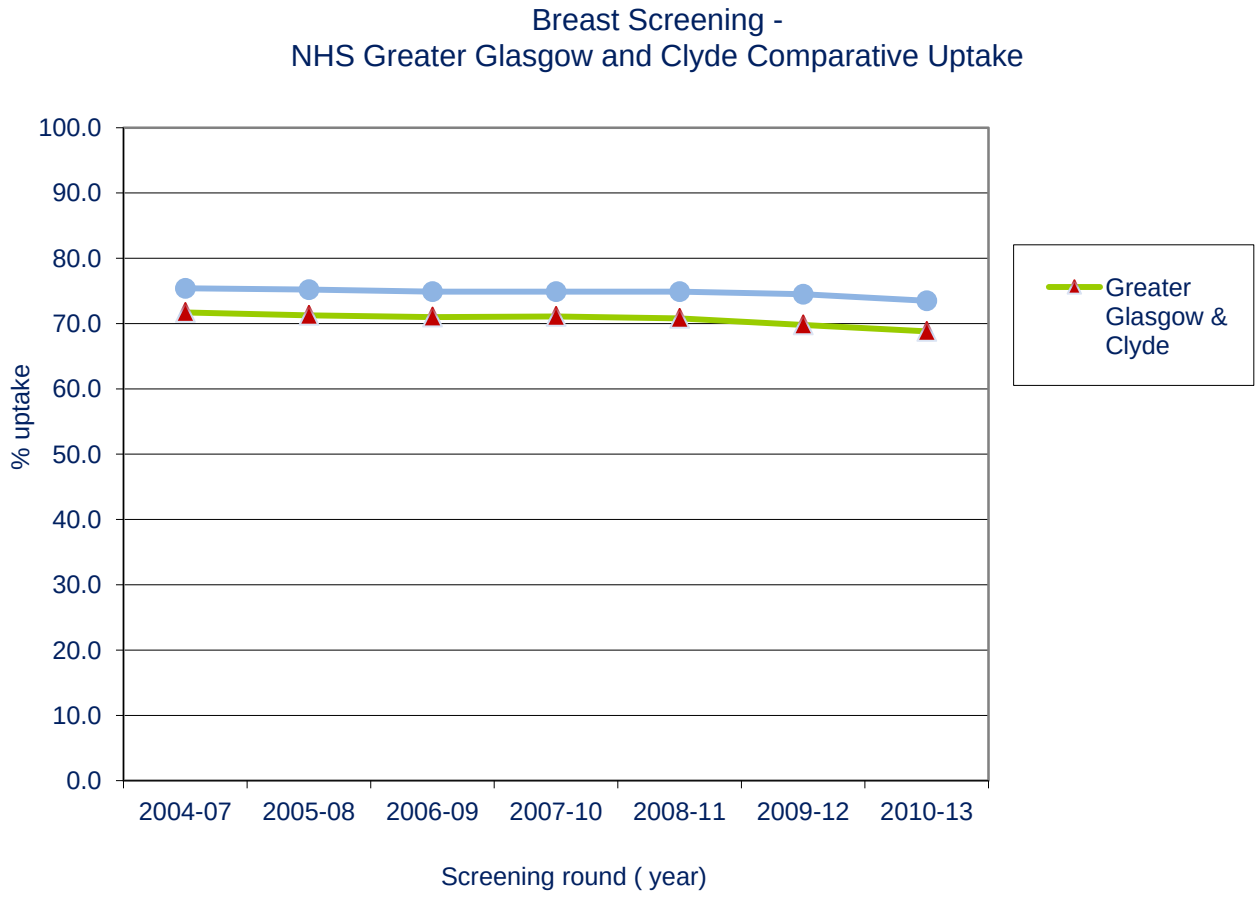
Greater Glasgow: Round commenced July 2013

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

96,214 (67.1%) women attended breast screening during the previous three years. This represents a decrease of 3% since 2006/09 when uptake was 70.1%. The minimum standard is 70%. There were 617 (0.4%) women who were diagnosed with breast cancer following screening.

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 2009/12 remained slightly above the minimum standard of 70% at 71%, compared to the Scottish average of 74%. In the three year round 2009/2012, uptake decreased to 69.8% in NHS Greater Glasgow and Clyde and in 2010/2013 decreased to a further 68.8%.

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



NHS Board	2004-07	2005-08	2006-09	2007-10	2008-11	2009-12	2010-13
Greater Glasgow & Clyde	71.7	71.3	71.0	71.1	70.8	69.8	68.8
Scotland	75.4	75.2	74.9	74.9	74.9	74.5	73.5

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.

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

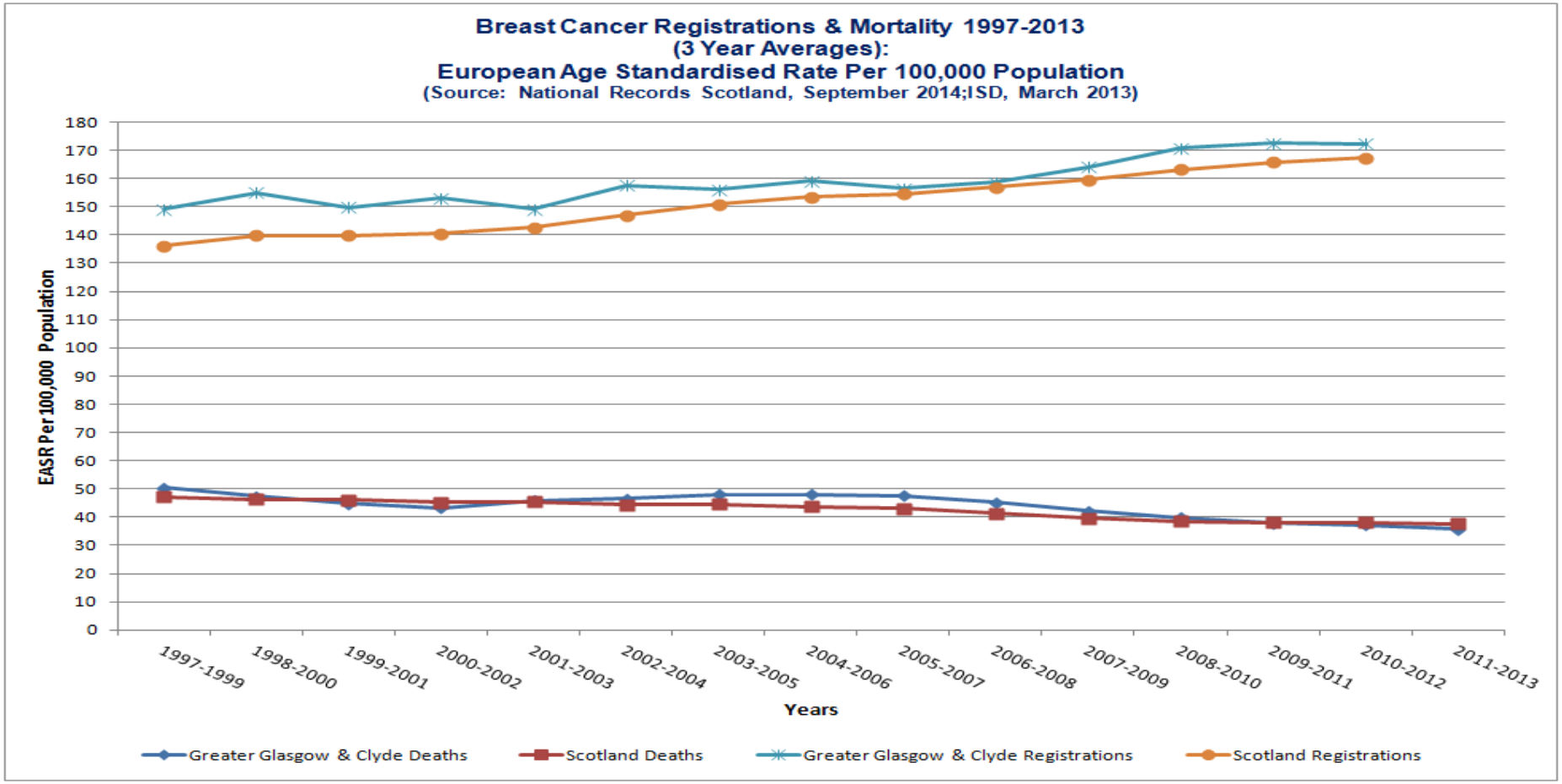
In 2012, the number of new breast cancers registered in NHS Greater Glasgow and Clyde was 1,082 (see Table 2.3). This gives a standardised incidence rate of 178.1 per 100,000 per population which is higher than that for Scotland (167.9).

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.

Table 2.3 shows that the number of deaths from breast cancer in NHS Greater Glasgow and Clyde and Scotland. In 2013, there were 200 deaths from breast cancer, giving a standardised rate of 32.3 per 100,000 population. This is slightly lower than that for Scotland (36.4).

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.

Figure 2.3 Breast Cancer Registrations and Morality rates 1997 – 2013



Source: Scottish Cancer Registry, ISD, 2014

Table 2.3: Breast cancer registrations and deaths across NHS Greater Glasgow and Clyde 1997 - 2013

Scotland

Registration

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Number	3,466	3,624	3,689	3,733	3,624	3,722	3,906	3,977	4,061	4,146	4,131	4,307	4,414	4,493	4,590	4595	
EASR	131.2	137.4	140.0	141.9	137.8	141.5	148.5	150.8	153.3	156.0	154.5	160.3	163.5	165.6	168.2	167.9	
- Lower 95% CI	*126.9*	*132.9*	*135.5*	*137.4*	*133.3*	*137.0*	*143.9*	*146.1*	*148.6*	*151.3*	*149.8*	*155.5*	*158.7*	*160.7*	*163.3*	163.1	
- Upper 95% CI	*135.7*	*141.9*	*144.6*	*146.5*	*142.3*	*146.1*	*153.2*	*155.5*	*158.1*	*160.8*	*159.3*	*165.1*	*168.4*	*170.5*	*173.1*	172.8	

Deaths

Number	1,154	1,142	1,129	1,116	1,143	1,105	1,138	1,082	1,144	1,108	1,062	1,043	1,002	1,022	1,036	1,063	1,013
EASR	48.0	47.3	46.5	45.4	46.2	44.5	45.7	43.0	44.9	43.4	40.9	39.8	38.2	37.9	38.0	38.6	36.4
- Lower 95% CI	*45.3*	*44.6*	*43.9*	*42.8*	*43.5*	*41.9*	*43.1*	*40.4*	*42.4*	*40.8*	*38.5*	*37.4*	*35.8*	*35.6*	*35.7*	*36.3*	*34.2*
- Upper 95% CI	*50.9*	*50.1*	*49.3*	*48.1*	*48.9*	*47.1*	*48.4*	*45.6*	*47.6*	*46.0*	*43.5*	*42.2*	*40.6*	*40.3*	*40.4*	*40.9*	*38.6*

Greater Glasgow & Clyde

Registration

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Number	841	875	843	942	788	900	883	934	878	941	896	936	1048	1032	980	1082	
EASR	147.7	152.5	147.4	165.1	137.0	157.2	153.3	162.1	152.8	162.2	154.3	159.5	178.3	174.4	164.5	178.1	
- Lower 95% CI	*137.9*	*142.5*	*137.5*	*154.6*	*127.6*	*147.0*	*143.3*	*151.8*	*142.8*	*151.9*	*144.3*	*149.4*	*167.6*	*163.9*	*154.4*	167.6	
- Upper 95% CI	*157.9*	*162.8*	*157.5*	*175.8*	*146.8*	*167.7*	*163.7*	*172.7*	*163.1*	*172.8*	*164.6*	*170.0*	*189.4*	*185.3*	*175.1*	188.9	

Deaths

Year	**1997**	**1998**	**1999**	**2000**	**2001**	**2002**	**2003**	**2004**	**2005**	**2006**	**2007**	**2008**	**2009**	**2010**	**2011**	**2012**	**2013**
Number	288	297	279	240	252	258	284	266	284	285	259	247	237	220	219	237	200
EASR	50.6	51.9	48.7	41.8	43.9	44.5	49.4	45.8	48.9	49.2	44.5	41.9	40.5	37.0	35.9	39.0	32.3
- Lower 95% CI	*44.9*	*46.2*	*43.1*	*36.7*	*38.6*	*39.2*	*43.8*	*40.4*	*43.4*	*43.6*	*39.2*	*36.8*	*35.5*	*32.2*	*31.3*	*34.2*	28.0
- Upper 95% CI	*56.7*	*58.0*	*54.6*	*47.3*	*49.5*	*50.1*	*55.3*	*51.5*	*54.8*	*55.1*	*50.1*	*47.4*	*45.9*	*42.1*	*40.9*	*44.2*	37.0

Breast Cancer (ICD10 C50, D05)

Deaths EASR: age-standardised incidence rate per 100,000 person-years at risk (European standard population) Source: National Records of Scotland (NRS) Data extracted: November 2014

Regist 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. Of the eligible women, 1,182 (52.8%) were detected through the breast screening programme and 1,055 (47.2%) breast cancers were symptomatic presentations (**Table 2.4**)

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

Detection Mode	Under Eligible Age		Eligible Age		Over Eligible Age		Total	
	N	%	N	%	N	%	N	%
Screen Detected	0	0.0	1,182	52.8	60	5.2	**1,242**	30.0
Symptomatic	757	100.0	1,055	47.2	1,091	94.8	**2,903**	70.0
Total	**757**		**2,237**		**1,151**		**4,145**	

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

Table 2.5 shows the numbers and percentages of breast cancers diagnosed by mode of detection from 2009 to 2012. Of the 4,145 breast cancers, 507 (12.2%) were potential interval cancers; 1,250 (30.2%) were screen detected and 2,388 (57.6%) were symptomatic. **Table 2.4** also shows a year on year increase in the number of cancers detected since 2009 to 2012.

Table 2.5 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**	**%**
Interval (symptompatic)	122	12.2	120	11.7	133	13.1	132	11.9	507	12.2%
Routine, Centre invitation	262	26.3	282	27.5	297	29.1	336	30.4	1,177	28.4%
Self Referrals - Over Elligible Age	13	1.3	10	1.0	17	1.7	10	0.9	50	1.2%
Self Referrals -Within Elligible Age	>5	0.5	10	1.0	>5	0.5	>3	0.3	23	0.6%
Symptomatic	595	59.7	602	58.8	567	55.6	624	56.5	2,388	57.6%
All Cancers	**997**		**1,024**		**1,019**		**1,105**		**4,145**	

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

Table 2.6 shows the stage at diagnosis for screen detected, interval and other symptomatic cancers. There is a higher proportion of stage 0 among screen detected cancer.

Table 2.6 Breast cancer diagnoses by stage and by mode of detection for period 2009 – 2012

	Screen Detected						Symptomatic					
Stage	**Routine, Centre invitation**		**Self Referrals - Over Eligible**		**Self Referrals - Within Eligible**		**Interval**		**Other Symptomatic**		**Total**	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Stage 0	193	16.5	11	22.0	<10	17.4	32	6.4	137	5.7	**377**	9.1
Stage A	448	38.3	20	40.0	<10	26.1	178	35.7	618	25.7	**1,270**	30.6
Stage IB/IIA	159	13.6	<10	14.0	<10	8.7	143	28.7	715	29.7	**1,026**	24.8
Stage IIIA	<10	0.3	0	0.0	0	0.0	23	4.6	75	3.1	**102**	2.5
Stage IIB	43	3.7	<10	6.0	<10	13.0	47	9.4	260	10.8	**356**	8.6
Stage IIIB	0	0.0	0	0.0	0	0.0	<10	1.2	86	3.6	**92**	2.2
Stage IIIC	<10	0.1	0	0.0	0	0.0	<10	0.6	<10	0.2	**10**	0.2
Stage IV	<10	0.7	0	0.0	0	0.0	26	5.2	210	8.7	**244**	5.9
Unassigned-Missing	192	16.4	<10	14.0	<10	34.8	32	6.4	235	9.8	**474**	11.4
Unassigned-T0N0M0	121	10.4	<10	4.0	0	0.0	<10	1.6	63	2.6	**194**	4.7
Total	**1,169**		**50**		**23**		**498**		**2,405**		**4,145**	

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

Records of 132 women with breast cancer diagnosed cancers in 2012 were planned to be reviewed. Records and images of 74 women were carried out. The review classification was carried out by three readers. The majority decision prevailed and, where there was lack of consensus amongst the three readers, an independent reader would lead a consensus discussion as to the classification. **Table 2.7** shows the final classifications to date. Ten out of the 74 images were identified to be false negative results while 48 of the 74 were true interval cancers.

Table 2.7 Interval cancers for 2012

Classification	**Number**
NI	7
TI	48
FN	10
MO	7
UNC	2
Total	**74**
Outstanding to be classified	**58**

Key	
NI	Not Interval
TI	True Interval
FN	False Negative
MO	Mammographically Occult
UNC	Unclassifiable

Outstanding classifications for 2012 will be submitted in November 2014; with classifications of calendar years 2009, 2010 and 2011 to follow.

Review of the literature confirms that thresholds for identifying possible abnormalities are much lower than 'real life' because of the nature of a retrospective review. All cases classified as false negative are reviewed by all staff to identify any learning pointers. Having established a manual method to identify and classify the cases, the remaining calendar years will be audited.

The interim audit protocol can be found 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 took part in the two year tomography trial. This trial has now completed and publication of results is awaited.

Health Improvement

A range of health improvement activities took place across NHS Greater Glasgow and Clyde. These included:

- targeting women in deprived areas in supermarkets, bingo halls and other community venues including Housing Associations.

- Working in partnership with Breast Cancer Care to train health improvement staff and local volunteers to deliver workshops to groups of people on being breast aware and encouraging attendance at breast screening appointments. This led on to a number of awareness sessions and talks being held for priority groups across NHSGGC, including an awareness stall targeted at BME communities at International Women's Day.

- A number of breast awareness sessions were delivered by Renfrewshire CHP in 2013, with over 500 brief interventions taking place with women from vulnerable groups including addictions services and disability resource centre.

- Supporting the national social marketing Detect Cancer Early breast awareness campaign distributing and displaying campaign materials at local community, NHS and local authority venues.

- Healthy Working Lives events were used to publicise breast cancer and screening messages (one event had an attendance of 120). The key messages were also promoted via staff news publications and staff emails.

Next step is to capitalise on the second phase of the national Detect Cancer Early social marketing campaign in summer/autumn 2014. This will involve:

- 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;

- engaging with women who previously did not take up breast screening by telephone to encourage them to attend their appointment.

- issuing text reminders to women new to the programme to reduce non attendance rates.

Challenges and Future Priorities

- Implementation of digital mammography.
- Implementation of audit of interval cancers.
- Implementation of 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 PROTOCOL

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

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

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.

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.

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

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

Audit Meeting

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

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

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 Screening Co-ordinator
Dr Hilary Dobson	Clinical Lead, West of Scotland Breast Cancer Centre
Dr Catriona Pagliari	Consultant Radiologist, WOSBS
Donna Wilson	Administration Manager, WOSBS
Marion Martin	Office 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 March 2014)

Dr Emilia Crighton	Consultant in Public Health Medicine (Chair)
Mrs Lin Calderwood	H&IT Service Delivery Manager
Ms Claire Donaghy	Health Improvement Senior
Dr Hilary Dobson	Clinical Director, Renfreshire CHP
Mrs Fiona Gilchrist	Assistant Programmes Manager, Screening Dept
Mrs Annette Little	Information Analyst
Miss Denise Lyden	Project Officer
Ms Janet Mair	Regional Registration 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
Miss Donna Wilson	Administration Manager

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. This chapter presents the full two year screening round 2012 - 2014.

- 381,529 residents in NHS Greater Glasgow and Clyde were invited to participate in the Bowel Screening programme

- 196,322 screening kits were completed and returned to the Bowel Screening laboratory for analysis. This gives an estimated uptake of 51.5%, representing an increase of 1.9% compared to data reported in 2012/2013 when uptake was 49.7%.

- The increase in uptake was due to the efforts of the national Detect Cancer Early Bowel Screening social marketing campaign.

- Overall, the lowest uptake was among residents living in the most deprived areas at 42.6%.

- The lowest uptake for bowel screening was among residents living in the most deprived areas in the Glasgow CHP sector North East (41.2%). Highest uptake was among residents living in the more affluent areas of West Dunbartonshire and East Dunbartonshire (64.3%).

- The percentage uptake among females at 53.9% was higher than the male population at 48.9%. The lowest uptake of 40% was among the 50-54 year old male population group.

- Of the 4,958 patients screened positive, 4,478 patients were pre-assessed prior to colonoscopy. 264 patients declined and 216 patients did not respond to the offer of a colonoscopy pre-assessment.

- The overall positivity rate was higher among men at 3.1% compared to women at 2.0% which is comparable to Scottish national average (ISD, 2013). Compared to all other groups, the male population aged 70 to 74 had the highest positivity rate of 4.3%.

- 4,459 (86.4%) patients completed colonoscopy investigations by 31 March 2014.

- 2,122 people with learning disability that were invited to take part in the bowel screening programme, 30.3% (642) completed the bowel screening test. 22 patients received positive results representing a positivity rate of 3.4%. No cancer was diagnosed following investigation.

- Of the total eligible population invited to take part in bowel screening, 198 cancers were detected.

- In 2012, the most recent year for which completed data is available, the number of new colorectal cancers registered in NHS Greater Glasgow and Clyde was 438 for men and 422 for females. This gives a standardised incidence rate of 98.4 and 71.0 respectively per 100,000 populations and is higher than that for Scotland at 97.8 and 64.0 respectively

- In 2013, the number of deaths from colorectal cancer in NHS Greater Glasgow and Clyde was 203 for male population and 176 in the female population. This gives a standardised rate of 48.5 and 28.7 respectively per 100,000 populations which is higher than the Scotland rates of 42.3 and 25.2 respectively.

- Of the 4,192 colorectal cancers diagnosed from 2009 to 2013, 3,060 were symptomatic and 757 were detected through the bowel screening programme. 375 were interval cancers giving a rate of 89.5 per 1,000 colorectal cancers.

- In 2014, Glasgow was chosen as the launch venue for the National Detect Cancer Early Bowel Screening social marketing campaign. The campaign targeted men living in deprived areas and involved television, radio and newspaper advertising, roadshow events, poster and leaflet campaigns.

- Funding has been identified to implement two health improvement projects:

  Telephone engagement project that will contact people new to the bowel screening programme to complete the kit and gain an understanding of the reasons people don't complete their kits in order to inform future work.

  A three year joint partnership between Cancer Research UK and NHSGGC to improve the prevention and earlier diagnosis of cancer. Primary care engagement facilitators will actively support practices to raise the profile of cancer, identify activities to improve uptake of bowel screening and cancer outcomes more generally and make change happen at a local level.

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, 2014*).* Every year in Scotland over 3,400 people are diagnosed with the disease. In NHS Greater Glasgow and Clyde, 860 people were diagnosed with bowel cancer in 2012 (Table 3.6). 95% of bowel cancers detected are among people aged over 50.

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

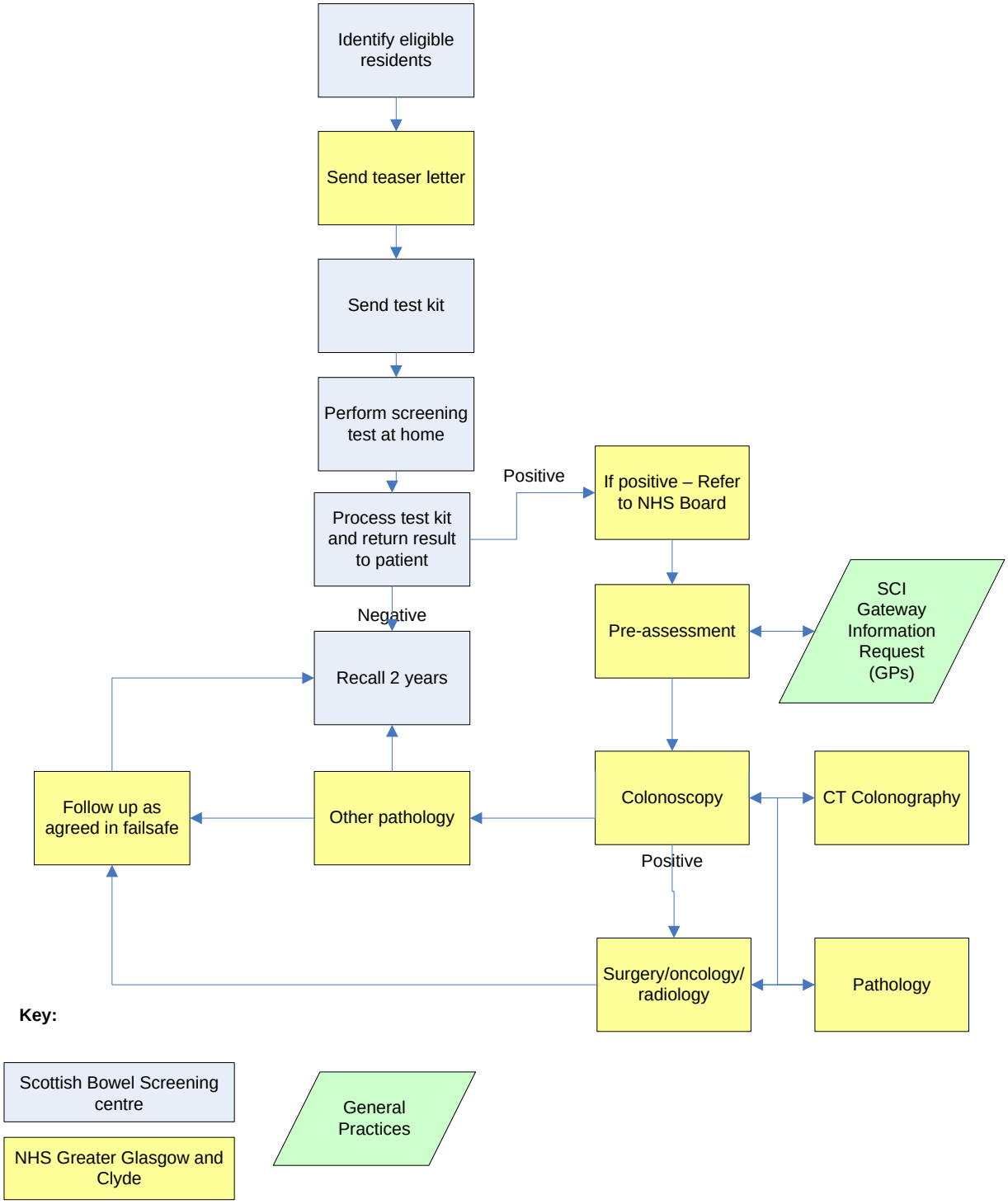
Eligible NHS Greater Glasgow and Clyde residents that are due to be invited to take part in the bowel screening programme are sent a “teaser” letter before they are sent an invitation letter and screening kit. The letter explains the programme and encourages participants to take the test.
The National 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 2012 to 31 March 2014, 381,529 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, 128,436 (33.6%) 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		
CHP/CH(C)P	**1**	**2**	**3**	**4**	**5**	**Unassigned[2]**	**Total**
East Dunbartonshire	1,099	5,610	2,896	7,181	21,811	32	38,629
East Renfrewshire	1,872	2,644	2,098	5,075	18,816	11	30,516
Glasgow North East	33,912	6,930	4,157	5,923	1,360	100	52,382
Glasgow North West	22,992	7,736	6,511	5,288	9,680	43	52,250
Glasgow South	27,002	15,283	8,363	8,269	5,311	89	64,317
Inverclyde	11,113	3,850	4,027	5,307	3,709	28	28,034
North Lanarkshire[1]	831	954	2,014	2,049	356	12	6,216
Renfrewshire	13,832	8,667	12,259	8,860	14,484	42	58,144
South Lanarkshire[1]	6,841	2,976	3,093	3,581	3,111	7	19,609
Stirling(GGC pt) [1]				6			6
West Dunbartonshire	8,941	9,600	6,940	3,782	1,786	19	31,068
Unassigned[2]						357	357
Total NHS GGC[3]	**128,436**	**64,250**	**52,358**	**55,321**	**80,424**	**740**	**381,529**

Source: Bowel Screening IT system (Data extracted May 2014)

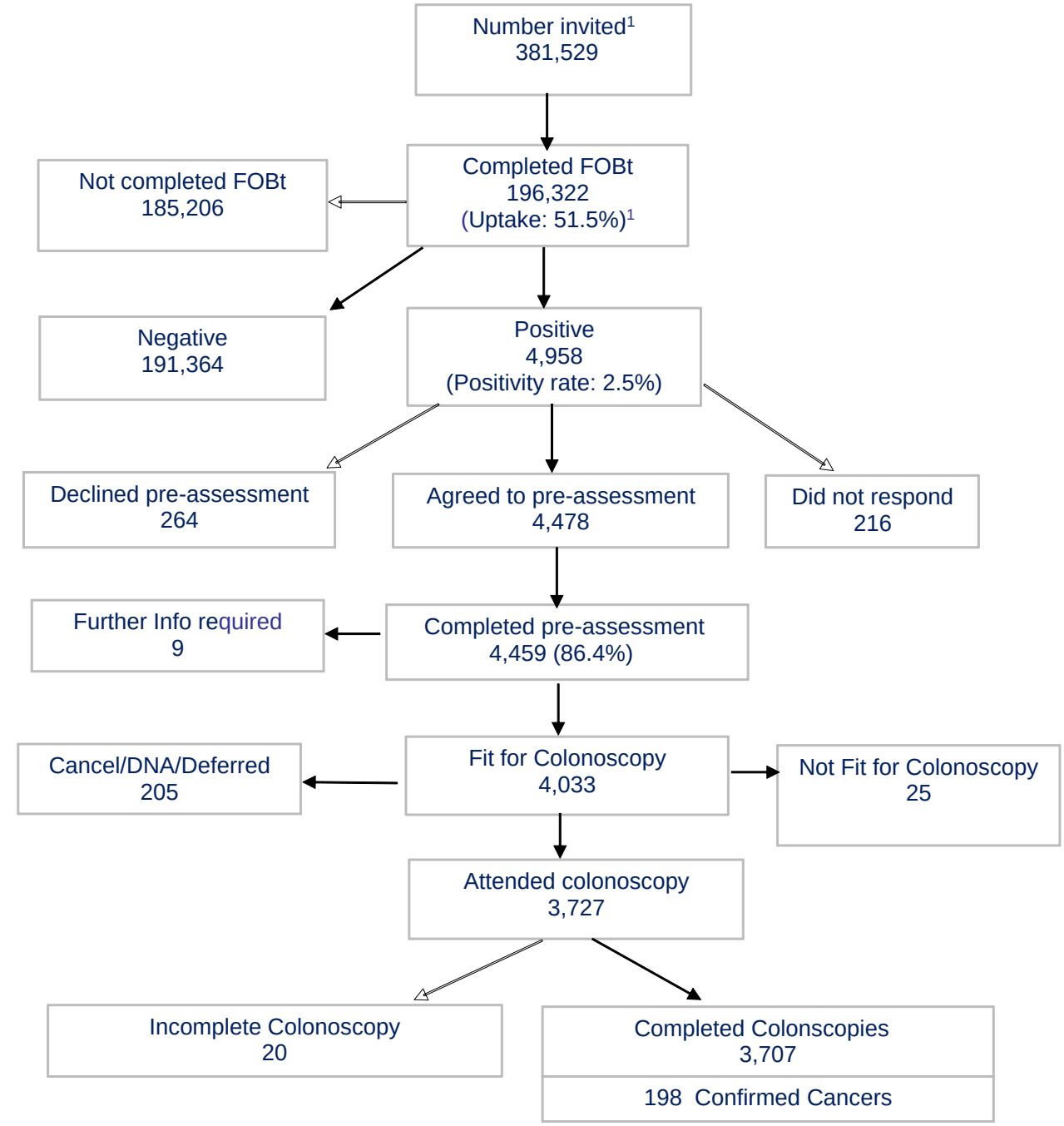
Notes:

1 NHSGGC residents only

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

Figure 3.2 illustrates the bowel screening activity. 196,322 screening kits were completed and returned to the Bowel Screening laboratory for analysis. This gives an estimated uptake of 51.5%, representing an increase of 1.9% compared to data reported in 2012/2013 when uptake was 49.7%. The increase was due to the efforts of the national Detect Cancer Early Bowel Screening social marketing campaign.

Figure 3.2 NHSGGC Bowel Screening activity 1 April 2012 to 31 March 2014



Source: NHS Greater Glasgow and Clyde Bowel Screening IT System (Extracted: May 2014)

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 2012 - 31st March 2014 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 residents living in the most deprived areas at 42.6%.

The lowest uptake for bowel screening was among residents living in the most deprived areas in the Glasgow CHP sector North East (41.2%). Highest uptake was among residents living in the more affluent areas of West Dunbartonshire and East Dunbartonshire (64.3%).

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

	Most Deprived		SIMD		Least Deprived	
CHP/CH(C)P	**1**	**2**	**3**	**4**	**5**	**Total**
East Dunbartonshire	43.9	50.2	56.8	61.8	64.3	60.6
East Renfrewshire	41.9	50.0	55.2	58.3	63.3	59.4
Glasgow North East	41.2	46.3	52.2	57.3	57.7	45.0
Glasgow North West	42.1	47.1	45.3	52.5	57.6	47.2
Glasgow South	41.6	45.5	49.5	55.1	59.2	46.7
Inverclyde	45.8	51.5	55.6	58.5	61.8	52.5
North Lanarkshire[1]	50.3	54.7	55.0	58.1	59.8	55.6
Renfrewshire	42.9	50.4	54.9	61.1	63.5	54.5
South Lanarkshire[1]	46.4	50.5	54.9	59.4	62.4	53.3
West Dunbartonshire	44.3	50.7	55.9	59.1	64.3	51.8
Unassigned[2]						30.3
Total NHSGGC	42.6	48.5	52.9	58.2	62.4	51.5

Source: Bowel Screening IT system (Data extracted May 2014)

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 53.9% was higher than the male population at 48.9%. The lowest uptake of 40% was among males aged 50-54 year olds.

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

	Uptake			Positvity		
Age Group	**Female**	**Male**	**Total**	**Female**	**Male**	**Total**
50-54	46.3	40.0	43.1	1.5	2.0	1.7
55-59	52.5	46.8	49.6	1.6	2.8	2.2
60-64	58.6	53.2	55.9	2.1	3.1	2.6
65-69	61.1	57.2	59.3	2.3	3.7	3.0
70-74	57.2	55.6	56.5	2.9	4.3	3.5
75+	51.7	52.9	52.2	3.1	4.2	3.6
Total	**53.9**	**48.9**	**51.5**	**2.0**	**3.1**	**2.5**

Source: Bowel Screening IT system (Data extracted May 2014)

The overall positivity rate was higher among men at 3.1% compared to women at 2.0% which is comparable to Scottish national average (ISD, 2013). Compared to all other groups, males aged 70 to 74 had the highest positivity rate of 4.3% (**Table 3.3**). There is a gradient in the positivity rate across deprivation categories. The positivity rate for residents living in the most deprived areas was 3.6% compared to 1.6% 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	
CHP/CH(C)P	**1**	**2**	**3**	**4**	**5**	**Total**
East Dunbartonshire	4.4	2.3	2.9	1.9	1.4	1.8
East Renfrewshire	4.6	3.0	1.9	1.8	1.7	1.9
Glasgow North East	4.0	2.9	2.5	2.3	1.8	3.4
Glasgow North West	3.7	3.8	2.2	1.7	1.7	2.8
Glasgow South	3.5	2.8	2.4	2.1	1.2	2.7
Inverclyde	3.4	2.9	2.1	1.7	1.5	2.5
North Lanarkshire[1]	4.1	2.3	1.9	2.1	3.3	2.4
Renfrewshire	3.4	3.0	2.0	1.9	1.6	2.3
South Lanarkshire[1]	3.4	3.3	2.7	2.0	2.0	2.7
West Dunbartonshire	3.1	2.6	2.6	1.7	1.6	2.5
Unassigned[2]						3.7
Total NHSGGC	3.6	2.9	2.3	1.9	1.6	2.5

Source: Bowel Screening IT system (Data extracted May 2014)

Notes:

1 NHSGGC residents only

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

Of the 4,958 patients screened positive, 4,478 patients were pre-assessed prior to colonoscopy. 264 patients declined and 216 patients did not respond to the offer of a colonoscopy pre-assessment (**Figure 3.2**).

4,459 (86.4%) patients completed colonoscopy investigations by 31 March 2014. 205 patients cancelled or did not turn up for their colonoscopy appointment. 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, 198 cancers were detected (**Figure 3.2**).

Of the 2,122 people with learning disability that were invited to take part in the bowel screening programme, 30.3% (642) completed the bowel screening test (**Table 3.5**). 22 patients received positive results representing a positivity rate of 3.4%. No cancer was diagnosed following investigations.

Table 3.5 NHSGGC Bowel Screening activity among people with learning disability

Activity	Female	Male	Total
Invited to participate	956	1,166	2,122
Completed Kits	312	330	642
Positive Result	9	13	22
Uptake (%)	32.6	28.3	30.3
Positivity Rate (%)	2.9	3.9	3.4

Source: Bowel Screening IT system (Data extracted May2014)/Learning Disability LES (November 2013)

Morbidity and mortality from colorectal cancer

In 2012, the most recent year for which completed data is available, the number of new colorectal cancers registered in NHS Greater Glasgow and Clyde was 438 for men and 422 for females (**see Table 3.6**). This gives a standardised incidence rate of 98.4 and 71.0 respectively per 100,000 populations and is higher than that for Scotland at 97.8 and 64.0 respectively (**see Tables 3.6 and 3.7**).

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 2013, the number of deaths from colorectal cancer in NHS Greater Glasgow and Clyde was 203 for male population and 176 in the female population (**see Table 3.6**). This gives a standardised rate of 48.5 and 28.7 respectively per 100,000 populations which is higher than the Scotland rates of 42.3 and 25.2 respectively (**see Tables 3.6 and 3.7**). **Figure 3.3** shows that the rate of deaths has remained consistent since 2004/06.

Table 3.6 Colorectal cancer incidence rate for 1997 - 2012 and mortality rates for 1997 to 2013 for NHS Greater Glasgow and Clyde

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Greater Glasgow & Clyde																	
MALES																	
Deaths																	
Number	219	194	175	197	184	203	183	213	172	182	186	203	183	159	179	165	203
EASR per 100,000 pop	60.8	51.3	50.1	55.8	48.2	54.4	49.9	56.5	46.7	49.3	47.57	52.24	46.27	39.2	44.36	41.8	48.5
Lower 95% Confidence Interval	*52.3*	*43.9*	*42.3*	*47.8*	*41.1*	*46.6*	*42.4*	*48.7*	*39.5*	*41.9*	*40.5*	*44.63*	*39.39*	*33.1*	*37.83*	*35.3*	41.8
Upper 95% Confidence Interval	*69.9*	*59.3*	*58.6*	*64.5*	*55.9*	*62.9*	*58.1*	*64.8*	*54.5*	*57.4*	*55.2*	*60.44*	*53.7*	*45.9*	*51.41*	*48.8*	55.6
Registrations																	
Number	428	406	387	412	415	428	436	406	410	425	428	421	478	451	523	438	
EASR per 100,000 pop	111.1	107.1	102.8	107.8	105.2	108.4	114.4	109.3	106.2	104.1	106.5	103.1	113.5	104.9	120.3	98.4	
Lower 95% Confidence Interval	*100.1*	*96.2*	*92.1*	*97.2*	*94.7*	*97.9*	*103.1*	*98.1*	*95.5*	*94.0*	*96.2*	*92.9*	*103.1*	*95.1*	*109.8*	89.1	
Upper 95% Confidence Interval	*122.7*	*118.6*	*114.1*	*119.0*	*116.3*	*119.4*	*126.2*	*121.0*	*117.5*	*114.7*	*117.4*	*113.7*	*124.4*	*115.1*	*131.2*	108.1	
FEMALES																	
Deaths																	
Number	185	181	177	192	204	156	166	165	156	168	165	178	175	177	127	191	176
EASR per 100,000 pop	31.6	31.1	30.4	33.0	34.6	26.2	28.7	28.4	26.7	29.2	28.2	30.6	29.8	29.5	20.9	31.9	28.7
Lower 95% Confidence Interval	*27.2*	*26.7*	*26.1*	*28.5*	*30.0*	*22.3*	*24.5*	*24.2*	*22.6*	*24.9*	*24.1*	*26.2*	*25.5*	*25.3*	*17.4*	*27.5*	24.6
Upper 95% Confidence Interval	*36.4*	*35.8*	*35.1*	*37.9*	*39.5*	*30.5*	*33.3*	*32.9*	*31.0*	*33.8*	*32.7*	*35.3*	*34.4*	*34.1*	*24.7*	*36.6*	33.2
Registrations																	
Number	367	346	386	365	414	361	344	351	362	391	357	419	409	409	404	422	
EASR per 100,000 pop	62.0	59.1	66.2	63.2	71.1	62.1	59.3	60.4	62.4	67.3	61.3	71.6	69.7	70.0	67.7	71.0	
Lower 95% Confidence Interval	*55.8*	*53.0*	*59.7*	*56.8*	*64.4*	*55.8*	*53.1*	*54.2*	*56.1*	*60.8*	*55.1*	*64.8*	*63.1*	*63.3*	*61.2*	64.4	
Upper 95% Confidence Interval	*68.6*	*65.5*	*73.0*	*69.8*	*78.1*	*68.7*	*65.7*	*66.9*	*69.0*	*74.2*	*67.9*	*78.6*	*76.7*	*77.0*	*74.5*	78.0	

Notes:
Colorectal Cancer (ICD10: C18-C20)
Mortality Source: National Records of Scotland (NRS). Date extracted November 2014 Registrations Source: Scottish Cancer Registry, ISD. Date extracted: March 2014

Table 3.7 Colorectal cancer incidence rates for 1997 to 2012 and mortality rates for 1997 to 2013 for Scotland

Scotland

		1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
MALES																		
	Deaths																	
	Number	889	848	870	839	835	842	830	844	855	835	812	829	825	782	824	837	871
	EASR per 100,000 pop	56.3	52.9	55.4	52.2	51.0	51.2	49.4	50.4	49.1	47.2	45.2	45.2	44.0	41.1	42.1	42.5	42.3
	Lower 95% Confidence Interval	*52.4*	*49.2*	*51.5*	*48.5*	*47.4*	*47.5*	*45.9*	*46.8*	*45.6*	*43.8*	*42.0*	*42.0*	*40.9*	*38.1*	*39.1*	*39.5*	39.5
	Upper 95% Confidence Interval	*60.3*	*56.8*	*59.4*	*56.0*	*54.8*	*55.1*	*53.1*	*54.2*	*52.7*	*50.6*	*48.6*	*48.6*	*47.3*	*44.2*	*45.1*	*45.5*	45.3
	Registrations																	
	Number	1803	1785	1819	1884	1847	1817	1902	1909	1894	1889	2016	2138	2165	2217	2252	2100	
	EASR per 100,000 pop	108.2	105.8	108.3	108.0	106.1	102.2	107.9	105.8	102.1	100.4	105.2	108.1	107.6	106.9	107.1	97.8	
	Lower 95% Confidence Interval	*103.0*	*100.6*	*103.1*	*102.9*	*101.0*	*97.3*	*102.8*	*100.8*	*97.4*	*95.7*	*100.4*	*103.4*	*102.9*	*102.3*	*102.6*	93.6	
	Upper 95% Confidence Interval	*113.6*	*111.1*	*113.6*	*113.1*	*111.3*	*107.3*	*113.2*	*110.9*	*107.0*	*105.2*	*110.0*	*112.9*	*112.4*	*111.5*	*111.7*	102.2	
FEMALES																		
	Deaths																	
	Number	781	791	792	757	780	713	752	706	695	715	727	736	730	719	702	784	707
	EASR per 100,000 pop	32.1	32.3	32.3	30.5	31.2	28.5	30.1	28.0	27.1	27.7	28.0	28.2	27.5	26.6	25.6	28.3	25.2
	Lower 95% Confidence Interval	*29.9*	*30.1*	*30.1*	*28.4*	*29.0*	*26.4*	*27.9*	*25.9*	*25.1*	*25.7*	*26.0*	*26.2*	*25.5*	*24.7*	*23.8*	*26.3*	23.3
	Upper 95% Confidence Interval	*34.4*	*34.6*	*34.6*	*32.7*	*33.4*	*30.6*	*32.3*	*30.1*	*29.2*	*29.8*	*30.1*	*30.3*	*29.5*	*28.6*	*27.6*	*30.3*	27.1
	Registrations																	
	Number	1,609	1,532	1,626	1,687	1,688	1,601	1,553	1,613	1,595	1632	1708	1772	1807	1822	1774	1749	
	EASR per 100,000 pop	66.1	62.9	66.5	68.7	68.2	64.5	62.0	63.9	62.8	63.7	66.0	67.8	68.4	68.4	65.6	64.0	
	Lower 95% Confidence Interval	*62.9*	*59.8*	*63.3*	*65.5*	*65.0*	*61.4*	*58.9*	*60.8*	*59.8*	*60.6*	*62.9*	*64.6*	*65.2*	*65.3*	*62.6*	61.1	
	Upper 95% Confidence Interval	*69.4*	*66.1*	*69.8*	*72.1*	*71.5*	*67.7*	*65.1*	*67.0*	*66.0*	*66.8*	*69.1*	*71.0*	*71.6*	*71.6*	*68.8*	67.1	

Notes:
Colorectal Cancer (ICD10: C18-C20)
Mortality Source: National Records of Scotland (NRS). Date extracted November 2014 Registrations Source: Scottish Cancer Registry, ISD. Date extracted: March 2014

Figure 3.3 Colorectal cancer incidence and mortality rates for 1997 to 2013 for NHS Greater Glasgow and Clyde and Scotland

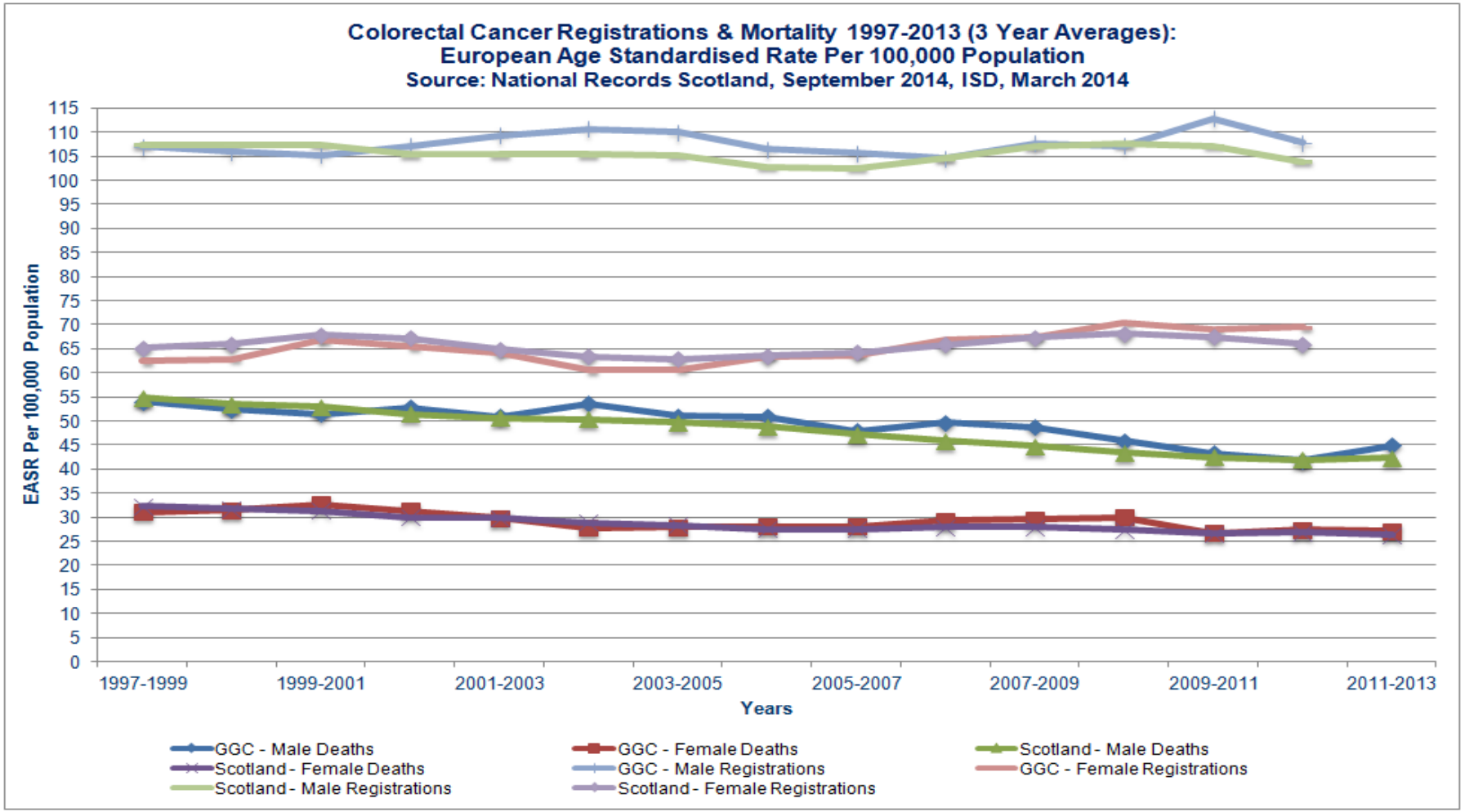


Table 3.8 shows the numbers and rates of colorectal cancers diagnosed from 2009 to 2013 by mode of detection and Dukes staging. Of the 4,192 colorectal cancers diagnosed over 5 years, 3,060 were symptomatic and 757 were detected through the bowel screening programme. 375 symptomatic cancers were identified as interval cancers giving a rate of 89.5 per 1,000 colorectal cancers.

Table 3.8 Numbers and rates of colorectal cancers by mode of detection and Dukes staging for period 2009 to 2013

	Dukes Staging							
Mode of Detection	**A**	**B**	**C1**	**C2**	**D**	**Not Known**	**Total**	**Rate Per 1000 Invasive Cancers**
Interval	74	84	95	13	37	72	375	89.5
Screening	259	172	168	12	18	128	757	180.6
Symptomatic	353	793	605	105	222	982	3060	730.0
All Invasive Cancers	686	1049	868	130	277	1182	4192	

Source: Bowel Screening IT System, June 2014, Cancer Audit Extract, November 2014

Table 3.9 illustrates the staging of screen detected colorectal cancers by gender and staging categories.

Table 3.9 Staging category of screen detected colorectal cancers by gender

	Dukes Staging								
Gender	**A**	**B**	**C1**	**C2**	**D**	**Not Known**	**Total**	**Polyp Cancers**	**% Polyp Cancers**
Female	19	14	14	1	2	5	55	6	10.9
Male	29	12	21	1	4	10	77	7	9.1
Total	48	26	35	2	6	15	132	13	9.8

Source: Bowel Screening IT System, June 2014, Cancer Audit Extract, November 2014

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

In 2014, Glasgow was chosen as the launch venue for the National Detect Cancer Early Bowel Screening social marketing campaign. The campaign targeted men living in deprived areas and involved television, radio and newspaper advertising, roadshow events, poster and leaflet campaigns. The campaign was also supported locally by NHSGGC Cancer Health Improvement Working Group, for example:

- targeting BME communities involving local radio shows and community bowel awareness workshops.
- publicising bowel cancer and screening messages through healthy working lives events, and staff news publications.
- training staff and NHS volunteers to discuss bowel screening with staff and in the community.
- training carers of people with learning disabilities on the use of NHSGGC's Bowel Health and Screening resource pack to increase uptake.
- distribution of campaign materials (posters and leaflets) in local community, NHS and local authority venues. These included translated materials for minority groups.

Funding has been identified to implement two projects in 2014/2015:

- Telephone engagement project: contacting people new to the bowel screening programme to discuss issues related to completing the test kit and gain an understanding of the reasons people do not complete their kits in order to inform future work.

- A three year joint partnership between Cancer Research UK and NHSGGC to improve the prevention and earlier diagnosis of cancer. Primary care engagement facilitators will actively support practices to raise the profile of cancer, identify activities to improve uptake of bowel screening and cancer outcomes more generally and make change happen at a local level.

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 projects.

Appendix 3.2

Members of Bowel Screening Steering Group (As at April 2014)

Dr Emilia Crighton	Consultant in Public Health Medicine, Chair
Mr John Anderson	Consultant Surgeon
Mrs Margaret Anderson	Lead Nurse - Endoscopy
Dr Stuart Ballantyne	Lead Clinician for Radiology
Ms Claire Donaghy	Health Improvement Senior
Dr Fraser Duthie	Lead Clinician for Pathology
Mr Ian Finlay	Consultant Surgeon - Bowel Screening Lead
Mrs Fiona Gilchrist	Assist Programmes Manager, Screening Dept
Dr Neil Jamieson	Lead Clinician for Endoscopy
Dr Rachel Green	Associate Medical Director
Mrs Annette Little	Information Analyst
Mr Iain Gorman	Interim 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	Interim General Manager
Mrs Tricia McKenna	Colorectal Nurse Endoscopist
Dr John Morris	Consultant Gastroenterologist
Dr Kenneth O'Neill	Clinical Director, South Sector CHP
Mrs Elizabeth Rennie	Programmes Manager, Screening Dept

SUMMARY

CHAPTER 4: PREGNANCY SCREENING

- There were 16,312 women booked to attend antenatal clinics across NHS Greater Glasgow and Clyde.

- 14,547 (89.2%) women booked into antenatal clinics were NHS Greater Glasgow and Clyde residents.

- 76.1% (11,072) of first antenatal booking appointments were offered within 12 weeks gestational age and 15.7% (2,289) between 13 to 16 weeks gestational age.

- 49.2% of pregnant women were overweight at the time of their first antenatal booking appointment**.** 21.8% (3,561) of women were classed as obese or severely obese.

- 14,547 women booked for their first antenatal screening. 96.2% (13,999) had taken up haemoglobinopathies screening.

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

- The overall uptake for Down syndrome was 77.5%.

- 9,193 (63.2%) samples were taken from women in their first trimester and 2,081 (14.3%) samples were taken from women in the second trimester.

- 77.1% of pregnant women had taken up congenital anomalies screening 1.8% of women were assigned to the 'higher chance' of Down syndrome group. Following the second trimester Down syndrome screening, 4.3% of women were assigned to the 'higher chance' of Down syndrome group.

- 11,184 fetal anomaly scans performed, 142 anomalies were detected and of that number 51 were confirmed. The outcomes for 51 anomalies are not known.

- 224 amniocentesis samples were analysed by the Cytogenetics Laboratory. 32 abnormalities were detected (14.29% of samples) and 22 of those (9.8% of total tests) had a diagnosis of trisomy (Down Syndrome).

- 114 chorionic villus biopsies were analysed by the Cytogenetics Laboratory in 2013/14. 27 abnormalities were detected (31.57% of tests) and 27 of those (23.7% of tests) had a diagnosis of trisomy (Down Syndrome).

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 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 – 4.8**.

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 4.9**. 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 for communicable diseases in pregnancy screening 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 16,312 women booked to attend antenatal clinics across NHS Greater Glasgow and Clyde (**Table 4.1)**. 14,547 (89.2%) 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 2013 to 31 March 2014

Maternity Unit	Appointed Referrals Not NHSGGC	Appointed Referrals NHSGGC Residents	Appointed Referrals Total	Bookers Not NHSGGC Residents	Bookers NHSGGC Residents	Bookers Total
Not assigned to a maternity unit	78	182	260	78	182	260
Princess Royal Maternity Hospital	1,154	5,920	7,074	1,016	5,188	6,204
Royal Alexandra Hospital	376	3,415	3,791	338	3,166	3,504
Southern General Hospital	379	6,851	7,230	333	6,011	6,344
Total	**1,987**	**16,368**	**18,355**	**1,765**	**14,547**	**16,312**

Source: Pregnancy & Newborn Screening System, June 2014

Table 4.2 shows that 76.1% (11,072) of first antenatal booking appointments were offered within 12 weeks gestational age and 15.7% (2,289) between 13 to 16 weeks gestational age.

Table 4.2 Gestational age at first antenatal booking appointment by maternity unit for period 1 April 2013 to 31 March 2014

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	% <=12Wks 6Dys
Not assigned to a maternity unit	61	74	30	9	6	-	2	182	*40.7*
Princess Royal Maternity Hospital	311	3,844	776	134	41	30	52	5,188	*74.1*
Royal Alexandra Hospital	191	2,687	199	43	10	14	22	3,166	*84.9*
Southern General Hospital	283	4,467	945	153	61	55	47	6,011	*74.3*
Total	**846**	**11,072**	**1,950**	**339**	**118**	**99**	**123**	**14,547**	***76.1***

Source: Pregnancy & Newborn Screening System, June 2014

Table 4.3 shows that 49.2% (8,024) of pregnant women were overweight at the time of their first antenatal booking appointment; 21.8% (3,561) were obese or severely obese**.**

Table 4.3 Number and percentage of women booked for their first antenatal appointments by body mass index and by maternity unit 1 April 2013 to 31 March 2014

Body Mass Index at 1st Antenatal Booking Appointment	Princess Royal Maternity Hospital (PRM)		Royal Alexandra Hospital (RAH)		Southern General Hospital (SGH)		Maternity unit not recorded on PNBS[1]		NHSGGC Total	
BMI not recorded	295	4.8%	42	1.2%	106	1.7%	27	10.4%	470	2.9%
Underweight (BMI<18.5)	166	2.7%	98	2.8%	186	2.9%	6	2.3%	456	2.8%
Normal (18.5<=BMI<25)	**2,584**	41.7%	**1,518**	43.3%	**3,144**	49.6%	**116**	44.6%	**7,362**	**45.1%**
Overweight (25<=BMI<30)	1,714	27.6%	967	27.6%	1,721	27.1%	61	23.5%	4,463	27.4%
Obese (30=<BMI<35)	907	14.6%	559	16.0%	763	12.0%	34	13.1%	2,263	13.9%
Severely Obese	361	5.8%	225	6.4%	293	4.6%	12	4.6%	891	5.5%
Severely Obese (BMI >=40)	177	2.9%	95	2.7%	131	2.1%	4	1.5%	407	2.5%
Overweight - Severely obsese (25<=BMI>=40)	**3,159**	50.9%	**1,846**	52.7%	**2,908**	45.8%	**111**	42.7%	**8,024**	**49.2%**
Total Number of bookers	**6,204**		**3,504**		**6,344**		**260**		**16,312**	

Source: Pregnancy & Newborn Screening System, June 2014

1. PNBS = Pregnancy & Newborn Screening IT application

Women with gestational diabetes are at increased risk of having a large baby, a stillborn baby or a baby who dies shortly after birth. They are more likely than non-diabetic women to require their labour to be induced and to have their baby delivered by caesarean section. There are also long term risks to the health of the baby, in particular it is more likely to become overweight or obese as a child. Finally the mother herself is more likely to become diabetic in later life.

NHSGGC Antenatal Haemoglobinopathies Screening Programme

Table 4.4 shows that, of the 14,547 women booked for their first antenatal screening, 96.2% (13,999) had taken up haemoglobinopathies screening.

Table 4.4 NHSGGC haemoglobinopathies screening activity for the period 1 April 2013 to 31 March 2014

Maternity Unit	Bookers	Consent	FOQ Completed	% Uptake
Not assigned to a maternity unit	182	159	157	*86.3*
Princess Royal Maternity	5,188	4,985	4,886	*94.2*
Royal Alexandra Hospital	3,166	3,118	3,100	*97.9*
Southern General	6,011	5,898	5,856	*97.4*
Total	**14,547**	**14,160**	**13,999**	***96.2***

Source: Pregnancy & Newborn Screening System, October 2014
FOQ = Family Original Questionnaire

Data on the number of carriers and foetuses at risk of sickle cell disease and thalassaemia through screening is not available for 2013/14.

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

Table 4.5 NHSGGC Communicable diseases tests and results

1st April 2013 - 31st March 2014					Results			
	Total number of samples	No. requesting individual test	No. not requesting individual test	uptake	Antibody detected[1,2,3]		antibody not detected [4]	
	(N)	(N)	(N)	%	(N)	%	(N)	%
HIV	16,103	16,025	78	99.5	20	0.12	16,005	99.88
HBV	16,103	16,040	63	99.6	90	0.56	15,950	99.44
Rubella	16,103	16,076	27	99.8	14,671	91.26	1,405	8.74
Syphilis	16,103	16,032	71	99.6	4	0.02	16,028	99.98

Sources: West of Scotland Specialist Virology Centre; NHSGGC Microbiology Laboratories (Clyde)

Notes:

1. 18 of the 20 HIV infections were previously known about
2. 52 of the 90 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

NHSGGC Down syndrome and other congenital anomalies screening programme

Table 4.6 shows that 11,274 samples were tested for Down syndrome, representing an overall uptake of 77.5%. 9,193 (63.2%) samples were taken from women in their first trimester and 2,081 (14.3%) samples were taken from women in the second trimester.

Table 4.6 Uptake rate of Down Syndrome tests, and type of screening test for the period 2013/2014

Maternity Unit	Number of Bookers	1st trimester	2nd trimester	Total number samples analysed	Overall uptake
PRM	5,257	3,459	965	4,424	**84.2%**
Royal Alexandra Hospital	3,225	2,121	320	2,441	**75.7%**
Southern General Hospital	6,065	3,613	796	4,409	**72.7%**
Total	**14,547**	**9,193**	**2,081**	**11,274**	**77.5%**

Source: West of Scotland Regional Prenatal Screening Service

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, 1.8% of women were assigned to the 'higher chance' of Down Syndrome group. Following the second trimester Down Syndrome screening, 4.3% of women were assigned to the 'higher chance' of Down Syndrome group.

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

1st Trimester Screening		
	N	%
- Higher Chance' of Down's syndrome	167	1.8%
2nd Trimester Screening		
	N	%
- Higher Chance' of Down's syndrome	90	4.3%

Source: West of Scotland Prenatal Screening Service
Note: CUB – combined ultrasound and biochemistry screening

77.1% of pregnant women had taken up congenital anomalies screening **(Table 4.8).**

Table 4.8 Uptake rate for other congenital anomalies (fetal anomaly scan) for the period 31 March 2013 to 1 April 2014

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	4,834	4,637	95.9%	3,666	79.1%	75.8%
Royal Alexandra Hospital	3,207	3,089	96.3%	2,622	84.9%	81.8%
Southern General Hospital	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 2014

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 4.9 shows that of the 11,184 fetal anomaly scans performed, 142 anomalies were detected and of that number 51 were confirmed. The outcomes for 51 anomalies are not known.

Table 4.9 Outcome of fetal anomaly scans performed for the period 1 April 2013 to 31 March 2014

Maternity Unit	Fetal anomaly scan performed	Fetal anomaly detected	% Fetal anomaly detected	Anomaly confirmed	No anomaly detected postnatally	Outcome not known
Not Assigned to a maternity unit	94	2	2.1	0	1	1
Princess Royal Maternity Hospital	3,908	38	1.0	16	8	14
Royal Alexandra Hospital	2,569	69	2.7	18	22	29
Southern General Hospital	4,613	33	0.7	17	9	7
Total	**11,184**	**142**	**1.3**	**51**	**40**	**51**

Source: Congenital Anomalies Surveillance Tool, Pregnancy & Newborn Screening System, June 2014

Table 4.10 shows that 224 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. 32 abnormalities were detected (14.29% of samples) and 22 of those (9.8% of total tests) had a diagnosis of trisomy (Down Syndrome).

Table 4.10 Cytogenetics analysis of amniocentesis samples by indication type for the period 1 April 2013-31 March 2014

	Biochemical Screening	Maternal Age	Abnormalities on Scan	Other	Total
Number of women (= number of tests)	109	31	59	25	224
% total referral reasons	48.7%	13.8%	26.3%	11.2%	100%
Number with normal results	98	31	41	24	194
Number with diagnostic trisomy	8	0	13	1	22
% number with diagnostic trisomy	7.34%	0.00%	22.03%	4.00%	9.80%
Number of other non trisomy abnormalities	4	0	6	0	10
Total number of abnormalities	**12**	**0**	**19**	**1**	**32**
% total number of abnormalities	**11.01%**	**0.00%**	**32.20%**	**4.00%**	**14.29%**

Table 4.11 shows that 114 chorionic villus biopsies were analysed by the Cytogenetics Laboratory in 2013/14. 27 abnormalities were detected (31.57% of tests) and 27 of those (23.7% of tests) had a diagnosis of trisomy (Down Syndrome).

Table 4.11 Cytogenetics analysis outcomes of chorionic Villus Biopsy samples by indication for the period 1 April 2013 to 31 March 2014

	Referral Type				
	Biochemical Screening	**Maternal Age**	**Abnormalities on Scan**	**Other**	**Total**
Number of women (= number of tests)	19	10	63	22	114
% total referral reasons	16.6%	8.8%	55.3%	19.3%	100.0%
Number with normal results	14	10	34	20	78
Number with diagnostic trisomy	5	0	21	1	27
% total with diagnostic trisomy	26.3%	0.0%	33.3%	4.5%	23.7%
Number of other non trisomy abnormalities	0	0	8	1	9
Total number of abnormalities	**5**	**0**	**29**	**2**	**36**
% total number of abnormalities	**26.32%**	**0.00%**	**46.03%**	**9.09%**	**31.57%**

Audit of Congenital Anomalies

An audit was undertaken of all live-births, stillbirths, fetal losses and terminations of pregnancy between 1st April 2013 and 31st March 2014 that were associated with one or more congenital abnormalities. **See Appendix 4.12** for full details of the audit results.

Information systems

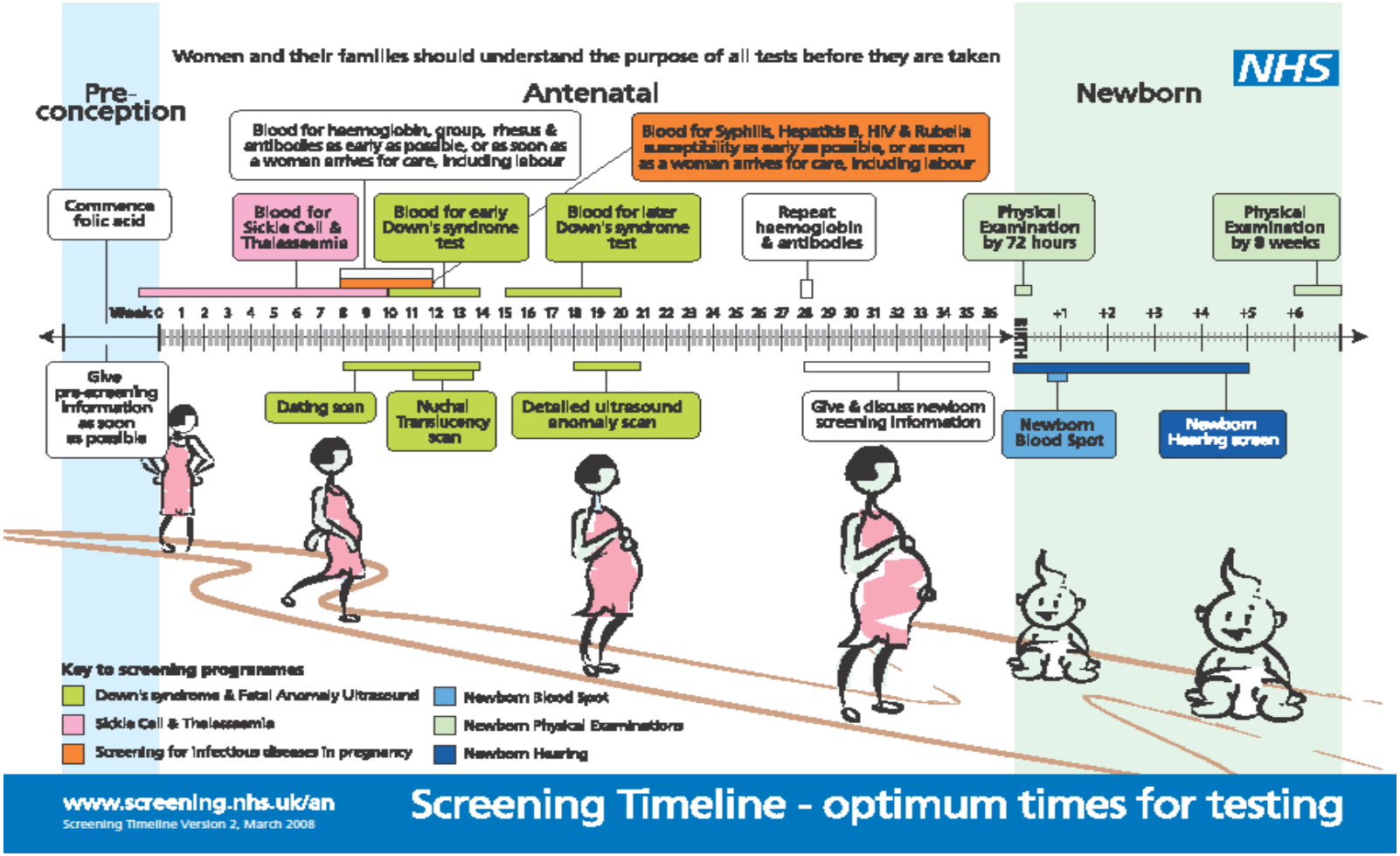
PNBS IT application is used to support all pregnancy and newborn screening programmes. The application brought improvements in both the reporting and management of cases identified through the programme. It introduced additional failsafe mechanisms into the screening programme.

Future development

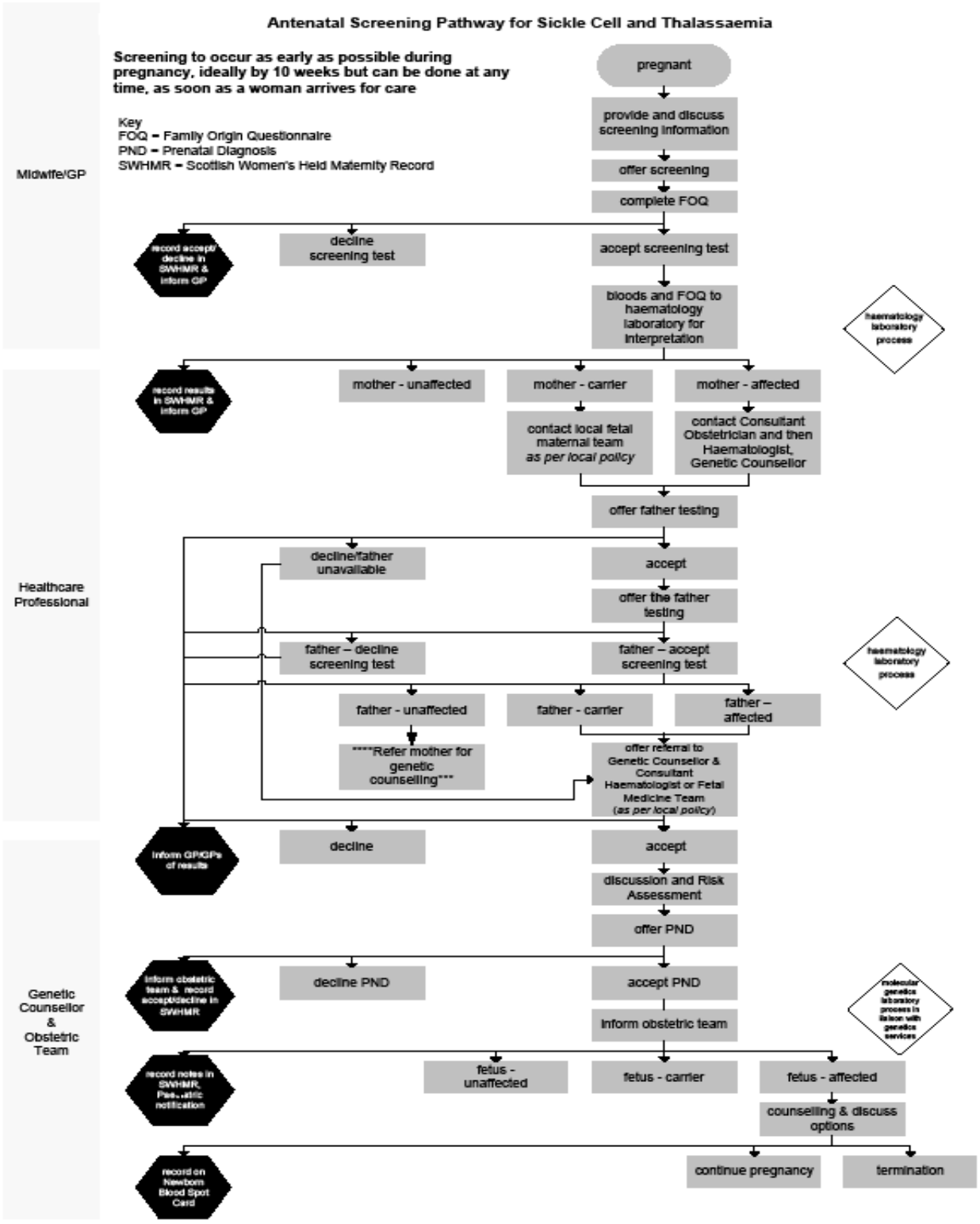
Plan is to implement gestational diabetes screening in pregnancy to reduce the

Challenges and Priorities

- Improving data completeness
- Capacity to deliver gestational diabetes screening in pregnancy

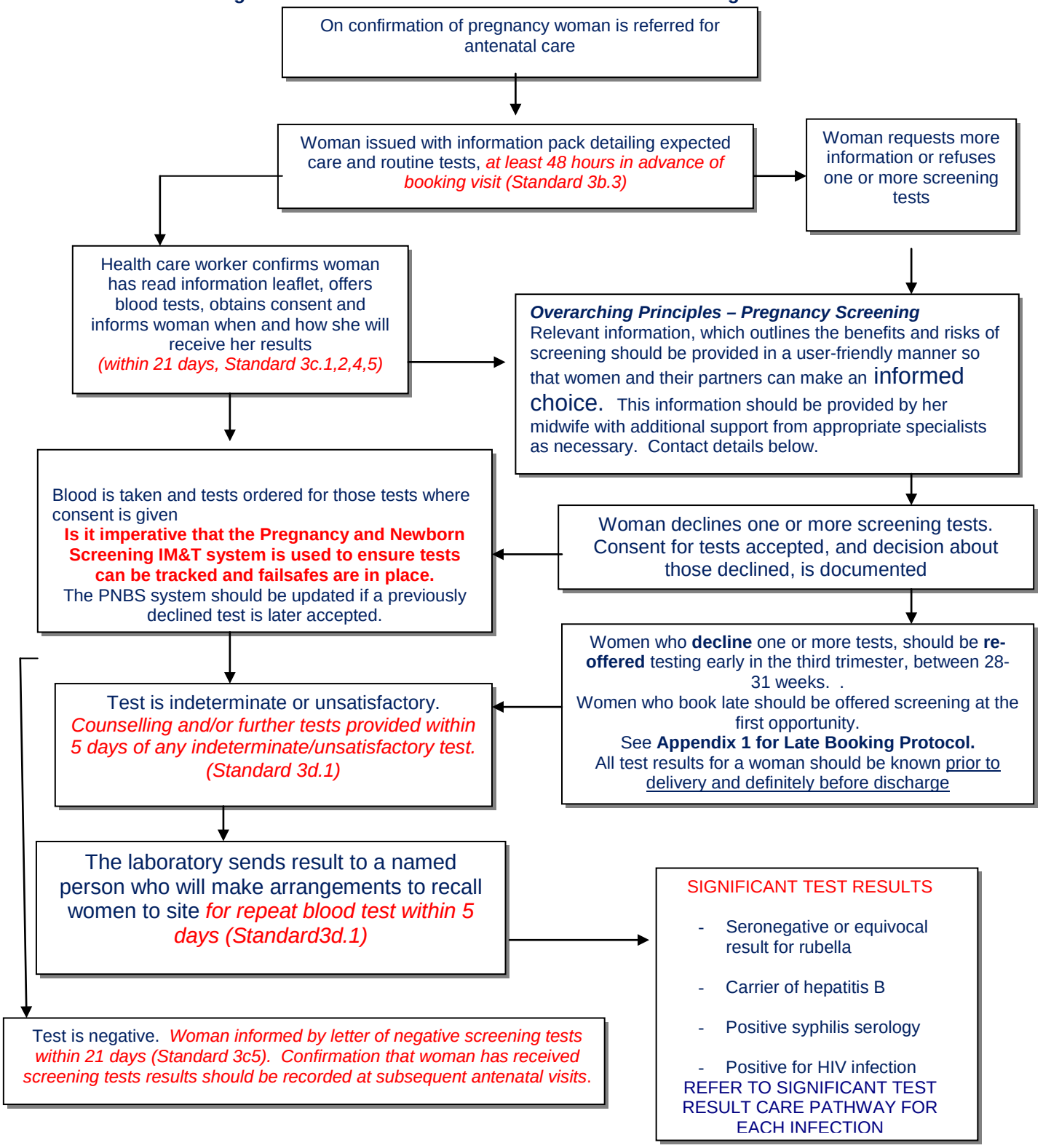

Women and their families should understand the purpose of all tests before they are taken
NHS
Pre-conception
Antenatal
Newborn
Blood for haemoglobin, group, rhesus & antibodies as early as possible, or as soon as a woman arrives for care, including labour
Blood for Syphilis, Hepatitis B, HIV & Rubella susceptibility as early as possible, or as soon as a woman arrives for care, including labour
Commence folic acid
Blood for Sickle Cell & Thalassaemia
Blood for early Down's syndrome test
Blood for later Down's syndrome test
Repeat haemoglobin & antibodies
Physical Examination by 72 hours
Physical Examination by 8 weeks
Week 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36
BIRTH
+1 +2 +3 +4 +5 +6
Give pre-screening information as soon as possible
Dating scan
Nuchal Translucency scan
Detailed ultrasound anomaly scan
Give & discuss newborn screening information
Newborn Blood Spot
Newborn Hearing screen
Key to screening programmes
Down's syndrome & Fetal Anomaly Ultrasound
Sickle Cell & Thalassaemia
Screening for infectious diseases in pregnancy
Newborn Blood Spot
Newborn Physical Examinations
Newborn Hearing
www.screening.nhs.uk/an
Screening Timeline Version 2, March 2008
Screening Timeline - optimum times for testing

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
record accept/ decline in SWHMR & inform GP
accept screening test
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 liaison 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

Offering Routine Antenatal Communicable Disease Screening Tests



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 & Support Team (CAST),** Brownlee Centre 0141 211 1089

Appendix 4.4

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 Specialist Virology Centre to let them know it is in the system. **(Tel 0141 201 8722)**
- 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.
- Please fill one 9ml bottle regardless of how many tests are requested. Sending multiple 5 ml tubes is not acceptable and the sample will not be processed.
- Ensure tests are recorded on PNBS at next opportunity
- Mark the sample as 'URGENT'.

- **In hours** (i.e. 9.00 – 17.00 Monday – Friday and 9.00 – 12.30 Saturday), telephone the **Laboratory (Tel 0141 201 8722)** and
    - explain that an urgent sample is being sent
    - discuss the travel arrangements
    - arrange when and to whom the results will be communicated. You must provide the laboratory with adequate contact details to include the name and preferably two contact numbers of the main results recipient and a deputy.

- **Out of hours** you must telephone the on-call virologist via the Switchboard 0141 211 3000 and discuss the above.
- If the timing of the local transport systems does not facilitate urgent transfer order a taxi to ensure the sample reaches the laboratory. (see NHSGGC Ammended Protocol Ordering and Use of Taxis and Courriers October 2011) http://www.staffnet.ggc.scot.nhs.uk/Corporate%20Services/Communications/Briefs/Documents/amended%20taxi%20protocol%20-%20phase%201_acute%20services.pdf

- In normal hours the lab is able to process and produce results within 1-2 hours of receipt. Note that reactive samples will need to be confirmed on the next day.

- Note that to view a result on portal a CHI number is essential

3) The woman presents <u>in labour:</u>

It is the responsibility of the labour ward staff to ensure that virology screening tests are offered and results received. Even intrapartum diagnosis can significantly, positively modify neonatal outcome therefore it is important to ensure women are offered screening tests no matter how late.

It is essential that you telephone the virology lab as soon as possible to discuss emergency testing of the woman.

- 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.
- Please fill one 9ml bottle regardless of how many tests are requested. Sending multiple 5 ml tubes is not acceptable and the sample will not be processed.
- Mark the sample as 'URGENT'.
- **In hours** (i.e. 9.00 – 17.00 Monday – Friday and 9.00 – 12.30 Saturday), telephone the **Laboratory (Tel 0141 201 8722)** and
    - explain that an urgent sample is being sent
    - discuss the travel arrangements
    - arrange when and to whom the results will be communicated. You must provide the laboratory with adequate contact details to include

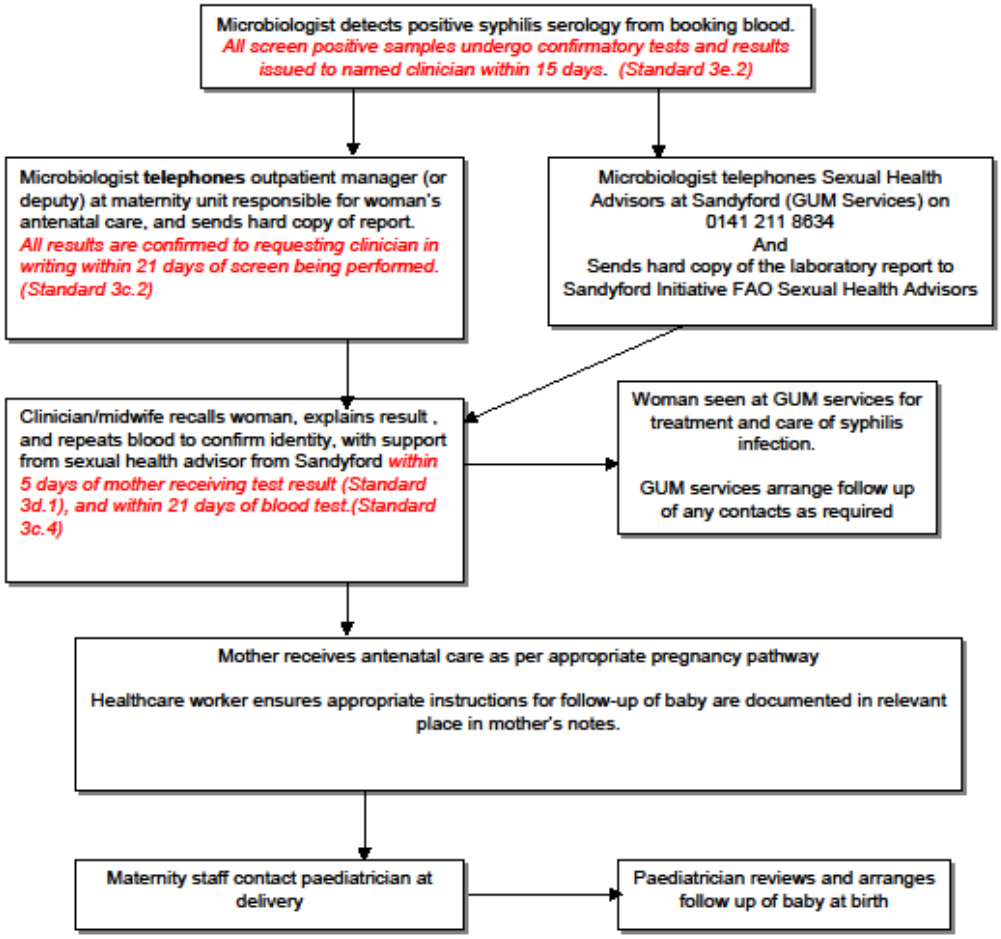
the name and preferably two contact numbers of the main results recipient and a deputy.

- **Out of hours** you must telephone the on-call virologist via the Switchboard 0141 211 3000 and discuss the above.
- Order a taxi to ensure the sample reaches the laboratory. (see NHSGGC Amended Protocol Ordering and Use of Taxis and Couriers October 2011)
- http://www.staffnet.ggc.scot.nhs.uk/Corporate%20Services/Communications/Briefs/Documents/amended%20taxi%20protocol%20-%20phase%201_acute%20services.pdf
- As with **ALL** emergency blood tests ensure results are followed up immediately they are available. In normal hours the lab is able to process and produce results within 1-2 hours of receipt.
- Communication with paediatricians is essential as their management may be significantly altered by these results however the responsibility for taking and sending these investigations and obtaining these results remains with the midwifery / obstetric team.
- Ensure tests are recorded on PNBS at next opportunity

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 2016

NHS Greater Glasgow and Clyde

Protocol for Significant Laboratory Results

HEPATITIS B (HBsAG)

Woman is found to be hepatitis B surface antigen positive (HBsAG)

Virologist sends a letter and copy of report, from West of Scotland Specialist Virology Centre (WoSSVC) 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 (including initial advice on management of the neonate)
- cc'd to Sandyford Shared Care Support Service – Tel: 0141 211 8639
- 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 the baby.

The woman is immediately referred to the local hepatitis service (Gastroenterology or Infectious Diseases) for clinical review and advice

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

The woman is given an appointment to attend for review at 28 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)

The woman's consultant ensures appropriate instructions received from the laboratory for initial management of the baby are documented in the proforma supplied by the virus lab. n.b. the Hep B DNA levels taken at 28 weeks may alter the initial advice given, and this should be documented accordingly .

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.

Maternity staff inform the paediatric team immediately after birth to ensure appropriate treatment is given as soon as is possible, and within 24 hours of birth. Immunisation form completed and faxed or emailed (HepB.Screening@ggc.scot.nhs.uk) to Community Screening Department within

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

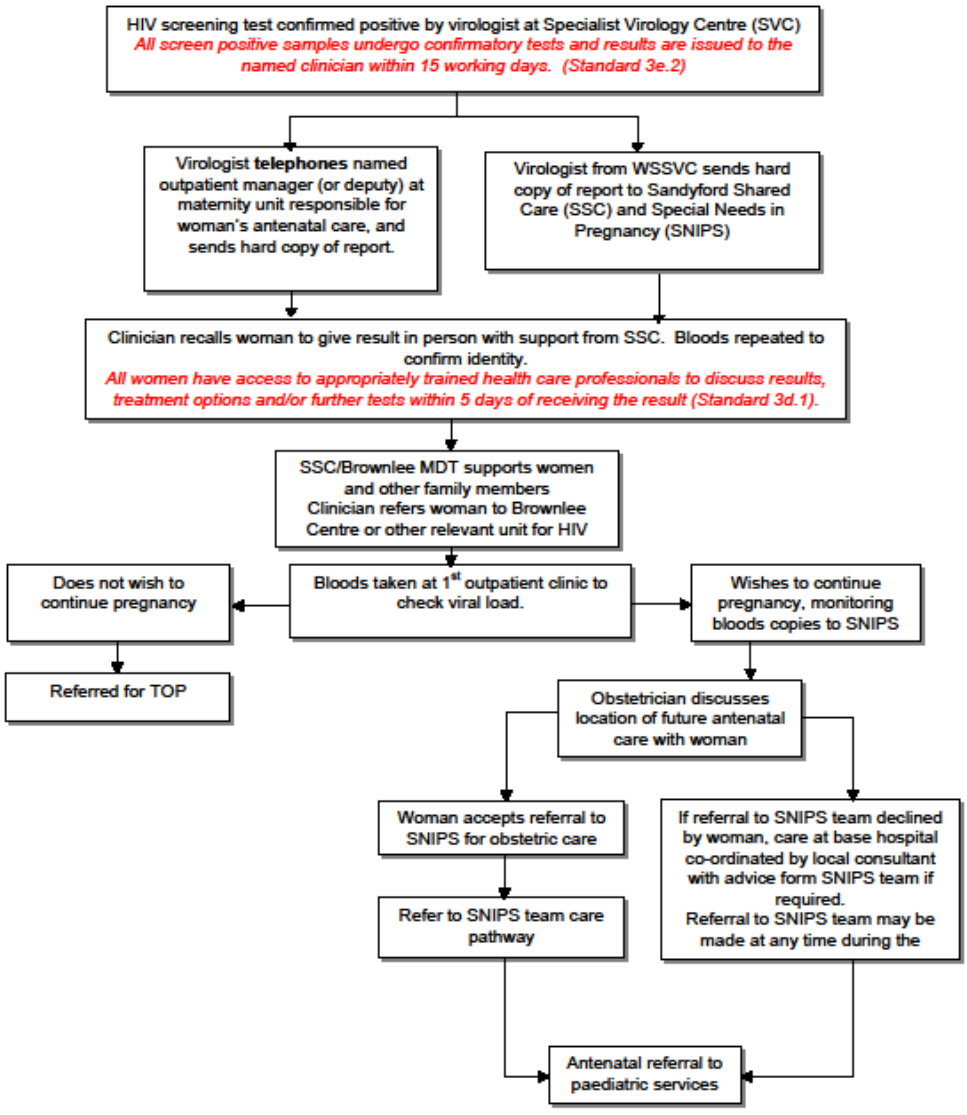
Paediatrician checks blood test and informs Community Screening department of result.

Version No: V6.2
Approved by: Communicable Diseases in Pregnancy Steering Group
Date Approved:
Next revision date:

NHS Greater Glasgow and Clyde

Protocol for Significant Laboratory Results

HIV

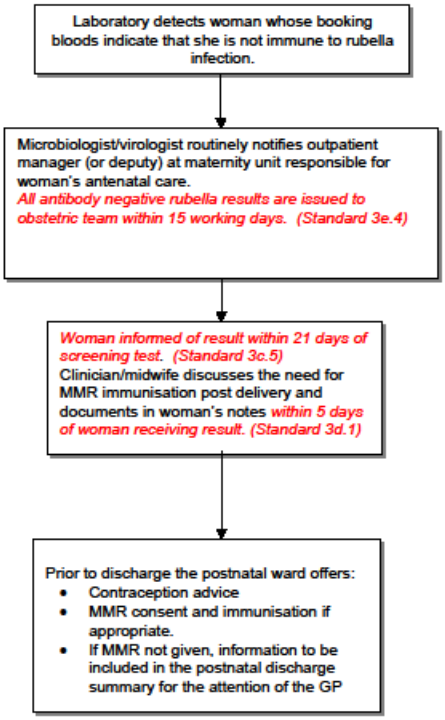


Version No:	V4.2
Approved by:	Communicable Diseases In Pregnancy Steering Group
Date Approved:	December 2012
Next revision date:	December 2013

NHS Greater Glasgow and Clyde

Protocol for Significant Laboratory Results

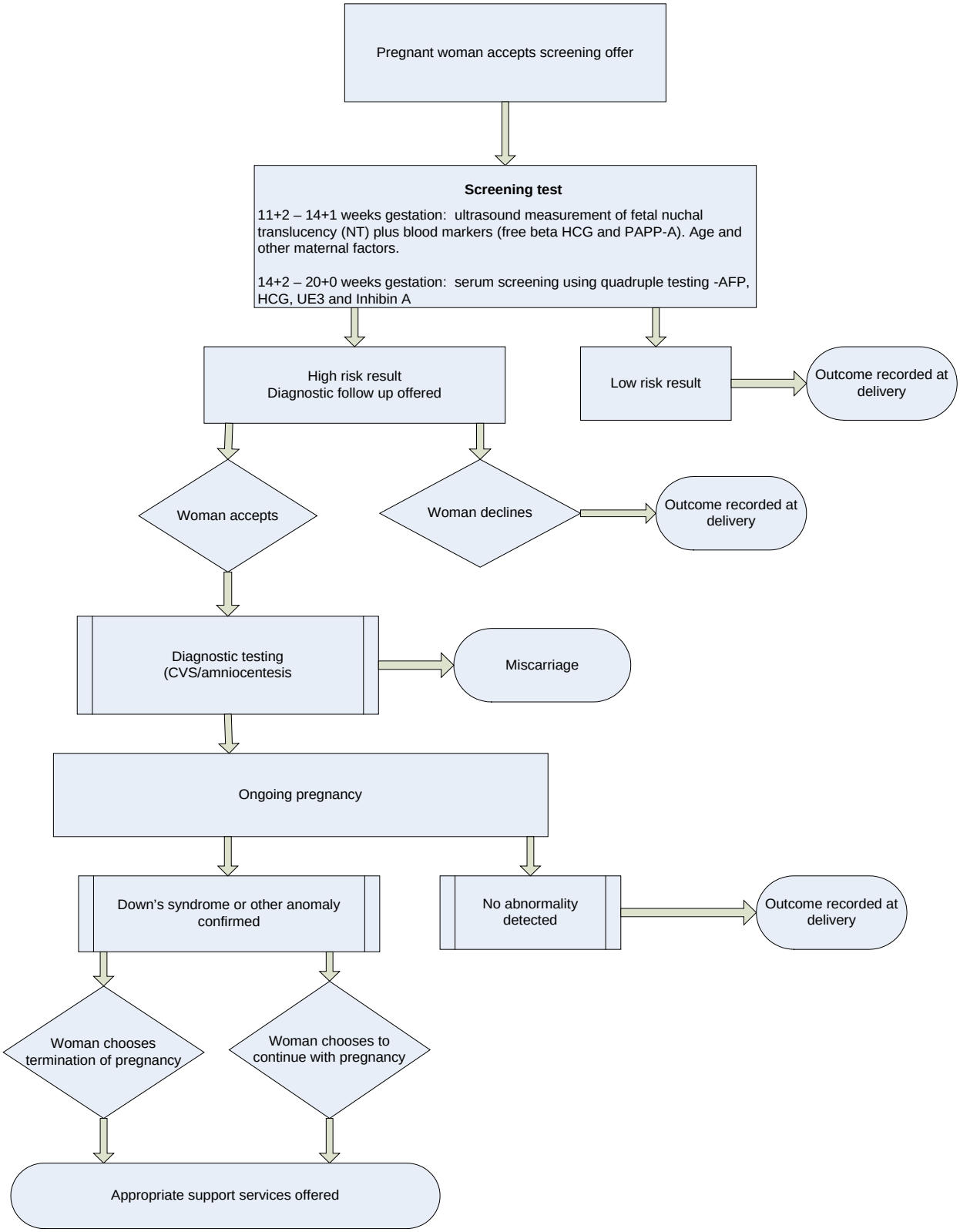
NOT IMMUNE TO RUBELLA INFECTION



Version No:	V4.2
Approved by:	Communicable Diseases in Pregnancy Steering Group
Date Approved:	December 2011
Next revision date:	December 2016

Appendix 4.9

Down's syndrome screening pathway



Appendix 4.10

Members of Pregnancy Screening Steering Group

(as at March 2014)

Dr Emilia Crighton	Consultant in Public Health Medicine (Chair)
Louise Brown	West of Scotland Pregnancy Laboratory
Bruce Barnett	Assistant General Manager, Laboratory Medicine
Lin Calderwood	HI&T Screening Service Delivery Manager
Dr Margaret J Cartwright	Chief Biomedical Scientist
Dr Elizabeth Chalmers	Consultant Haematologist
Dr Rosemarie Davidson	Consultant Clinical Geneticist
Ian Fergus	Site Technical Manager, Diagnostics
Cathy Harkins	Lead Midwife
Marilyn Horne	Deputy Health Records Manager
Denise Lyden	Project Officer
Dr Alan Mathers	Clinical Director, Women's and Children's
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
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 2014)

Dr Gillian Penrice	Public Health Protection Unit (Chair)
Ms Maxine Anderson	Counsellor
Mrs Louise Carroll	Programme Manager HIV/STIs
Ms Flora Dick	Special Needs (SNIPS) Midwife
Ms Rose Dougan	Special Needs (SNIPS) Midwife
Ms Catherine Frew	Data Analyst, Specialist Virology Centre
Ms Claire Glover	Clinical Nurse Specialist
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
Ms Christine McGee	Community Midwife
Mrs Katie McEwan	Clinical Service Manager
Mrs Marion McNabb	Lead Community Midwife
Ms Jane McOwan	Technical Manager, Specialist Virology Centre
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

Appendix 4.12

CONGENITAL ANOMALIES SURVEILLANCE 2013-2014

REVIEW OF DATA RELATING TO CONGENITAL ANOMALIES DETECTED IN NHS GG&C BETWEEN 1ST APRIL 2013 AND 31ST MARCH 2014

Dr. James Robins

Source data provided by Hilary Jordan of Information Services

Final

Definitions

A **congenital disorder**, or congenital disease, is a condition existing at birth. The disorder may be the result of genetic abnormality, errors of morphogenesis, the intrauterine environment, infection or chromosomal abnormality.

Birth defect is a widely used term for congenital malformation which is recognizable at birth.
Congenital anomalies are of four clinically significant types.

- Malformations
- Deformations
- Disruptions
- Dysplasias

Malformation: In a malformation the development of a structure is arrested delayed or misdirected early in embryonic life and the effect is permanent.

Deformations: Are distinct from malformations in both timing and impact. They are conditions that arise from the application of mechanical stress to normally formed tissues. They may occur later in pregnancy and can be temporary.

Disruptions: Describes a complete breakdown of normal tissues

Dysplasias: Cellular abnormality of the originating tissue e.g. expansion of immature cells with a corresponding decrease in the number and location of mature cells.

Congenital disorders may consist of more than one abnormality. When multiple effects occur in a specified order the disorder is known as a **sequence**.

BINOCAR: The British Isles Network of Congenital Anomaly Registers. A group of regional disease specific registers collecting information about congenital abnormalities occurring in England, Ireland, Scotland & Wales. BINOCAR was set up jointly, in 1996, by the Office for National Statistics and Dr. David Stone at the Glasgow Register of Congenital Anomalies

EUROCAT: European Surveillance of Congenital Anomalies. A study based on a network of population based registries for the epidemiological surveillance of congenital anomalies. It was established in 1979 as one of the first Concerted Action Research Programmes funded by the European Commission and surveys more than 1.7M births per year in Europe.

Incidence or Birth Prevalence? The incidence is the rate of occurrence of new cases of a disease or condition over a specified period of time expressed as a ratio or percentage.

$$\text{Incidence} = \frac{\text{number of new cases over specified period of time}}{\text{size of population under consideration}}$$

In previous reports incidence has been used in preference to prevalence, which describes how frequently a disease or condition occurs in a specified population at a particular point in time.

The appropriate denominator for calculation of the incidence, (the size of the population under consideration who are initially disease free), is debatable. In the circumstances of this study it should be the number of maternities booked through antenatal services over the year 1st April 2013 and 31st March 2014, (Appendix 1).

All congenital anomaly registers report the number of babies with anomalies born during a calendar year. Perhaps this should mean that they would all report incidence rates. However in practice the majority of congenital anomaly registers actually report prevalence estimates.

The reason given is that it is not possible to ascertain all 'new' cases of any particular anomaly as a proportion of pregnancies affected with an anomaly will miscarry spontaneously before being diagnosed. Indeed, although 16,312 women booked with NHS GG&C between 1st April 2013 and 31st March 2014, a total of 18,355 appointed referrals were made during the same time period. This means that at least 2,043 pregnancies were 'lost' from time of referral to booking, (Appendix 1).

As a consequence congenital anomaly registers, such as EUROCAT and BINOCAR, report prevalence estimates per 1,000 or 10,000 total births, (live and stillbirths). These are referred to as birth prevalence estimates even though the pregnancy may not result in a 'birth' because of late miscarriage or termination of pregnancy for fetal anomaly, (fetal loss less than 20 weeks gestation is excluded from prevalence data).

Prenatal Diagnosis: A diagnosis of abnormality made in a live fetus at any gestation.
Prenatal Screening: Test for identifying a fetus that may be at a high risk for a defined congenital abnormality such as Down Syndrome .
Stillbirth: Late fetal deaths from 24 completed weeks' gestation.
Termination for fetal anomaly: Deliberate ending of pregnancy, with intention that the fetus will not survive, following the prenatal diagnosis of major congenital anomaly

Links to Previous Reports

Previous reports are available on-line for download through the GG&C Public Health Screening website:-

GG&C Congenital Anomaly Report for 2012-2013
http://library.nhsggc.org.uk/mediaAssets/Public%20Health%20Screening/CongenitalAnomaly2012-2013_FinalDraft.pdf

GG&C Congenital Anomaly Report for 2011-2012
http://library.nhsgg.org.uk/mediaAssets/Public%20Health%20Screening/Review%20of%20Congential%20Anomalies%20J%20Robins%202013.pdf

GG&C Congenital Anomaly Report for 2010-2011
http://library.nhsgg.org.uk/mediaAssets/Public%20Health%20Screening/NHSGGC%20Publci%20Health%20Screening%20Annual%20report%202010-11%20final.pdf

GG&C Congenital Anomaly Report for 2009-2010
http://library.nhsggc.org.uk/mediaAssets/Public%20Health%20Screening/PHSU%20Annual%20report%202009-2010%20final.pdf

1. Core Data

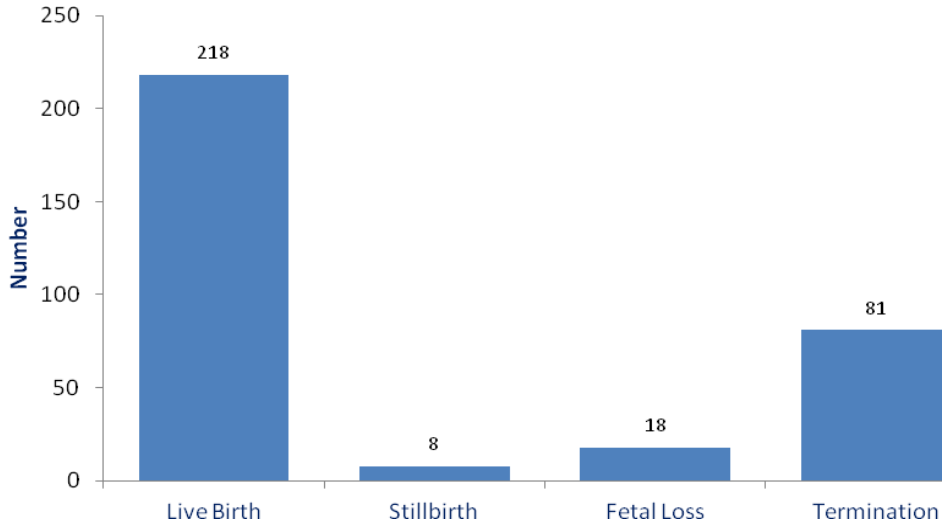
This report considers all live-births, stillbirths, fetal losses and terminations of pregnancy between 1st April 2013 and 31st March 2014 that were associated with one or more congenital abnormalities. Congenital anomaly data are collected from a number of different sources. The contents of the report are merely a 'snapshot'. The data set is constantly updated as further congenital abnormalities are recognized within the cohort.

1.1. Case based review

A total of 325 cases were identified from 325 pregnancies. This gives a case rate for congenital anomaly of 244/10,000 live and stillbirths[1]. This is slightly less than reported for the 2012-2013 cohort but does not imply any 'improvement' in numbers of congenital anomaly. The data taken to compile this current report has been extracted a little earlier than for previous reports.

The majority of cases were live-births, (n=218, 67%). There were 8 stillbirths (2%) and 18 fetal losses (6%). Termination of pregnancy following prenatal diagnosis of abnormality accounted for 81 cases, (25%), (Figure 1.1).

Figure 1.1: Pregnancy Outcome, (n=325).



Overall a total of 558 abnormalities were classified in these 325 cases using the ICD10 system, the primary abnormality and a variable number of associated abnormalities. In 209 cases only the primary abnormality is listed. However in 116 cases, (36%), two or more abnormalities have been classified, (Figure 1.2). In two cases a total of 8 abnormalities were defined.

The data on the 325 cases, including associated abnormalities, has been provided as a list which has been ordered on the basis of the primary abnormality as defined under ICD10, (Figure 1.3). Additional information has also been collected on gestational age at time of birth or termination, gestational age at 'point of diagnosis' if antenatal, maternal age, birth order for multiple pregnancy and gender.

[1] This is calculated from the number of live and still births for GG&C for the time period 1st April 2013 to 31st March 2014 which is 13,321, (GRO Births & Stillbirths Data extract at 9th July 2014).

Further supporting data has been made available from the Pregnancy & Newborn Screening data base, (PNBS).

Figure 1.2: Abnormalities per case, (n=325).

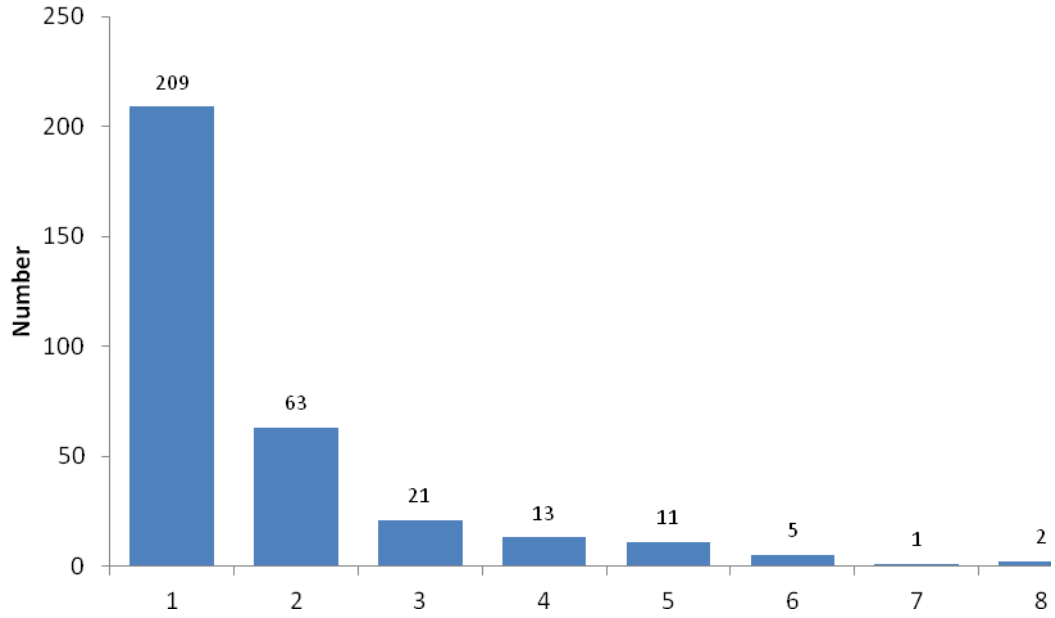
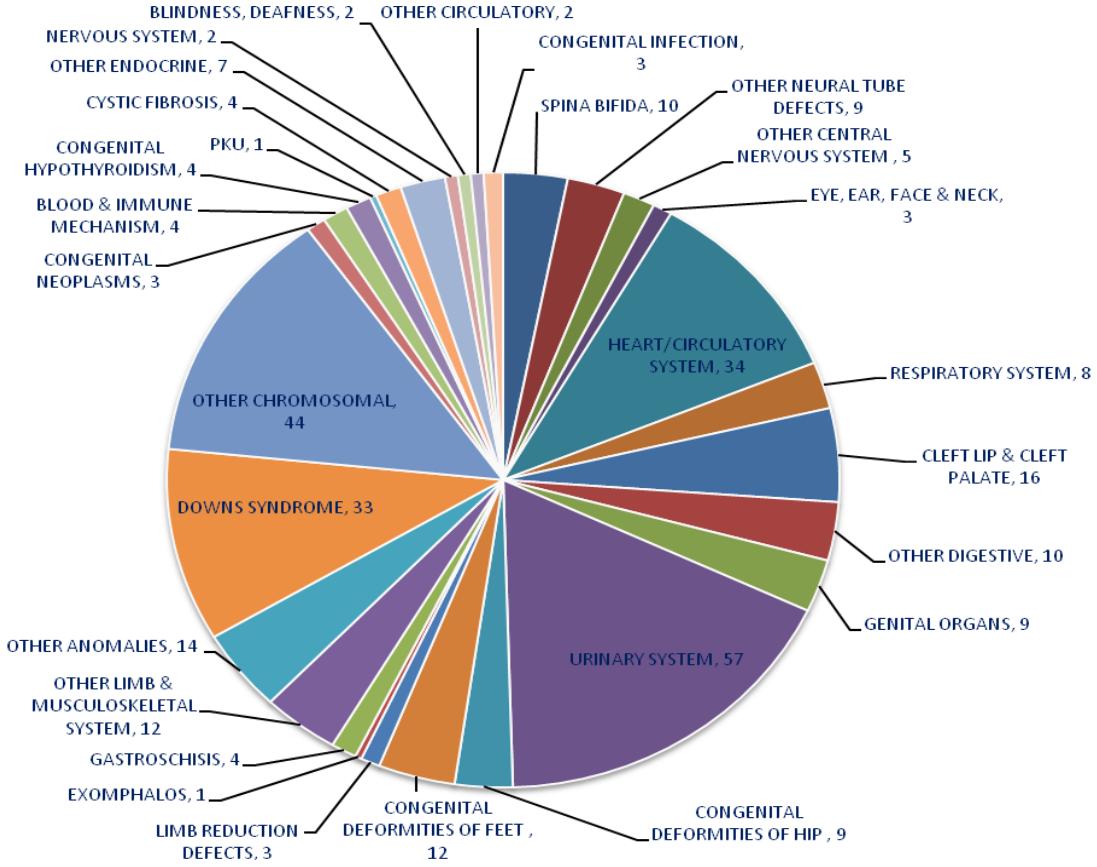


Figure 1.3: Classification according to Primary Abnormality (ICD10), (n=325).



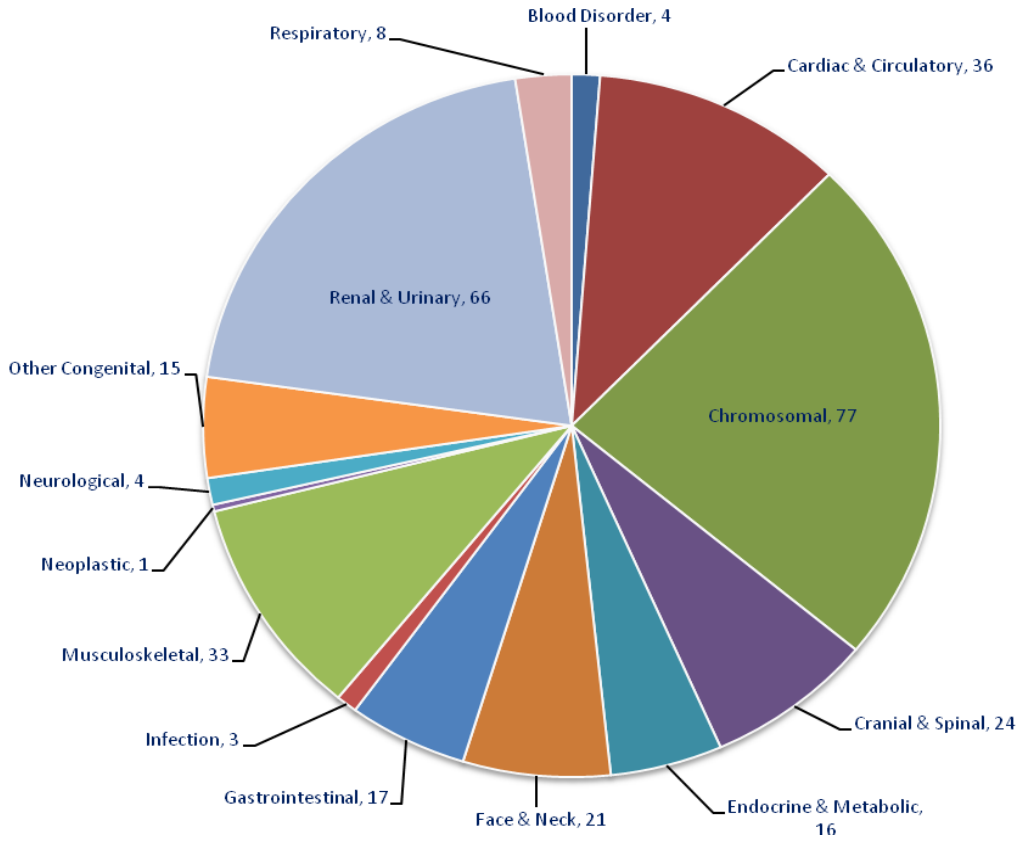
Chromosomal abnormality, ('Down Syndrome' and 'Other Chromosomal Disorders'), is the most common primary classification accounting for up to 23.7% of cases, (n=77). Congenital anomalies of the Genitourinary system, ('Genital Organs' and 'Urinary System'), are the next most common primary abnormality, (n=66; 20.3%).

There are a total of 41 cases where a primary abnormality of the musculoskeletal system, ('Congenital Deformities of Hip', 'Congenital Deformities of Feet', 'Limb Reduction Defects' and 'Other Limb & Musculoskeletal System'), is classified under ICD10. This number also includes congenital diaphragmatic hernia, exomphalos, gastroschisis and amniotic band sequence.

Disorders of the Heart and Circulatory System, ('Circulatory System' and 'Other Circulatory'), are classified as the primary abnormality in a total of 36 cases, (11.1%). Cranial and spinal abnormality, ('Spina Bifida', 'Other Neural Tube Defects' and 'Other Central Nervous System'), is the preferred primary classification in 24 cases, (7.3%).

Clearly some disorders, as classified and ordered under ICD10, are typically reviewed under other 'systems' and hence an aggregated and simplified chart based on primary abnormality is presented in Figure 1.4. For example in the 'simplified' classification exomphalos and gastroschisis are included as abnormalities of the gastrointestinal rather than musculoskeletal system.

Figure 1.4: Simplified Classification by Primary Abnormality, (n=325).



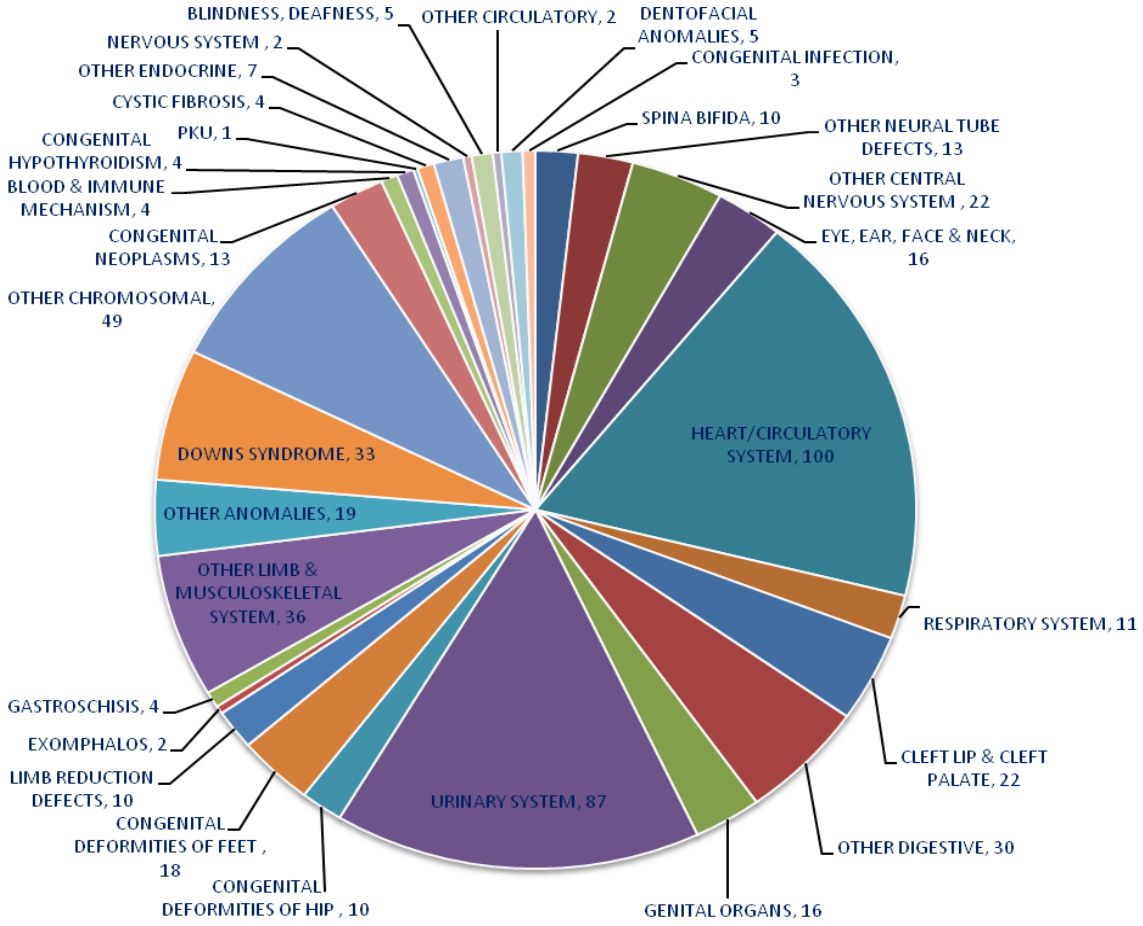
1.2. Abnormality based review

The situation becomes a little more complex when all of the 558 abnormalities, as defined under the ICD10 classification, are considered, (Figure 1.5). The overall rate for anomalies is 399/10,000 live and stillbirths[2]. This is higher than comparable data from both BINOCAR and EUROCAT.

Disorders of the Genital, Renal & Urinary System account for the majority of defined abnormalities, (n=103, 18.5%). Thereafter Cardiac & Circulatory abnormalities form the second most common grouping, (n=102, 18.2%). Chromosomal disorders remain prevalent accounting for 14.7% of all recorded congenital anomalies, (n=82).

The single most common defined abnormality was talipes equino varus which was listed on 17 occasions, the majority, (n=11), as a primary diagnosis. The next most common anomalies were VSD and Duplex Kidney. The most common single diagnosis was Down Syndrome.

Figure 1.5: Anomalies in any diagnostic position, (ICD10 & not mutually exclusive), (n=558)

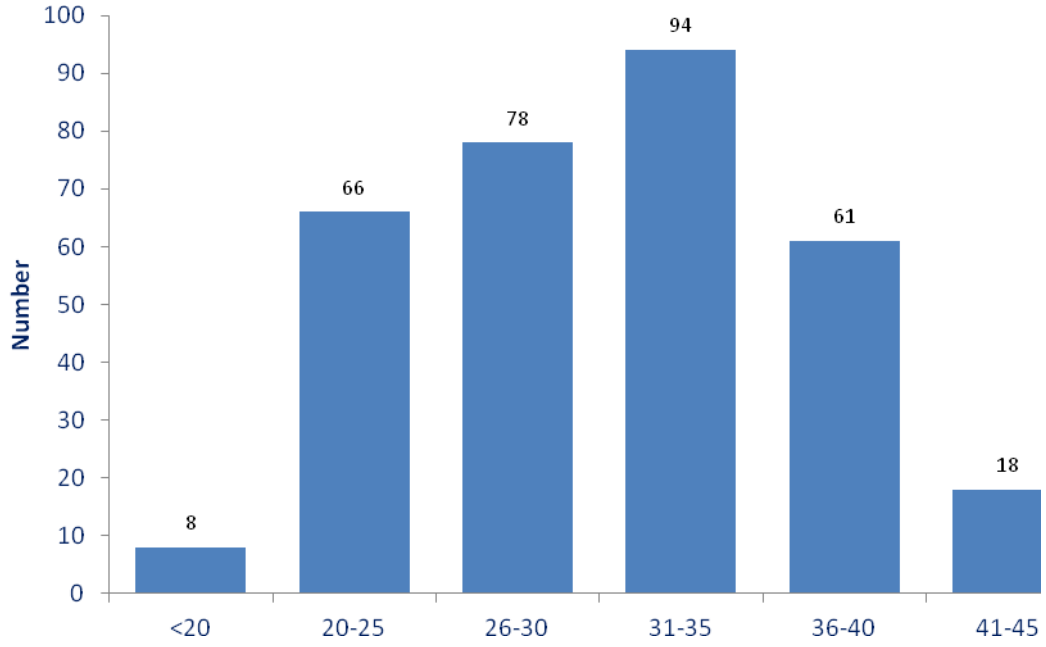


[2] Abnormalities associated with spontaneous fetal loss are excluded in this calculation.

1.3. Maternal Age

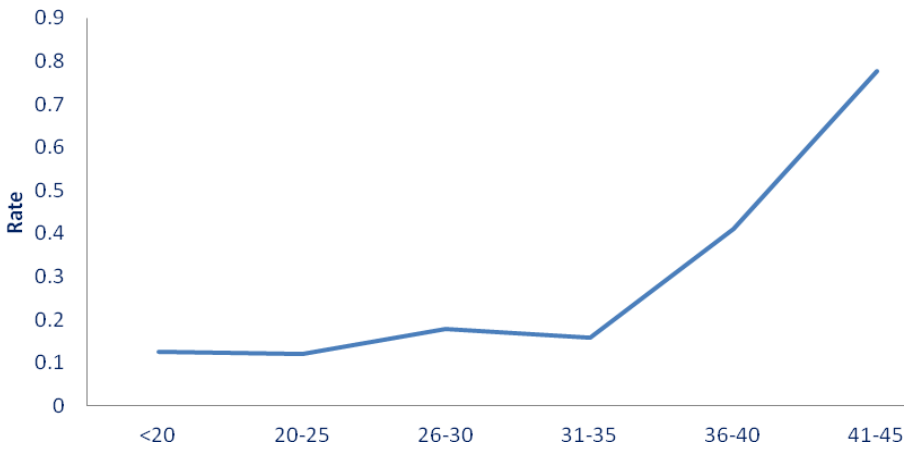
Overall 325 pregnancies accounted for the 325 classified cases of abnormality. Maternal age at time of delivery, miscarriage or termination ranged from 17 to 45 years, (Figure 1.6). The mean age was 30.8 years. Although maternal age is recorded in the register no information is held on paternal age.

Figure 1.6: Maternal age at delivery or loss, (n=325)



Data from BINOCAR would suggest that mothers under the age of 20 years have the highest prevalence of non-chromosomal anomalies when compared with older mothers whereas the birth prevalence of chromosomal anomalies increases with age. Rudimentary analysis of GG&C data for 2013-2014 confirms a higher rate of chromosomal abnormalities in older mothers, (Figure 1.7).

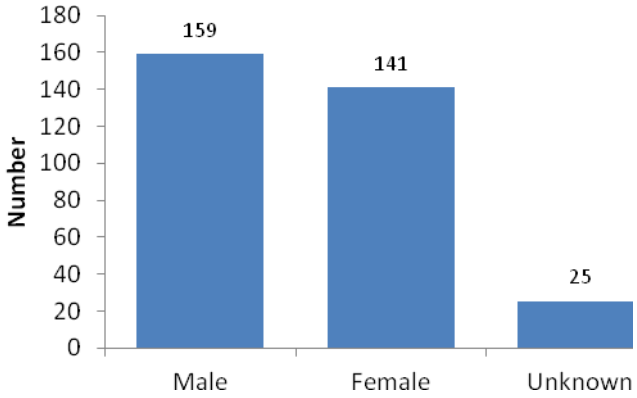
Figure 1.7: Rate of primary chromosomal abnormality as proportion of all primary abnormalities within each given maternal age group (years).



1.4. Gender

Gender is given for 300 cases. Congenital abnormality was slightly more prevalent in males than females, (ratio 1.12:1). In the remaining 25 cases gender is recorded as unknown, (Figure 1.8).

Figure 1.8: Fetal & Infant Gender, (n=325)



The mean gestation at delivery for cases of 'unknown' gender is 15.5 weeks. They were either terminations, (n=21), or early spontaneous fetal losses, (n=4). In all but one case a prenatal diagnosis of abnormality was made. Six cases were terminated following the prenatal diagnosis of chromosomal abnormality so it is likely that the genetic sex will be known.

1.5. Multiple Pregnancy

Eight cases are recorded from twin pregnancies. All were live births, (mean gestation at delivery 36.5 weeks). In each case the co-twin showed no evidence of congenital abnormality.

	CONGENITALLY CORRECTED	Prenatal diagnosis; Female; 2nd twin
Q205	TGA	
Q213	TETRALOGY OF FALLOT	Anal atresia with fistula; male; 2nd twin
Q234	HYPOPLASTIC (L) HEART	Prenatal diagnosis
Q6580	DDH ®	Female; 2nd twin; Diagnosis 1-12 months
Q660	TEV - BILAT	Male; 1st twin
Q660	CTEV ®	Male; 2nd twin
Q8706	MOEBIUS	Prenatal diagnosis; Bilateral talipes
Q8710	AARSKOG-SCOTT	Prenatal diagnosis; Male; 2nd twin; hypospadius

Moebius is a rare condition with paralysis of the VIth and VIIth cranial nerves leading to expressionless facial features, limitation of tongue movement, feeding difficulties, speech defect, and ptosis. Skeletal defects such as limb hypoplasia, webbing of the digits and rib defects are also common as is a degree of developmental delay[3].

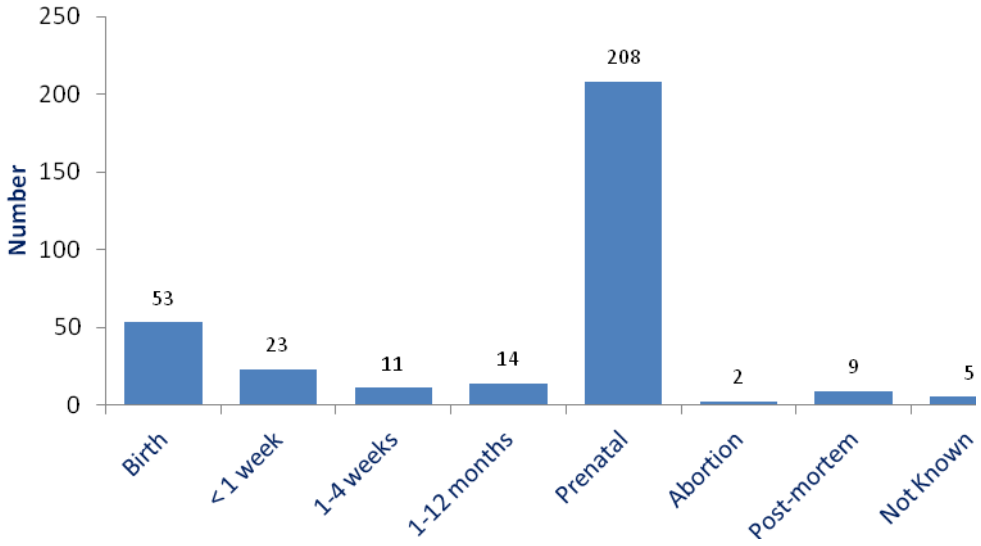
[3] It is unlikely that the diagnosis of Moebius was achieved on prenatal scan. However bilateral talipes would have been evident on ultrasound and it is this that defines the point of diagnosis, (see next).

Aarskog-Scott is also very rare. First described in 1970's it is an X-linked recessive disorder characterized by short stature with facial, genital and skeletal anomalies. Females may have milder features. Prevalence is said to be in the order of1:1,000,000 births but mildly affected individuals may not be identified and so the incidence may be higher. Diagnosis is typically based on recognition of the distinctive pattern of craniofacial anomalies, short stature, urogenital abnormalities and shortening of distal extremities.

2. Point of Diagnosis

Data are available for the 'point of diagnosis', or 'date of discovery' if it is preferred, (Figure 2.1). It should however be clear from the example given above that this does not necessarily imply the point at which the primary abnormality was first recognized and some care must be exercised in interpreting the data. Under EUROCAT definitions the 'point of diagnosis' or 'date of discovery' is the date on which the fetus or infant is first suspected or recognized as being malformed, even if a detailed diagnosis is not available.

Figure 2.1: Point of Diagnosis for Primary Abnormality, (n=325)



Over 64%, (n=208), of primary abnormalities were diagnosed prenatally. In 76 cases, (23.4%), the diagnosis was made at birth or within the first week of life. Fourteen cases, (4.3%), were diagnosed after the first month but within 1 year. Nine cases, (2.7%), were diagnosed at post-mortem. In a further 5 cases the point of diagnosis is recorded as 'unknown'.

A chart demonstrating Point of Diagnosis for primary abnormality, as defined by the 'simplified' classification described above, is produced, (Figure 2.2).

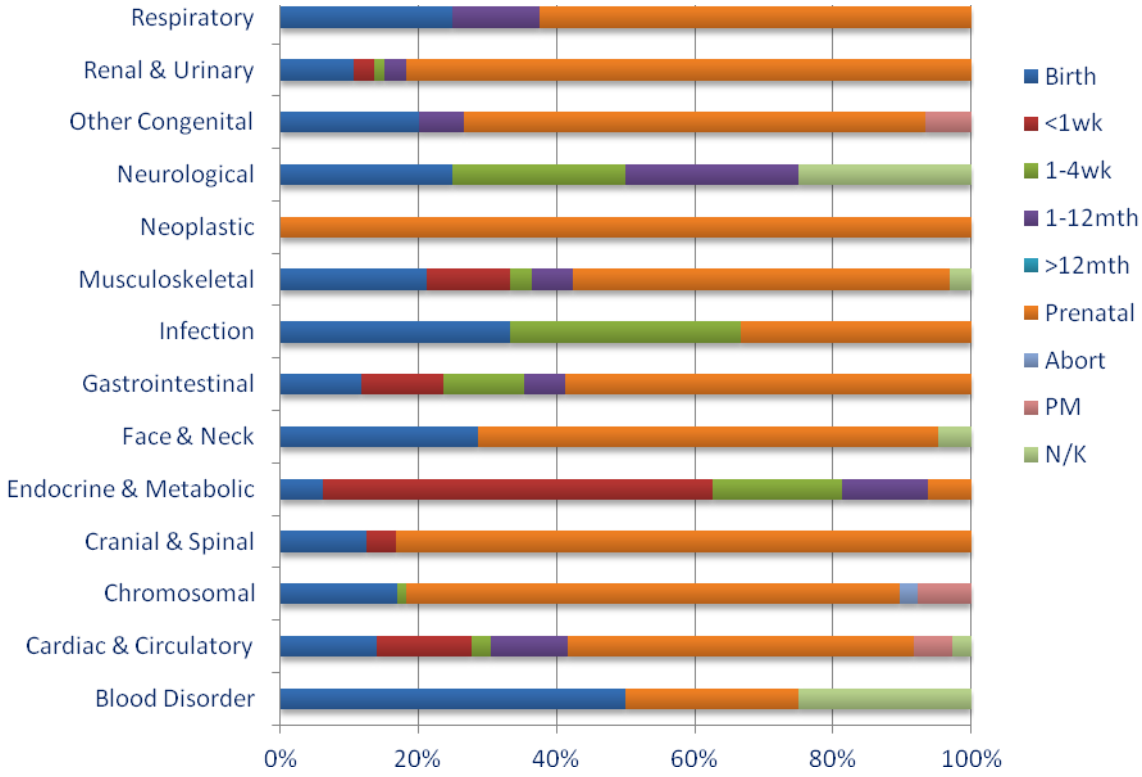
Typically most diagnoses of primary abnormality are made either antenatally or within the first week of life. Eighty-four percent of all 'Cranial & Spinal' abnormalities, eighty-two percent of 'Renal & Urinary' abnormalities and seventy-four percent of 'Chromosomal' abnormalities are diagnosed prenatally. The only lesion classified as 'Neoplastic', a posterior fossa brain tumour, was a prenatal diagnosis.

The results of routine blood spot analysis dictate that 'Endocrine & Metabolic' disorders will usually be diagnosed around 1- 4 weeks.

Although the majority of primary 'Cardiac & Circulatory' disorders are picked up either on antenatal scan or during the first week of life, a proportion, (11%), are not diagnosed until 1 – 12 months of life. This is also true of 'Neurological' disorders although the numbers are much smaller.

There were four cases of primary 'Blood Disorder'. Two of these were cases of severe Haemophilia A diagnosed at birth. A case of Fanconi's anaemia, associated with the typical reduction defects of the upper limbs, was diagnosed prenatally and terminated. The remaining case was one of Di George which is considered later because the point of diagnosis is recorded as 'unknown', (although most likely to have been at birth).

Figure 2.2: Point of Diagnosis for Main ICD10 Category, (Simplified), (n=325)



2.1. At Birth

Fifty-three primary abnormalities are coded as being diagnosed at birth, (Figure 2.3).

Chromosomal disorders again comprise the largest group, (n=13, 24.5%). Eleven cases of Trisomy 21 were diagnosed at birth. Further information extracted from the Pregnancy & Newborn Screening Programme database reveals that out of these eleven cases, two women had declined Down Syndrome screening, two had been screened as high risk but declined invasive testing, six had been found to be low risk on screening and the remaining case was a late antenatal booker.

Hypospadius accounted for six of the seven 'Renal & Urinary' system diagnoses made at birth, (all male). The other case was one of a patent urachus in a term male infant.

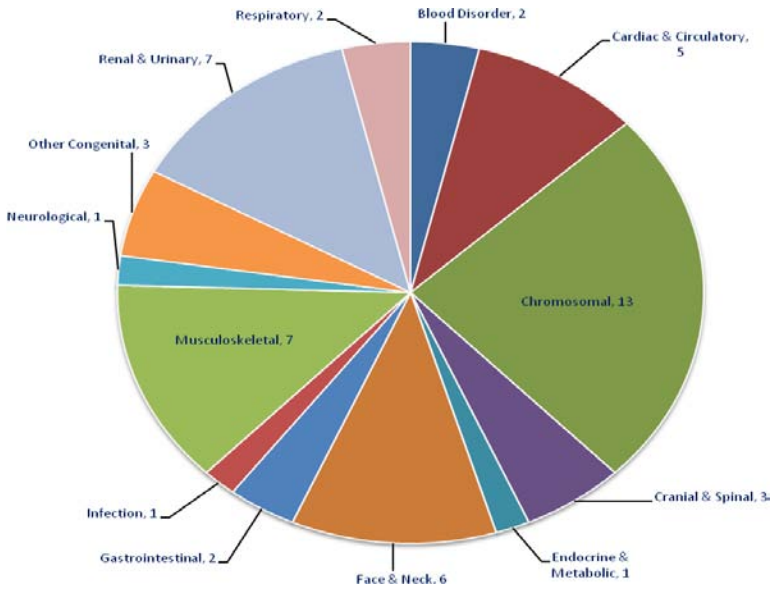
Abnormalities of the ‘Face & Neck’ first diagnosed at birth included an extensive left sided nuchal lymphangioma in a preterm male infant, two cases of congenital cataracts, two cases of isolated cleft palate and a right sided branchial remnant seen in a female infant delivered at term.

Cardiac abnormalities diagnosed at birth included pulmonary valve stenosis, total anomlaous pulmonary venous drainage and two cases of Tetralogy of Fallot. A male infant delivered at term was also found to have a persistent supra-ventricular tachycardia (SVT) and posterior uretheral valves.

Congenital cytomegalovirus (CMV) infection was diagnosed shortly after birth in a male infant delivered at term. No associated features are noted. CMV is the most common congenital infection in the UK. Intrauterine transmission occurs in 25-50% of primary maternal infections. Some 10% of infected fetuses show severe CNS involvement with features such as mental retardation, microcephaly, hydrocephalus, and deafness. Hepatosplenomegaly and petichiae are common. There are often no clinical clues to an at risk pregnancy. Like herpes simplex virus, cytomegalovirus also shows the property of latency and recurrence is not unknown in subsequent pregnancy, although the risk of having a second congenitally infected child is low.

A case of Type 1 Spinal Muscular Atrophy (SMA), a severe neurological condition, was also diagnosed at birth in a female infant. Spinal Muscular Atrophy Types I, II, and III belong to a group of hereditary diseases that cause weakness and wasting of the voluntary muscles in the arms and legs of infants and children. The disorders are caused by an abnormal or missing gene known as the survival motor neuron gene 1 (SMN1). As a consequence lower motor neurons in the spinal cord degenerate and die. Type I (also known as Werdnig-Hoffman disease) is typically evident at birth or within the first few months. Symptoms include floppy limbs and trunk, feeble movements of the arms and legs, swallowing and feeding difficulties, and impaired breathing. The prognosis is poor for babies with SMA Type I.

Figure 2.3: Diagnosis made at Birth by Primary Abnormality, (Simplified), (n=53)



2.2. Within 1st week

Congenital abnormality was diagnosed in 23 cases during the first week of life. Endocrine and metabolic abnormalities predominate and account for 39.1% of all diagnoses made in the first week of life, (n=9). There were three cases of congenital hypothyroidism and a further three cases of cystic fibrosis. Other diagnoses within this category were congenital hyperinsulinism and phenylketonuria.

There were five cases classified as having an abnormality of the cardiac and circulatory system. These were cases of congenitally corrected TGV, pulmonary stenosis, aortic valve stenosis, coarctation of the aorta and dysplastic aortic valve.

A diagnosis of microcephaly was made in a female infant delivered at term. There were no associated abnormalities.

Four cases, (all female), were related to the diagnosis of developmental dysplasia of the hips, (DDH).

A male infant, delivered at term, was found to have a number of abnormalities including imperforate anus, a prostatic-uretheral fistula, posterior uretheral valves and an unspecified congenital malformation of the spine. Two further cases of hypospadias, one severe, were also confirmed

The remaining case was one of malrotation of the gut in a male infant. There were no associated abnormalities

2.3. Between 1-4 weeks

Overall 11 cases are recorded as being diagnosed with 1 and 4 weeks. As expected a number of disorders are still being picked up as a result of routine newborn screening processes including sensorineural deafness as well as endocrine and metabolic disorders.

E039	CONGENITAL HYPOTHYROIDISM	Female infant
E742	GALACTOSAEMIA - GALT DEFICIENCY	Male infant
E840	CYSTIC FIBROSIS	Talipes
H903	CONGENITAL SENSORINEURAL DEAFNESS	Female infant
P358	CONGENITAL VARICELLA	Cataract; Microcepaly
Q262	TAPVD	
Q431	HIRSCHSPRUNG'S DISEASE	
Q431	HIRSCHSPRUNG'S DISEASE	Malrotation of gut
Q600	RENAL AGENESIS (L)	
Q6580	DDH (L)	
	MOSAIC TRISOMY FOR A PARTIAL RING 14	TAPVD; VSD
Q928	CHROMOSOME	

Hirschsprung's disease typically presents with abdominal distension and failure of passage of meconium within the first 48 hours following delivery.

A ring chromosome is a circular structure that occurs when a chromosome breaks in two places and its ends fuse together. Several critical genes near the end of the long (q) arm of chromosome 14 are lost when the ring chromosome forms. The loss of these genes can lead to intellectual disability and delayed development. Epilepsy is a common feature of ring chromosome s. The case described was a male infant delivered at term to an older mother.

2.4. Diagnosed after 1 month but within 1 year

There were a total of 14 cases in which the primary abnormality was diagnosed after 1 month but within 1 year.

E703	ALBINISM - OCULOCUTANEOUS	Male
E713	MCAD DEFICIENCY	Male
G120	SMA TYPE 1	Female
I420	DILATED CARDIOMYOPATHY	Female
Q250	PDA	Female
Q250	PDA	Female
	PULMONARY ARTERY STENOSIS - (L)	Male; Preterm delivery at 36 weeks
Q256	BRANCH	
Q300	CHOANAL ATRESIA (L)	Female; Preterm delivery at 26 weeks
Q540	HYPOSPADIAS - CORONAL	Male
Q630	DUPLEX KIDNEY (L)	Female
Q6580	DDH ®	Female
Q6580	DDH ®	Female
Q790	DIAPHRAGMATIC HERNIA	Male
Q899	UNDIAGNOSED GENETIC	Female; Multiple abnormalities

Just over a quarter of cases, (n=4), were cardiac or circulatory in origin with two cases relating to persistence of a patent ductus arteriosus in term infants.

Endocrine and metabolic disorders are still being defined and diagnoses of developmental dysplasia of the hips are still being made.

A further case of Type I Spinal muscular atrophy (Werdnig-Hoffman disease) is seen as a later diagnosis, (Part 2.1, Page 15).

2.5. Diagnosis after 12 months

No diagnoses after 12 months are recorded for this cohort. For the compilation of this report an extract has been taken a little earlier than for previous annual reviews. The data set for the 2013-2014 continues to develop and evolve. Further diagnoses will continue to be made and this data set will increase over and above that presented in this current report.

2.6. Prenatal Diagnosis

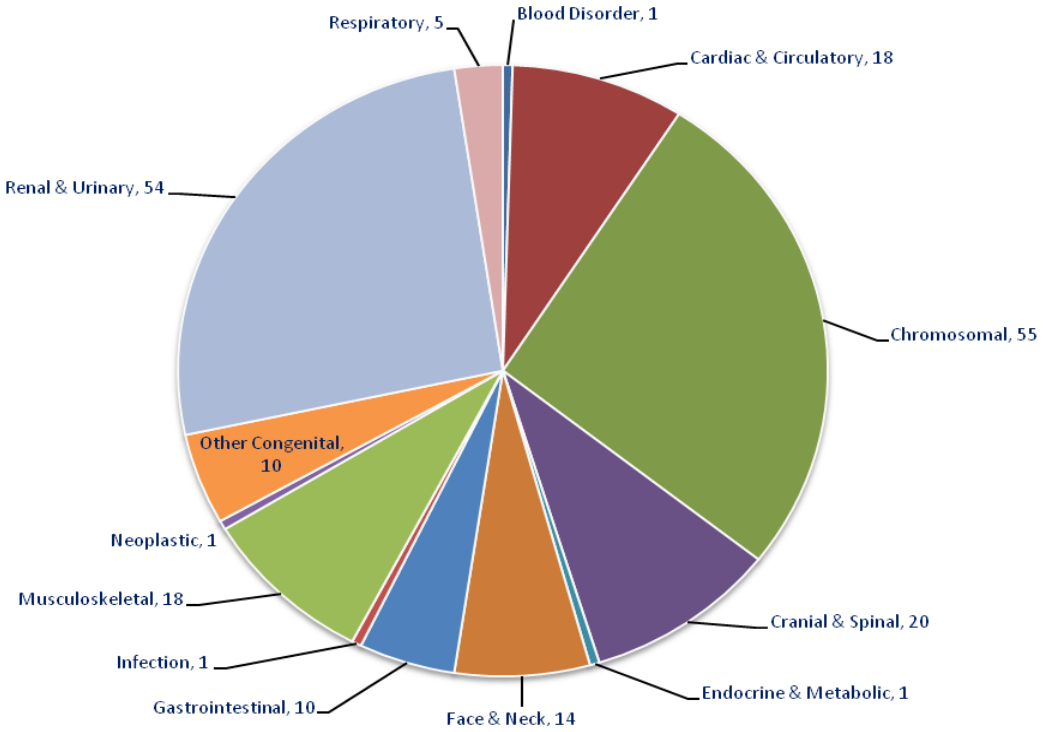
The majority of primary abnormalities were diagnosed during the antenatal period, (n=208, 64%), (Figure 2.4).

Fifty-five cases were associated with chromosomal abnormality of which the majority, (n=22, 40%), were Down Syndrome . There were also sixteen cases of Trisomy 18, five cases of Trisomy 13 and a further five cases of Turner .

The next largest grouping relates to disorders of the ‘Renal & Urinary’ system. Renal agenesis, either bilateral or unilateral, was an antenatal diagnosis on fourteen occasions. There were eight cases of multicystic dysplastic kidney disease. Congenital hydronephrosis, usually left sided was seen in seven cases. Other abnormalities included duplex kidney, (n=9), ectopic kidney, (n=1), congenital hydronephrosis,(n=7) and posterior uretheral valves, (n=2).

Ninety-one percent of all neural tube defects, (anencephaly, spina bifida and encephalocoele), were diagnosed on prenatal scan.

Figure 2.4: Prenatal Diagnosis by Primary Abnormality (Simplified Classification), (n=208)



Cardiac and circulatory disorders diagnosed on antenatal scan included hypoplastic left heart, (n=4), Tetralogy of Fallot, (n=6), pulmonary atresia (n=1) and coarctation of the aorta, (n=1).

Primary disorders of the gastrointestinal system subject to prenatal diagnosis included four cases of gastroschisis and one case of exomphalos. Isolated duodenal atresia was picked up in two cases.

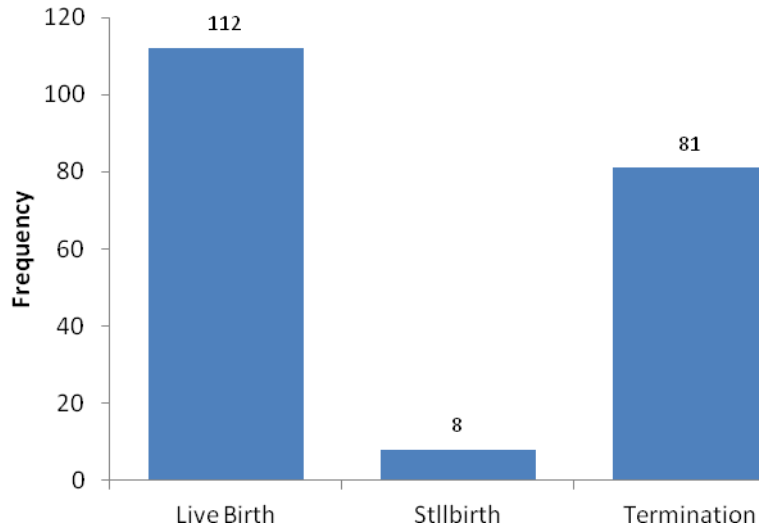
Cleft lip (with or without an associated cleft palate) accounted for the majority, (n=13) of abnormalities of the face and neck detected by prenatal scan. The remaining case was of a right sided lymphangioma of the neck and jaw which was picked up at 36 weeks gestation.

Talipes equino varus accounted for more than fifty-six percent of prental diagnoses of musculoskeletal abnormality. Arthrogryposis, achondroplasia, and limb reduction defects were also diagnosed by ultrasound examination.

The finding of significant upper limb reduction defects was the likely precursor to the diagnosis of Fanconi's anaemia, (Part 3.4, Page 23).

Where a prenatal diagnosis of abnormality was made eighty-one cases were terminated, (38.9%), but in the majority of cases, (n=112; 53.8%) the pregnancy continued to live-birth. Eight cases, (3.8%), were stillborn following prenatal diagnosis of congenital abnormality, (Figure 2.5).

Figure 2.5: Outcome of pregnancies in which there was prenatal diagnosis of abnormality, (n=208)



2.7. Unknown

There were five cases in which the point of diagnosis is recorded as 'unknown'. All were live-born and it is likely that diagnosis of abnormality was made soon after birth.

D821	DI GEORGE	Tetralogy of Fallot
H903	BILAT SEVERE SENSORINEURAL HEARING LOSS	
Q245	AORTOPULMONARY COLLATERAL VESSEL FORMATION	Preterm at 25 weeks
Q356	CLEFT PALATE - MIDLINE SOFT	
Q6580	DDH ®	Term female infant

2.8. Post-mortem

There were nine cases where the diagnosis has been recorded as having been made at post-mortem. All were associated with fetal loss, (gestational age range of 9 - 20 weeks). Fetal aneuploidy predominates as a diagnosis, (66.6%).

Q2115	SINGLE ATRIUM	Congenital malformation of pulmonary artery
Q2510	COARCT AORTA - PRE-DUCTAL	
Q893	SITUS INVERSUS	Malrotation of gut
Q910	TRISOMY 18	
Q969	TURNER , (XO)	
Q998	TRISOMY 15	
Q998	TRISOMY 16	
Q998	TRISOMY 15	Klinefelter 47, XXY
Q998	TRISOMY 15	

3. Pregnancy Outcome

A pregnancy outcome is recorded for all 325 cases. The majority of cases were live-born, (Figure 3.1 and Figure 3.2).

Figure 3.1: Pregnancy Outcome, (n=325).

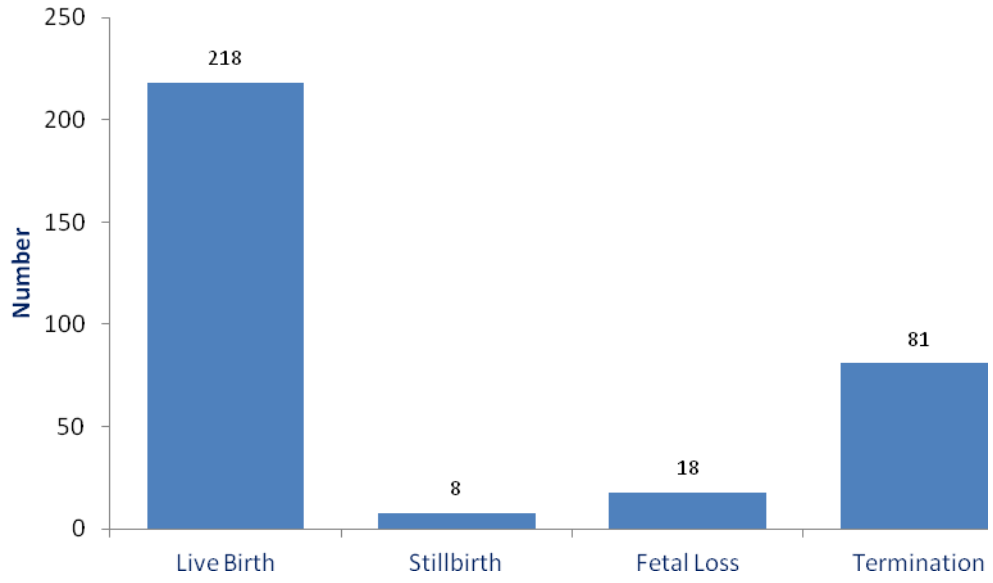
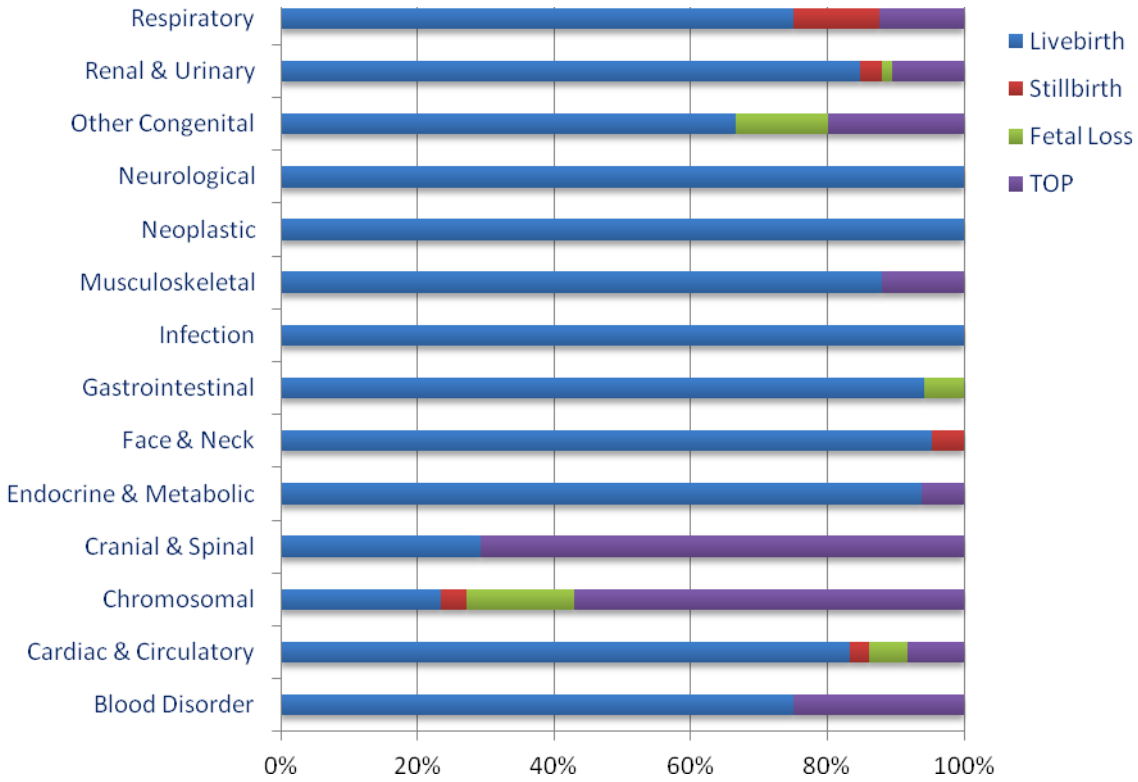


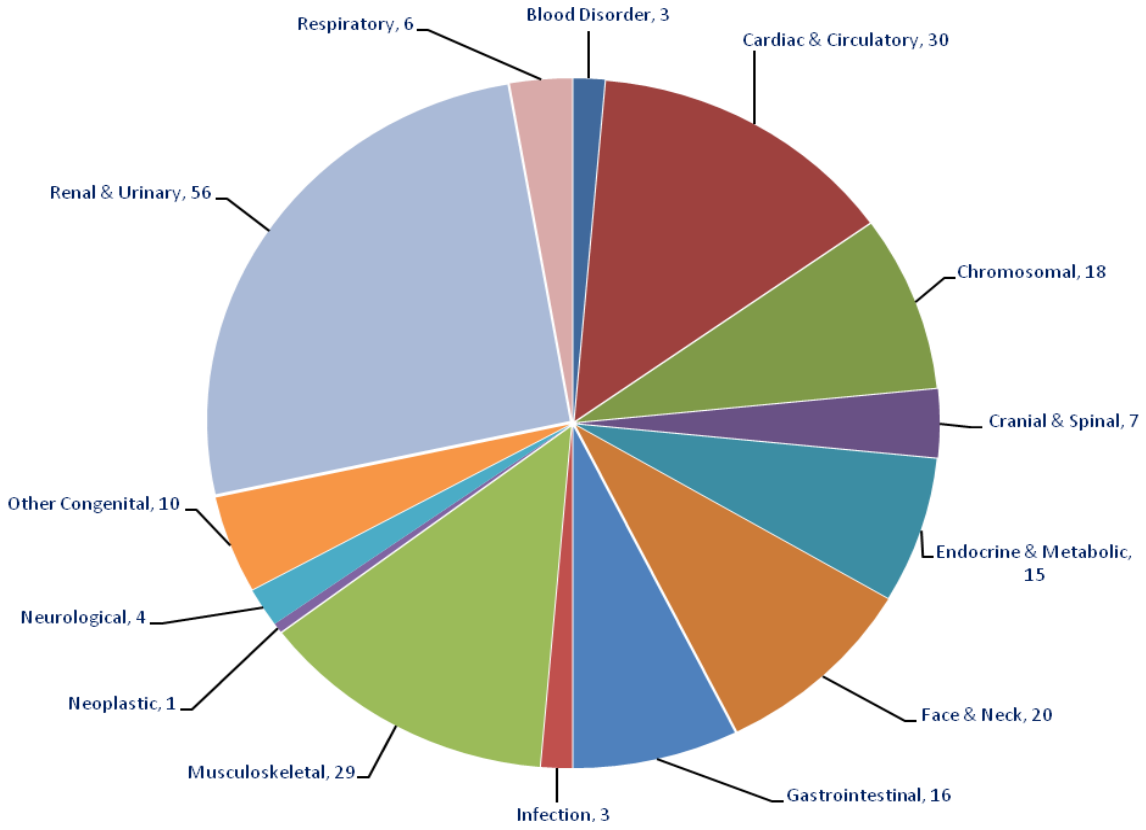
Figure 3.2: Outcome by simplified classification, (n=325).



3.1. Live-birth

Live-birth was the documented outcome for 67% of cases, (n=218), (Figure 3.3). The mean gestation at delivery was 38.4 weeks, (range 25 to 42 weeks).

Figure 3.3: Live-birth by Primary Abnormality (Simplified Classification), (n=218)



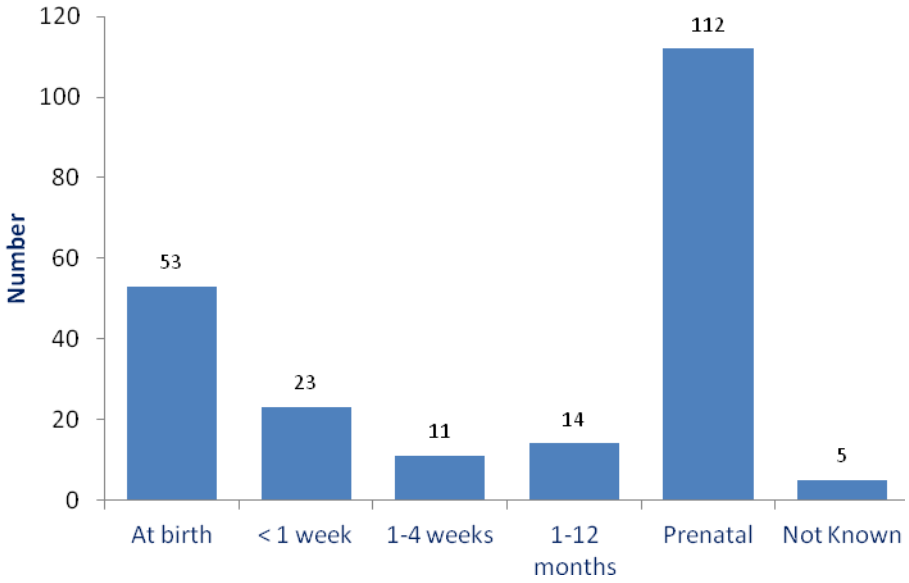
Diagnosis was made at birth for 24% of cases, (n=53), (Figure 3.4). Prenatal diagnosis of the primary abnormality was achieved for 51%, (n=112), of live-born infants.

Among the 'Cranial & Spinal' abnormalities were two cases, both in male infants delivered at term, where a disorder of the spine was associated with a fibrolipoma. In one case a fibrolipoma was associated with diastematomyelia and in the other the cord was tethered with a fibrolipoma of the filum terminale.

Three infants were born with congenital blood disorder: There were two cases of Haemophilia A, Factor VIII deficiency diagnosed in term male infants, with both classified as severe disorders. The remaining abnormality was a case of Di George which is classified under ICD10 as a primary haematological disorder.

The ICD10 code of Q828 is used to describe 'Other Specified Congenital Malformations of the Skin'. In the current data it is applied to a case of 'Microscopic Peri-umbilical Lymphatic Malformation'[4]. This was apparently picked-up on ultrasound scan at 20 weeks gestation, (although an abnormality was recognized it is unlikely that an exact diagnosis was made). The pregnancy continued to the live birth of a female infant at 37 weeks gestation. No other abnormality was seen.

Figure 3.4: Point of Diagnosis of Primary Abnormality for Live-births, (n=218)



3.2. Stillbirth

The data records eight stillbirths with a defined abnormality during the study period. The mean gestation at delivery was 30.3 weeks. In all cases the primary abnormality was diagnosed on antenatal ultrasound scan prior to the loss. The mean gestation of diagnosis, (for the seven cases in which this data is available), was 17.6 weeks.

Q220	PULMONARY ATRESIA	Hypoplastic ® Heart; VSD; Upper limb defect
Q318	LARYNGEAL ATRESIA	Male; Prenatal diagnosis
Q3799	CLEFT LIP & PALATE - COMPLEX	Situs inversus; AVSD; Atrial isomerism
Q6140	MULTICYSTIC DYSPLASTIC KIDNEY (L)	Coarctation of aorta; VSD;
Q643	URETHRAL OBSTRUCTION SEQUENCE	Male; Prenatal diagnosis
Q900	TRISOMY 21	Male; Prenatal diagnosis
Q900	TRISOMY 21	AVSD; Short rib
Q910	TRISOMY 18	AVSD

The case of complex cleft lip and palate had a number of associated cardiac abnormalities including AVSD, atrial isomerism, mitral and aortic valve malformations, and malformations of the great arteries against a background of situs inversus[5].

[4] It is likely that this was a 'microcystic' rather than a 'microscopic' lesion.

[5] Situs inversus is an autosomal recessive condition with 2 sub-groups – dextrocardia and levocardia. An individual has levocardia if the heart is on the left (normal) side but all other organs are reversed. A further case where situs inversus was the primary diagnosis recorded as a fetal loss

This case may have been better classified as a primarily cardiac abnormality. Likewise the case of pulmonary atresia was associated with hypoplastic right heart and a reduction defect of the upper limbs.

3.3. Spontaneous Fetal Loss

There were eighteen fetal losses recorded in the 2013-2014 data. Previous reviews have documented a high proportion of chromosomal abnormalities in this group and once again 67% of losses were associated with fetal aneuploidy. The mean gestation at time of loss was 13.5 weeks, (range 9 – 20 weeks)

Q2115	SINGLE ATRIUM PRE-DUCTAL COARCTATION	15 weeks; Cong. malformation pulm. artery
Q2510	AORTA LOWER URINARY TRACT	20 weeks; Malposition of heart
Q649	OBSTRUCTION	14 weeks
Q792	EXOMPHALOS	15 weeks; Talipes; Mosaic monosomy X
Q8724	SIRENOMELIA	15 weeks
Q893	SITUS INVERSUS	19 week; Malrotation of gut
Q910	TRISOMY 18	16 weeks; Cystic hygroma
Q910	TRISOMY 18	11 weeks
Q914	TRISOMY 13	13 weeks; Cystic hygroma
Q927	TETRAPLOIDY	11 weeks
Q960	TURNERS	19 weeks
Q960	TURNER (MONOSOMY X)	12 weeks
Q960	TURNER	15 weeks; Cystic hygroma
Q969	TURNER	11 weeks
Q998	TRISOMY 15	8 weeks
Q998	TRISOMY 16	11 weeks
Q998	TRISOMY 15	9 weeks; Klinefelter XXY
Q998	TRISOMY 15	9 weeks

The ICD10 coding of Q872 covers congenital malformation s predominantly involving limbs and includes sirenomelia and VATER/VACTERL association.

3.4. Termination of Pregnancy

A total of eighty-one cases were terminated following prenatal diagnosis, (Figure 3.5). The mean gestation at termination was 16.3 weeks, (range 11 to 23 weeks).

Chromosomal abnormality was the commonest indication for termination, (n=44), followed by neural tube defects and other cranial and spinal abnormalities, (n=17). Cranial and Spinal indications for termination included seven cases of anencephaly, seven cases of spina bifida and single cases of exencephaly, alobar holoprosencephaly and encephalocoele, (large posterior). Termination of pregnancy was also undertaken for cases of transposition of the great vessels, hypoplastic right heart and hypoplastic left heart.

Fanconi anaemia is a rare, inherited blood disorder that leads to bone marrow failure but over 50% of individuals with Fanconi anaemia also have physical abnormalities. Recognized features of Fanconi anaemia include malformed thumbs or forearms and other skeletal problems including short stature; malformed or absent kidneys and other defects of the urinary tract; gastrointestinal abnormalities; heart defects; eye

abnormalities such as small or abnormally shaped eyes; and malformed ears and hearing loss. Eighty to ninety percent of cases of Fanconi anaemia are due to mutations in one of three genes, *FANCA*, *FANCC*, and *FANCG*. Fanconi anaemia is most often inherited in an autosomal recessive pattern but rarely, this condition is inherited in an X-linked recessive pattern. The case described was a termination of pregnancy at 20 weeks gestation following prenatal diagnosis.
Reduction defects of the upper limbs and deformity of the skull were the predominant features on scan. Fetal gender is not recorded.

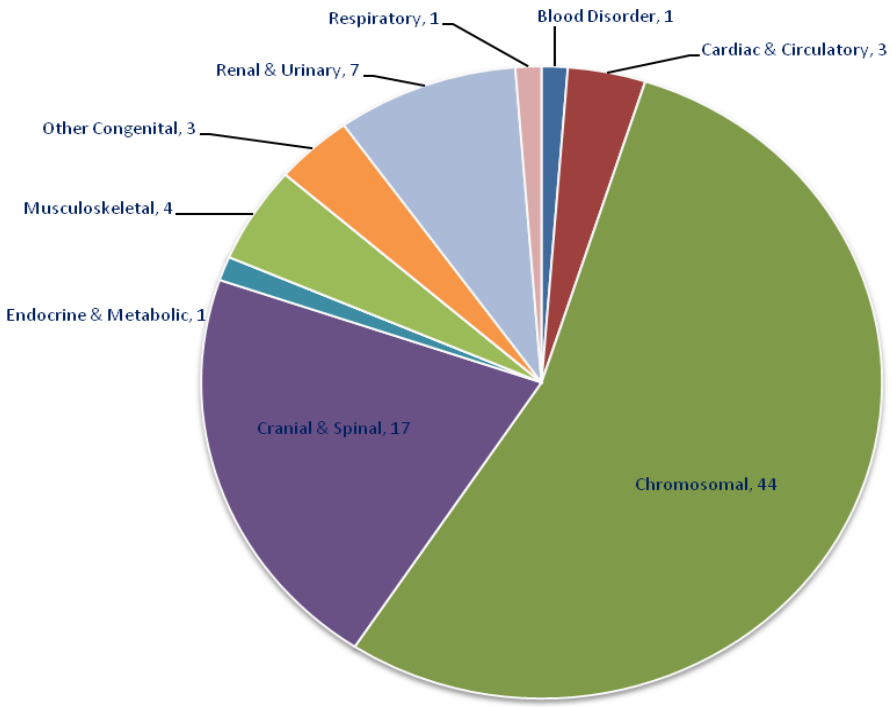
A fetus with methylmalonic aciduria was terminated at nineteen weeks following prenatal diagnosis.

Termination of pregnancy was performed at 21 weeks gestation following the prenatal diagnosis of laryngeal stenosis. There were a number of associated abnormalities.

Cases classified as having 'Other Congenital Abnormality' included amniotic band sequence, Fryn's and Pentralogy of Cantrell.

A female fetus with a primary diagnosis of 'hyperextended legs' was terminated at 21 weeks gestation after routine anomaly scan had demonstrated hand deformities, talipes and an unspecified malformation of the neck. Termination was also performed for cases of arthrogryposis and flexion contractures of all limbs.

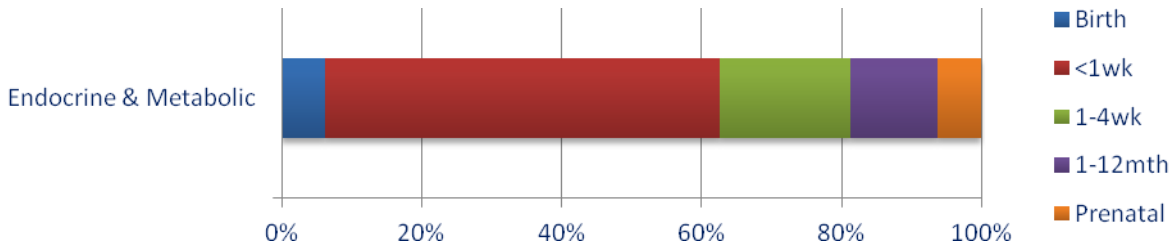
Figure 3.5: Diagnostic indication for Termination of Pregnancy (Simplified Classification), (n=81)



4.1. Endocrine & Metabolic Disorders

These disorders are typically diagnosed as a consequence of Newborn Bloodspot screening within the first few weeks of life, (Figure 4.1).

Figure 4.1: Point of Diagnosis: Endocrine & Metabolic Disorders, (n=16).



4.1.1. Congenital Hypothyroidism, (E0310; E0312; E039)

Congenital hypothyroidism can be the result of a missing or 'misplaced' thyroid gland, hereditary, maternal iodine deficiency and maternal thyroid conditions and medication. Four cases of congenital hypothyroidism are described. All were live born female infants with no associated abnormalities.

E0312	CONGENITAL HYPOTHYROIDISM - ECTOPIC THYROID TISSUE
E0312	CONGENITAL HYPOTHYROIDISM - ECTOPIC THYROID
E039	CONGENITAL HYPOTHYROIDISM
E039	CONGENITAL HYPOTHYROIDISM

4.1.2. Congenital Hyper-insulinism, (E161, E169)

Congenital hyperinsulinism, (CHI), describes a variety of disorders in which hypoglycaemia results as a consequence of excessive insulin secretion. This may be manifest in a variety of ways. For example, irritability, lethargy, cyanosis, hypothermia, and seizures are all associated with neonatal hypoglycaemia. Transient hyperinsulinaemia can also be seen in infants of diabetic mothers or as a consequence of IUGR.

There were two cases of congenital hyperinsulinism recorded. In both cases the diagnosis was made between 1 and 4 weeks of life.

E161	CONGENITAL HYPERINSULINISM	Male; Live-birth at 39 weeks
E169	CONGENITAL HYPERINSULINISM	Female; Live-birth at 39 weeks; PDA

In the past a number of different terms have been used to describe this condition including beta cell dysregulation , islet cell adenomatosis, and nesidoblastosis. The ICD10 classification is still a little vague. The ICD10 code 'E161' simply means 'Other hypoglycaemia' and includes functional non-hyperinsulinaemic hypoglycaemia as well as hyperinsulinaemia and post hypoglycaemic coma encephalopathy. Likewise 'E169' encompasses any disorder of pancreatic cell secretion such as islet cell hyperplasia.

4.1.3. In-born Errors of Metabolism

In-born errors of metabolism, (IEM), are a group of disorders in which a single gene defect causes a clinically significant block in a metabolic pathway leading either to an accumulation of the substrate or a deficiency of the product. They are individually rare but collectively common.

4.1.4. Disorders of Aromatic Amino-Acid Metabolism, (E70)

Phenylketonuria, (PKU), (E700)

Phenylketonuria is an autosomal recessive metabolic disorder of the hepatic enzyme phenylalanine hydroxylase. A single case of phenylketonuria was seen in a female infant delivered at term.

E700	PKU	Live-birth; Diagnosis in 1st week

The diagnosis was made on blood spot testing in the first week of life.

Albinism, (E703)

Two cases of albinism are described. They share the same ICD10 classification but differ in regard to clinical features, genetic mutation and inheritance pattern.

E703	WAARDENBURG ALBINISM-	Live-birth; Diagnosed at birth; Hearing loss
E703	OCULOCUTANEOUS	Live-birth; Diagnosed after 1 month

Oculo-cutaneous albinism is a group of conditions that affect pigmentation. Affected individuals typically have very fair skin and white or light-coloured hair. Oculo-cutaneous albinism also reduces pigmentation of the iris and retina. Hence visual problems such as reduced acuity, nystagmus and photophobia are common. There are four types of oculo-cutaneous albinism designated as type 1 (OCA1) through type 4 (OCA4). The four types of oculo-cutaneous albinism are most accurately distinguished by their genetic cause because the clinical features often overlap. All are inherited in an autosomal recessive pattern.

Similarly Waardenburg is associated with disorder of skin and hair pigmentation but it is usually inherited in an autosomal dominant pattern. The four known types of Waardenburg are distinguished by their physical characteristics and sometimes by their genetic cause. It is likely that this was a case of type II Waardenburg on the basis of the associated hearing loss. The hearing loss can be profound. Although type 1 is remarkably similar there is often hypertelorism. Type III is associated with limb defects and hearing loss. Type IV has signs and symptoms of Hirschsprung's disease.

4.1.5. Disorders of Branched Chain Amino-Acid and Fatty Acid Metabolism, (E71)

Methylmalonic aciduria with homocystinuria, (E7113)

The organic acidaemias, such as methylmalonicaciduria, are characterized by marked metabolic acidosis with ketotosis often with elevated lactate and hyperammonaemia.

The central error is a disorder of enzyme methylmalonyl-CoA-mutase which converts methylmalonyl CoA to succinyl CoA. Vitamin B12 is a co-factor in this process. It is inherited as an autosomal recessive disorder. Cases are typically diagnosed in the the early neonatal period with vomiting, neutropenia, thrombocytopenia, progressive encephalopathy and hyperammonaemia.

Homocystinuria describes an increased excretion of the thio-amino acid homocysteine in the urine. The source of this increase may be one of many metabolic factors and not just a failure of the enzyme cystathione beta synthase.

E7113	METHYLMALONIC ACIDURIA	Prenatal diagnosis; Termination

Methylmalonic acid, (MMA), increases in the amniotic fluid of affected fetus and prenatal diagnosis can be achieved[6].

Medium-chain Acyl-CoA Dehydrogenase Deficiency, (MCAD), (E713)
Fatty acid oxidation defects such as MCAD are a distinct type of organic acid disorder characterized by hypoketotic hypoglycaemia, hyperammonaemia and cardiomyopathy.

MCAD is among the most common of all IEM's and is also believed to account for up to 5% of all SIDS cases. It is caused by a mutation in the *ACADM* gene on chromosome 1. As a consequence of this mutation gluconeogenesis is effectively inhibited and the body is unable to metabolize fats during periods of fasting or metabolic stress. The clinical result is severe hypoglycaemia and hypoketonuria with elevated acylcarnitines such as octanoylcarnitine in the blood.

E713	MCAD DEFICIENCY	Live-birth; Male infant; Diagnosed after 1 month

MCAD deficiency is identified by quantitative detection of acylcarnitines from dried blood spots.

4.1.6. Other Disorders of Carbohydrate Metabolism

'Classic' Galactosaemia – GALT deficiency, (E742)
This is a rare disorder of carbohydrate metabolism which is inherited in an autosomal recessive manner. It results from a deficiency of the enzyme galactose-1-phosphate uridyl transferase. Affected infants are normal at birth but develop jaundice, vomiting and diarrhoea shortly after commencement of milk feeds. If the disorder remains unrecognized liver disease, cataracts and mental retardation will result. Luckily most infants are diagnosed on new born screening.

E742	GALACTOSAEMIA- GALT DEFICIENCY	Live-birth; Male infant; Diagnosed after 1 week

4.1.7. Cystic Fibrosis, (E840; E841; E849)

Approximately 1:2,500 babies born in the UK have cystic fibrosis. It is inherited as an autosomal recessive condition and affects the lungs, pancreas, liver and intestine. It is caused by any one of many different mutations in the gene for the protein cystic fibrosis transmembrane conductance regulator, (CFTR).

[6] Inove Y & Ohse M. Anal. Bioanal.Chem 2011:400(7); 1953-8

The most common mutation, ΔF508, is a deletion of three nucleotides that result in the loss of the amino acid phenylalanine at the 508th position on the protein. This mutation causes 70% of cases of cystic fibrosis world-wide.

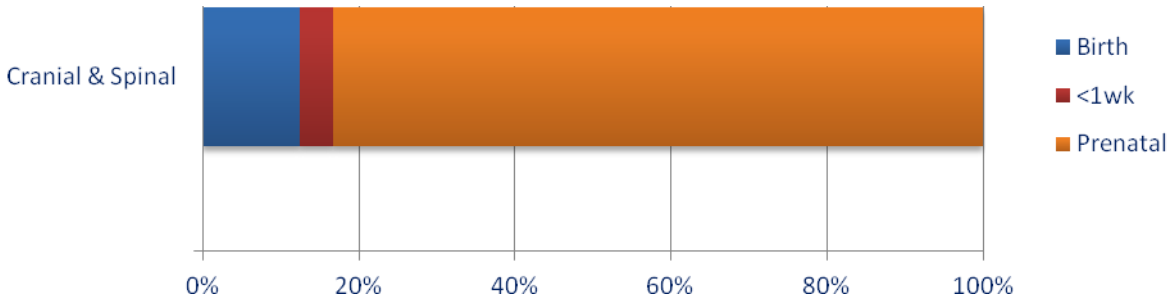
There were four cases of cystic fibrosis diagnosed in 2013-2014, all were live births.

E840	CYSTIC FIBROSIS	Male; Lymphangioma; Diagnosed < 1 week
E840	CYSTIC FIBROSIS	Female; Talipes equino-varus; Diagnosed 1 – 4 weeks
E840	CYSTIC FIBROSIS	Male; Diagnosed < 1 week
E840	CYSTIC FIBROSIS	Female; Diagnosed < 1 week

4.2. Cranial & Spinal Abnormalities

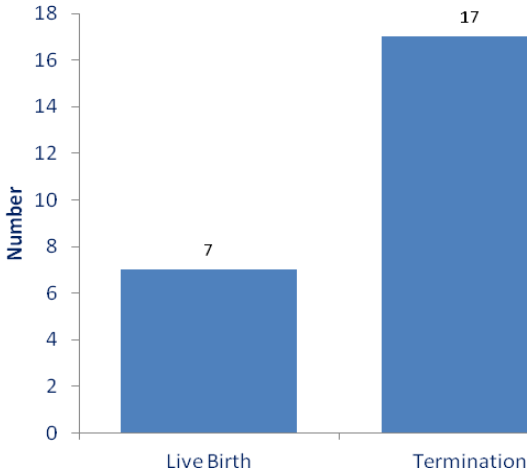
A total of 45 abnormalities of the central nervous system were recorded with 24 in the primary diagnostic position, (53%). Nearly eighty-four percent, (n=20), of the primary abnormalities are diagnosed on prenatal ultrasound scan assessment, (Figure 4.2).

Figure 4.2: Point of Diagnosis of Primary Cranial & Spinal Abnormality



The majority of pregnancies in which a primary diagnosis of cranial spinal abnormality was made ended in termination following prenatal diagnosis, (n=17, 70.8%), (Figure 4.3)

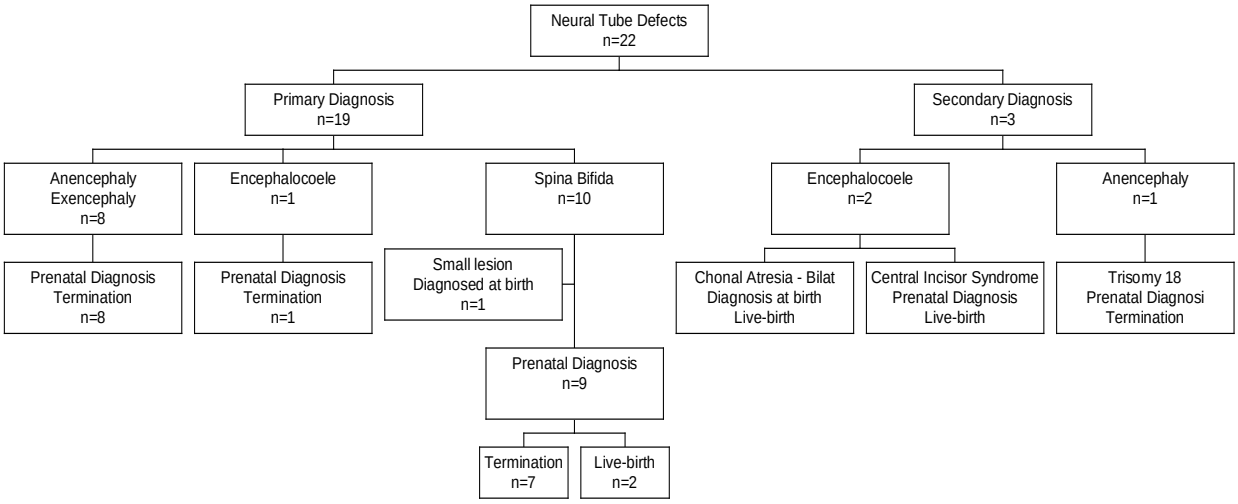
Figure 4.3: Outcome of Pregnancy with Primary Cranial & Spinal Abnormality



4.2.1. Neural Tube Defect, (NTD)

Neural Tube Defects are malformations of the brain and spinal cord. The clinical spectrum includes anencephaly, encephalocoele, craniorachischsis, hydranencephaly, iniencephaly[7], spina bifida cystica and spina bifida occulta. Twenty-two NTD's were defined in the 2013-2014 data, (Figure 4.4).

Figure 4.4: Overview of Neural Tube Defects



Anencephaly, Acrania & Exencephaly, (Q000)

Anencephaly is defined as absence of the superior vault and cerebrum. It is the most common and severe anomaly of the central nervous system. The most striking feature at ultrasound is the presence of large bulging eyes marking the superior boundary of the fetus. Abrupt spasmodic body movements are not uncommon. The prognosis is grave and the severity of the condition justifies termination of the pregnancy. There were 9 cases of anencephaly/exencephaly. The majority were listed in the primary position and were all evident on prenatal scan.

Q000	ANENCEPHALY	Prenatal diagnosis; Termination
Q000	ANENCEPHALY	Prenatal diagnosis; Termination
Q000	ANENCEPHALY	Prenatal diagnosis; Termination
Q000	ANENCEPHALY	Prenatal diagnosis; Termination
Q000	ANENCEPHALY	Prenatal diagnosis; Termination
Q000	ANENCEPHALY	Prenatal diagnosis; Termination
Q000	ANENCEPHALY	Prenatal diagnosis; Termination
Q000	EXENCEPHALY	Prenatal diagnosis; Termination

The remaining case was seen in association with Trisomy 18

Q910	TRISOMY 18	Prenatal diagnosis; Termination at 9 weeks

[7] Iniencephaly is a rare malformation characterized by the triad of occipital bone defect, cervical dysraphism and fixed retroflexion of the fetal head.

Encephalocoele, (Q010, Q012, Q019)
A cephalocoecele is a defect in the bony skull through which meninges and brain substance may protrude. It is a result of a defect of neural tube closure during the sixth week of gestation. The location of the defect is mid-occipital in 75% of cases, fronto-ethmoidal in 13% and parietal in 12%. The bony defect is usually small in relation to the hernial sac. Differentiation is required from cystic hygroma, teratoma and amniotic band . Cephaloceles may occur in isolation or as a feature of various s, (e.g. Meckel-Gruber).

One case of encephalocoele was diagnosed on prenatal scan and listed in the primary diagnostic position. This was a female fetus with no associated abnormalities.

Q018	ENCEPHALOCELE - LARGE POSTERIOR	Prenatal diagnosis; Termination at 20 weeks

Two further cases of encephalocoele are described. A number of similarities are noted between these two cases despite the markedly different ICD10 classification.

Q300	CHOANAL ATRESIA - BILAT	Live-birth
Q878	SOLITARY MEDIAN MAXILLARY CENTRAL INCISOR	Live-birth

Frontal encephalocoele was associated with bilateral chonal atresia, coloboma, cleft soft palate, plagiocephaly and pre-auricular cyst in a female infant delivered at term. There had been no suspicion of abnormality prior to delivery.

The unusual case of Solitary Median Maxillary Central Incisor in a male infant delivered at 36 weeks gestation is discussed later, (Part 4.5.5, Page 43).

Spina Bifida, (Q0511, Q0521, Q0531, Q055, Q0572, Q0582, Q059)
Spina bifida is a combined defect involving the spinal canal and its contents and is characterized by partial or complete absence of the vertebral arches. Spina bifida results from a primary failure of closure of the posterior vertebral arches involving one of more spinal segments. Posterior defects of neural tube closure are among the most common fetal abnormalities. Studies have shown that NTD's are ultimately based on the inadequate expression of certain pattern control genes. This may be caused by gene deletion, exogenous teratogenic agents, (e.g. valproic acid), or vitamin deficiency.

A total of ten cases of spina bifida are listed.

Q052	LUMBAR MELOMENINGOCELE (LARGE)	
Q052	L/S MYELOMENINGOCELE	
Q052	L/S SPINA BIFIDA	Arnold-Chiari Malformation
Q0521	L/S MYELOMENINGOCELE (OPEN) WITH HYDROCEPHALUS	Arnold-Chiari Malformation
Q053	SACRAL MYELOMENINGOCELE	Arnold-Chiari Malformation
Q0531	SACRAL MYELOMENINGOCELE	Arnold-Chiari Malformation
Q0572	L/S MYELOMENINGOCELE (CLOSED)	Arnold-Chiari Malformation
Q059	L/S SPINA BIFIDA	
Q059	L/S SPINA BIFIDA	
Q059	MYELOMENINGOCELE (SMALL), BASE OF SPINE	

The majority of diagnoses of spina bifida, (n=9, 90%), were made on prenatal ultrasound scan. Two pregnancies continued to live-birth at 37-39 weeks gestation following prenatal diagnosis. In seven cases termination of pregnancy was performed.

A small sacral myelomeningocoele was diagnosed at time of delivery in a male infant at term. There had been no antenatal suspicion of abnormality.

4.2.2. Holoprosencephaly, (Q042)

This is a condition in which only a single large ventricle is seen or with a small skull containing no midline echo, disorganized cerebral ventricles and prominent cerebral peduncles. The disorder is associated with chromosomal defects, typically Trisomy 13.

Three forms are distinguished: alobar, semi-lobar and lobar holoprosencephaly. Both the alobar and semilobar forms are characterized by a single cystic cavity between the two hemispheres in the anterior part of the skull. Although holoprosencephaly is essentially a midline defect differentiation is required from pronounced hydrocephalus; in contrast to hydrocephalus ultrasound scan will show an absence of the midline echo and cavum septi pellucidi. Varying degrees of thalamic fusion are seen depending on the form. Prognosis depends on the form. The alobar form is fatal but the semi-lobar and lobar forms are compatible with life at least until childhood. Significant mental retardation is to be expected.

Holoprosencephaly was recorded as a primary abnormality in one case. A secondary abnormality is coded as Q935. This is an ICD10 code for “Other deletion of part of chromosome”.

Q042	HOLOPROSENCEPHALY - ALOBAR	Pre-natal diagnosis; Termination

Holoprosencephaly was also seen as a secondary diagnosis in association with fetal aneuploidy.

Q910	TRISOMY 18	Pre-natal diagnosis; Termination
Q914	TRISOMY 13	Pre-natal diagnosis; Termination

Trisomy 18 was diagnosed following the finding of a cystic hygroma on booking scan at 11 weeks gestation. The case of Trisomy 13 was a later diagnosis made at time of the fetal anomaly scan. This case was associated with a number of other abnormalities including cleft lip and palate, abnormal nose, polydactyly and aplasia cutis congenita[8].

4.2.3. Microcephaly, (Q02X)

Microcephaly is relatively rare with an incidence of 1:8500 births. The ultrasound diagnosis is based on the detection of a small skull. Craniometric parameters must be seen to be reduced on serial scans. Microcephaly is associated with many causes and usually results in severe mental retardation. Causes include CNS malformations, infections (CMV, rubella, and toxoplasmosis), chromosomal abnormalities, maternal PKU and certain teratogens, (including alcohol and cocaine).

[8] Aplasia cutis is a condition with congenital absence of an area of skin. It is classically associated with Trisomy 13 but may also be seen following maternal exposure to methimazole and carbimazole.

There were three cases of microcephaly described in the data. In one case microcephaly is the primary diagnosis. This was a female infant delivered at term. The diagnosis of microcephaly was made between 1 and 4 weeks of life. There were no other associated features.

Q02X	MICROCEPHALY	Term delivery; Live-birth; Female;

Two further cases of microcephaly are listed with the abnormality as a secondary feature.

Q899	UNDIAGNOSED GENETIC	Term delivery; Live-birth; Female
P358	CONGENITAL VARICELLA	Preterm delivery; Live-birth; Female

A female infant delivered at term was noted to have a number of abnormalities including microcephaly, abnormalities of the upper limbs, coloboma, malrotation of the gut, accessory kidney, ASD and stenosis of the lacrimal duct. The 'undiagnosis' was made between 1 and 12 months of life.

Overall the varicella zoster virus carries a relatively low risk to the fetus. However there is a well defined congenital varicella that is recognized to follow primary maternal infection. Congenital varicella is characterized by limb hypoplasia, cutaneous scars, cataracts, cerebral cortical atrophy and cerebellar hypoplasia[9]. The CNS manifestations result in microcephaly. The case listed above was a female infant delivered to an older mother prematurely at 30 weeks gestation. The diagnosis of congenital varicella was made after the first month of life. Associated abnormalities included congenital cataracts and agenesis of the corpus callosum in addition to microcephaly, (see below).

4.2.4. Hydrocephalus, (Q030, Q039)

Surprisingly no cases of isolated hydrocephalus were described in the 2013-2014 data.

4.2.5. Other Cranial & Spinal Abnormalities

Agenesis of the Corpus Callosum, (Q0400)

The corpus callosum is a transverse fibre tract that connects the cerebral hemispheres at the base of the longitudinal fissure. It is not fully developed until 20 weeks gestation. The true frequency with which the corpus callosum fails to form is not known. There may well be asymptomatic individuals with partial or complete callosal agenesis. The ultrasound detection of a corpus callosum defect is difficult and requires a very detailed examination. Agenesis of the Corpus Callosum, (ACC), is commonly associated with other abnormalities and is listed as a secondary diagnosis in four cases.

Q758	POOR DEVELOPMENT OF MID-FACE	Termination
Q878	SOLITARY MEDIAN MAXILLARY CENTRAL INCISOR	Live-birth
Q935	DELETION 1p22	Female; Live-birth
P358	CONGENITAL VARICELLA	Female; Live-birth

The case listed as 'Poor Development of Mid-Face' was a termination of pregnancy at 17 weeks gestation following the prenatal diagnosis of multiple fetal abnormalities including micrognathia, reduction defects of the lower limbs, renal dysplasia as well as agenesis of the corpus callosum.

[9] Sauerbrei A & Wutzler P. The Congenital Varicella . J. Perinatol. 2000; 20:548-54

Arachnoid Cyst, (Q046)
Arachnoid cysts are rare intracranial cystic masses arising from the arachnoid membrane. They can be primary or secondary. Primary arachnoid cysts are a developmental anomaly whereas secondary cysts are acquired as a consequence of trauma, inflammation or intracerebral haemorrhage. The ultrasound appearances are of a fluid filled cyst that maybe midline or at an asymmetrical site. Generally the prognosis is good.

Q046	ARACHNOID CYST ® - LARGE	Prenatal diagnosis (late); Live-birth at term

The case listed above describes a male infant delivered at term. The presence of an arachnoid cyst was diagnosed on ultrasound just a few days prior to delivery.

NOTE:
Malformations such as congenital spondylolisthesis and hemivertebral s, (but not spina bifida occulta), are classified under 'Congenital disorders of the Musculoskeletal System'.

4.3. Cardiac & Circulatory

Disorders of the 'Heart & Circulatory System' are the second most common grouping of defined abnormalities, (n=102, 18.3%), and 35.3% of these abnormalities are in the primary diagnostic position, (36/102).

The most common cardiac abnormality was ventricular septal defect (VSD), (n=14), which was always recorded as a secondary diagnosis.

The severest forms of Congenital Heart Disease (CHD) should be identifiable on prenatal ultrasound scan by 24 weeks gestation. The classic 'four-chamber view' will diagnose the majority but certainly not all of these abnormalities. Additional views including visualization of both left and right outflow tracts are recommended to improve diagnostic ascertainment[10].

As part of its review process EUROCAT defines a list of Severe Congenital Heart Defects, (Table 4.1). These, in essence, are those cardiac malformations that require surgical resolution.

Overall thirty-five cases displayed forty-one abnormalities that would fulfil the EUROCAT criteria for Severe Congenital Heart Disease. EUROCAT defined Severe Congenital Heart Defects are not always defined as the primary abnormality – they are secondary abnormalities in 50% of cases.

Table 4.1: EUROCAT Severe Congenital Heart Disease

Common arterial truncus (Q200)	No cases;
Transposition of Great arteries (Q203) ‡***	4; (1 primary, 3 secondary)
Single ventricle (Q204) *	1; (1 primary)
Atrioventricular septal defect (Q212)	7; (7 secondary)
Tetralogy of Fallot (Q213)	9; (8 primary, 1 secondary)
Tricuspid Atresia & Stenosis (Q224) ‡*	1; (1 secondary)
Ebstein's anomaly (Q225)	No cases;
Pulmonary valve atresia (Q220, Q221)*	5; (4 primary, 1 secondary)

[10] NSC Recommendations.

Aortic valve atresia/stenosis (Q230)	1; (1 primary)
Hypoplastic left heart (Q234)	3; (3 primary)
Hypoplastic right heart (Q226) ‡**	3; (1 primary, 2 secondary)
Coarctation of aorta (Q251)	5; (3 primary, 2 secondary)
Total anomalous pulmonary venous return (Q262)	2; (2 primary)

* Four cases had two EUROCAT defined abnormalities.
‡ One case had three EUROCAT defined abnormalities, (hypoplastic right heart, tricuspid atresia and TGA).

Seventy-four percent of cases of EUROCAT defined severe congenital heart disease, (n=26) were live births, (Figure 4.5). Three cases were terminated following prenatal diagnosis of abnormality, two with a combination of transposition of the great vessels and hypoplastic right heart and the other with multiple abnormalities including hypoplastic left heart, aortic atresia, mitral stenosis and limb defects.

Overall twenty-one of these thirty-five EUROCAT defined severe cardiac cases had an abnormality diagnosed on prenatal scan giving a case detection rate of 60%, (Figure 4.6). The prenatal detection rate for the thirty-six cases classified as having a primary cardiac abnormality was 50%, (Figure 4.7).

Figure 4.5: Outcome of pregnancies associated with EUROCAT defined Severe Cardiac Abnormality, (n=35).

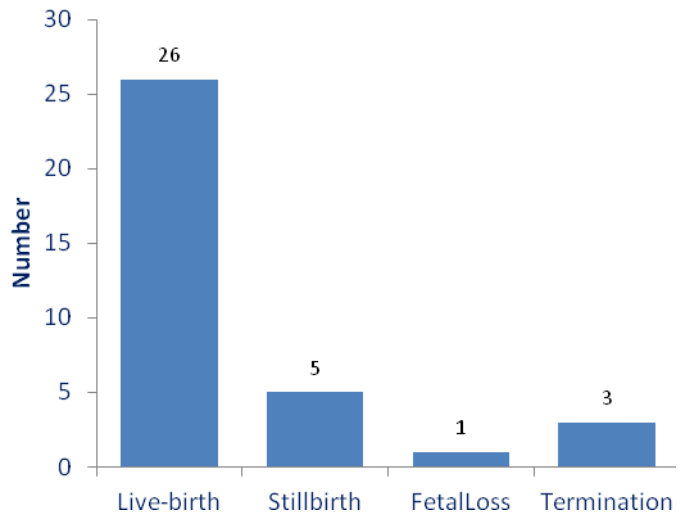


Figure 4.6: Point of Diagnosis of EUROCAT defined Severe Cardiac Abnormality, (n=35).

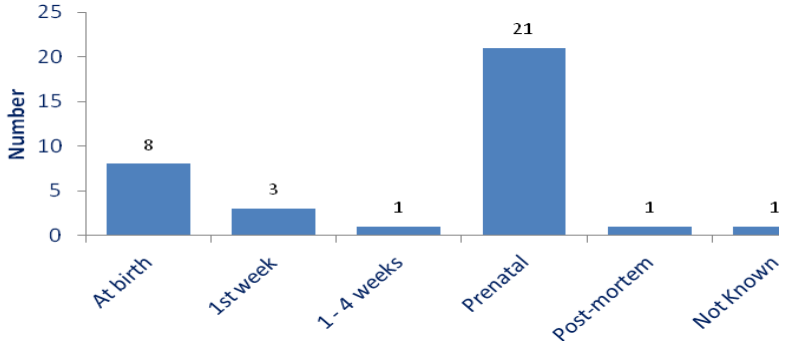
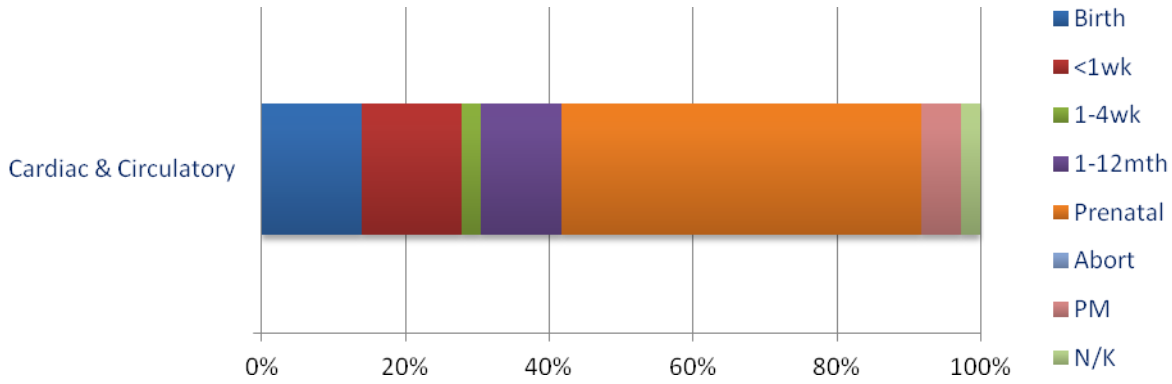


Figure 4.7: Point of diagnosis of ALL primary cardiac abnormalities, (n=36)



4.3.1. Transposition of the Great Vessels, (Q203)

In this anomaly there is ventriculo-arterial discordance with the aorta arising from the right ventricle and the pulmonary trunk from the left ventricle. However the connections between the atria and ventricles are other wise normal. It is a relatively frequent cardiac anomaly occurring in about 5-7% of all live births with a congenital heart defect.

This abnormality results from an abnormal division of the truncus arteriosus. In transposition the septum dividing the truncus has failed to rotate so that the aorta arises from the right ventricle and the pulmonary artery from the left. This leads to two independent circulations and would be incompatible with ex-utero life if it wasn't for the fact that there is nearly always a communication in the form of ASD, VSD or PDA. Extra-cardiac abnormalities are rare and prognosis is generally good.

Dextro-transposition of the great arteries cannot be detected prenatally with the standard four-chamber view: the four chamber view appears normal except in cases with an associated VSD. Its detection requires evaluation of the origin and course of the two great vessels. Defining the parallel course of both major vessels, along with their valves, in one plane is characteristic. In the less commonly used short-axis view the aorta is located anterior to the pulmonary trunk and the 'circle and sausage' sign is absent.

There were four cases where Transposition of the Great Vessels is recorded. In one case it is the primary abnormality whereas in the remaining three it is associated with other severe cardiac malformation.

Q203	TGV	Prenatal diagnosis; Termination
Q204	HYPOPLASTIC (L) HEART	Prenatal diagnosis; Live-birth
Q226	HYPOPLASTIC ® HEART	Prenatal diagnosis; Termination
	DEXTROCARDIA WITH SITUS	Prenatal diagnosis; Live-birth
Q8930	INVERSUS	

Two additional cases were seen of discordant atrioventricular connection that don't fall into the strict EUROCAT definition of transposition of the great vessels, and are therefore not included in the diagnostic figures. They are included for completeness.

	CONGENITALLY CORRECTED	Live-birth; Male; Diagnosed at birth
Q205	TGV	
	CONGENITALLY CORRECTED	Prenatal diagnosis; Live-birth; Female
Q205	TGA	

In both cases there were additional cardiac abnormalities.

4.3.2. Atrioventricular Septal Defect, (AVSD), (Q212)

These defects involve a combination of low atrial and high ventricular septal defects and result from a failure of endocardial cushion development. An AVSD is usually associated with extracardiac anomalies particularly Trisomy 21. An AVSD is also often found in association with an abnormal cardiac position such as left or right sided isomerism. The prognosis depends on the associated extracardiac anomalies.

Q240	DEXTROCARDIA	Prenatal diagnosis; Live-birth
Q3799	CLEFT LIP & PALATE - COMPLEX	Prenatal diagnosis; Live-birth
Q900	TRISOMY 21	Live-birth; Diagnosis at birth
Q900	TRISOMY 21	Live-birth; Diagnosis at birth
Q900	TRISOMY 21	Prenatal diagnosis; Stillbirth
Q900	TRISOMY 21	Live-birth; Diagnosis at birth
Q910	TRISOMY 18	Prenatal diagnosis; Stillbirth

This diagnosis should be considered whenever a defect is noted in the portion of the atrial septum near the AV valves on a standard four-chamber view.

The prenatal detection rate of atrio-ventricular septal defect was only 57.1% in this series,
(66% in 2012-2013).

4.3.3. Fallot's Tetralogy, (Q213)

Fallot's Tetralogy is a single error of development with four consequences. The septum dividing the truncus instead of joining up with the inter-ventricular septum deviates to the right. The right ventricular outflow is therefore restricted, (pulmonary stenosis or atresia), the aorta extends to the right of the septum, (over-riding aorta), and receives blood from both ventricles and there is a deficiency in the upper part of the membranous septum, (VSD). The right ventricle hypertrophies to pump blood through both a narrowed pulmonary orifice and the aorta.

Only two of the four abnormalities that characterize Fallot's Tetralogy, (the VSD and the over-riding aorta), can be definitively detected on prenatal scan. The pulmonary stenosis is a consequence of under perfusion of the valve and therefore 'evolves' during intrauterine and postnatal life. Right ventricular hypertrophy is secondary to the increased workload of the right ventricle and is generally diagnosed after delivery but a few severe cases are detected on scan in pregnancy.

Nine cases of Fallot's Tetralogy are listed in the 2013-2014 data. All were live-births at term. In the majority the abnormality is recorded in the primary position.

Q213	TETRALOGY OF FALLOT	Prenatal diagnosis
Q213	TETRALOGY OF FALLOT	Prenatal diagnosis
Q213	TETRALOGY OF FALLOT	Prenatal diagnosis; Cong. abnormality of pulmonary artery
Q213	TETRALOGY OF FALLOT	Prenatal diagnosis
Q213	TETRALOGY OF FALLOT	Prenatal diagnosis
Q213	TETRALOGY OF FALLOT	Diagnosed at birth
Q213	TETRALOGY OF FALLOT	Anal atresia with fistula; Diagnosed at birth
Q213	TETRALOGY OF FALLOT	Prenatal diagnosis

The severity is variable and, as mentioned, earlier 'mild' cases are likely to be missed by ultrasound. However, prenatal diagnosis was achieved in a six cases: a prenatal diagnosis rate of 75%. The two remaining cases were diagnosed at birth.

The anomaly is recorded as an associated diagnosis in one further case.

D821	DI GEORGE	Tetralogy of Fallot; Thyroglossal cyst; Hypospadias

The point of diagnosis for this case is not recorded but this was also a live-birth at term. The ICD10 code 'Q935' or 'Other deletion of part of a chromosome', is also listed against this case. This is not surprising in that Di George is more appropriately considered as a 22q11.2 deletion sequence rather than a primary disorder of the haematological system!

4.3.4. Pulmonary Valve Atresia & Stenosis, (Q220, Q221)

Pulmonary valve atresia leads to hypoplasia of the right ventricle with pronounced myocardial hypertrophy and secondary dysplasia of the tricuspid valve. An atrial septal defect is often present as an associated cardiac anomaly. The standard four-chamber view may demonstrate hypoplasia, myocardial hyperplasia and hypokinesia of the right ventricle.

Pulmonary stenosis, on the other hand, refers to narrowing of the right ventricular outflow tract in the area of the pulmonary valve. The stenosis is classified by location as valvular, sub-valvular and supra-valvular. Extra-cardiac anomalies are uncommon and it is rarely associated with chromosomal abnormality.

A case where multiple abnormalities were detected on ultrasound scan at 11 weeks gestation was a stillbirth at 25 weeks. Abnormalities included hypoplastic right heart, VSD, reduction defects of the upper limbs and webbed fingers.

Q220	PULMONARY ATRESIA	Prenatal diagnosis; Stillbirth
Q221	PULMONARY VALVE STENOSIS	Live-birth; Diagnosed at birth
Q221	DYSPLASTIC THICKENED TRILEAFLET PULMONARY VALVE	Prenatal diagnosis; Live-birth
Q221	PULMONARY VALVE STENOSIS	Live-birth; Diagnosis in 1st wk.
Q998	UNBAL TRANSLOC: 10q24 DUPLICATION & 4q13 DELETION	Live-birth; Diagnosed at birth.

4.3.5. Hypoplastic Left Heart , (Q234)

This is a group of defects in which the left ventricle may be absent or extremely hypoplastic as a result of a combination of aortic atresia and mitral valve atresia or stenosis. Approximately 10% of cases are associated with a chromosomal abnormality, usually Trisomy 13, Trisomy 18 or Turner . Hypoplastic Left Heart is readily diagnosed on prenatal scan. In severe cases the four-chamber view is already abnormal in the second trimester. The lumen of the left ventricle may be extremely small or simply not visualized. The aorta is extremely hypoplastic and its origin and course are difficult to define. Compensatory dilatation of the right ventricle and pulmonary trunk may be present.

Incidence is typically quoted at 0.2/1000 live-births, (0.02%). Hypoplastic left heart accounts for 7-9% of all cases of congenital heart disease diagnosed during the first year of life.

Three cases of hypoplastic left heart , (Q234), were diagnosed in NHS GG&C during 2013-2014.

Q234	HYPOPLASTIC (L) HEART	Prenatal diagnosis; Live-birth
Q234	HYPOPLASTIC (L) HEART	Prenatal diagnosis; Multiple cardiac anomalies; Termination
Q234	HYPOPLASTIC (L) HEART	Prenatal diagnosis; Live-birth

There was a further case of what was essentially hypoplastic left heart that was labelled as ‘Single Ventricle’ under the ICD10 code of Q204. That case was also associated with TGA and pulmonary artery stenosis.

4.3.6. Coarctation of the Aorta, (Q251)

A simple coarctation of the aorta is difficult to diagnose on prenatal scan. Visualization of the aortic arch in longitudinal section is not a regular feature of prenatal ultrasound scan. There may be disproportion between the left and right ventricles and between the aortic arch and pulmonary trunk. However, this is not a reliable diagnostic feature as a slight discrepancy in size between left and right ventricle will be seen in a healthy third trimester fetus.

Coarctation of the aorta is accompanied by extra-cardiac anomalies in 25% of cases. Typical anomalies include those whose embryonic development coincides with the timing and location of aortic arch development and include upper gastrointestinal tract anomalies such as oesophageal atresia and diaphragmatic defect.

A total of five cases of coarctation of the aorta were seen during 2013-2014. The prenatal detection rate for this EUROCAT defined Severe Congenital Heart Defect was 60%, (n=3).

Q251	COARCTATION AORTA	Prenatal diagnosis; VSD
Q251	COARCTATION AORTA	Isolated; Diagnosed between 1 – 4 weeks
Q2510	COARCT AORTA - PRE-DUCTAL	Fetal loss at 20 weeks
Q6140	MULTICYSTIC DYSPLASTIC KIDNEY (L)	Stillbirth; Multiple cardiac anomalies
Q8930	DEXTROCARDIA WITH SITUS INVERSUS	Live-birth; Multiple cardiac anomalies

4.3.5. Total Anomalous Pulmonary Venous Drainage, (TAPVD), (Q262)
Total (or partial) anomalous pulmonary venous return is present when all or some of the pulmonary veins drain into the right atrium or into the venae cavae that enter the right atrium.

Total Anomalous Pulmonary Venous Drainage (TAPVD) is difficult to diagnose on prenatal scan unless the drainage is grossly distorted. Possible suggestive signs include a left atrium that is somewhat smaller than the right atrium or the presence of a persistent left superior vena cava, (often best seen in the 'three vessel view' where it appears as a 4th vessel to the left of the pulmonary trunk). However, prognosis is generally good.

Q262	TAPVD	Live-birth; Diagnosis 1 – 4 weeks
Q262	TAPVC	Live-birth; Diagnosis at birth

A case of partial anomalous pulmonary venous connection, (Q263), was seen in association with mosaic trisomy for a partial ring 14 chromosome in a male infant delivered at 39 weeks gestation. The formal diagnosis was made between 1 and 4 weeks of life. A VSD was also present.

Q928	MOSAIC TRISOMY FOR A PARTIAL RING 14 CHROMOSOME

4.4. Congenital Malformations of the Respiratory System.

A total of eight respiratory tract abnormalities are classified in the primary diagnostic position.

4.4.1. Choanal Atresia, (Q300)
This abnormality results from a failure of recanalization of the nasal fossae during fetal development. Consequently the choana remain blocked by bony and/or membranous tissue.

The blockage may be unilateral or bilateral. Any condition that causes significant depression of the nasal bridge or mid-face can be associated with choanal atresia. Neonates are obligate nose breathers and bilateral choanal atresia can be a serious issue.

Q300	CHOANAL ATRESIA (L)	Preterm at 26 weeks
Q300	CHOANAL ATRESIA - BILAT	Female: Term delivery
Q878	SOLITARY MEDIAN MAXILLARY CENTRAL INCISOR	Live-birth at 36 weeks

There were three cases of choanal atresia described, one in association with Solitary Medial Maxillary Central Incisor , (Part 4.5.5, Page 43). All were live-births with the diagnosis of choanal atresia being made shortly after birth in two cases.
A female infant delivered prematurely at 26 weeks gestation had a unilateral (left-sided) choanal atresia which was diagnosed between 1 and 12 months of life.

The female infant with bilateral choanal atresia also demonstrated a number of additional malformations including frontal encephalocoele, coloboma, cleft soft palate, plagiocephaly and a pre-auricular cyst. There had been no suggestion of abnormality prior to delivery, (Part 4.2.1, Page 30).

4.4.2. Laryngeal Atresia, (Q318)

Congenital atresia of the larynx is a rare abnormality of the upper airway. Prenatal diagnosis can be difficult but diagnosis has been made as early as 15 weeks[11]. Increased lung echogenicity, a fluid filled trachea and ascites are the typical diagnostic features and inversion of the diaphragm may be present. Polyhydramnios may also be seen.

The two cases listed in the current data were diagnosed on prenatal scan at 19 weeks

Q318	LARYNGEAL STENOSIS	Multiple abnormalities
Q318	LARYNGEAL ATRESIA	Stillbirth at 34 weeks

Laryngeal atresia/stenosis can be associated with other structural and genetic abnormalities particularly renal agenesis and intestinal malformations. Termination of pregnancy was performed at 21 weeks gestation following the prenatal diagnosis of laryngeal stenosis and other malformations including malformation of the cardiac septa, renal dysplasia, polysyndactyly, lissencephaly and Meckel diverticulum.

4.4.3. Congenital Cystic Adenomatoid Malformation, (Q338, Q3380)

The respiratory system starts to develop at around 3 week's gestation. Aberrations in the developmental process may give rise to a group of structural malformations collectively referred to as broncho-pulmonary foregut malformations, (BPFM's). The three commonest are Sequestration, Congenital Cystic Adenomatoid Malformation and Congenital Lobar Emphysema.

[11] Chaemsaithong P et al. Case Rep. Radiol. 2012.

Congenital Cystic Adenomatoid Malformation, (Q338, Q3380).
Congenital cystic adenomatoid malformation (CCAM) is a rare unilateral hamartomatous dysplasia of the lung. Three pathological types are recognized: Type 1 with cysts >2cm diameter, Type II with cysts <1cm diameter and Type III a predominantly solid type with microcycts. The ultrasound features are consistent with the pathological changes. The affected lung is markedly enlarged in all three types and leads to a mediastinal shift to the opposite side and as a result normal lung tissues become compressed. The mediastinal displacement can also compromise venous return leading to fetal hydrops. Prognosis is dependent upon histological type, (in general Types II and III are associated with a poor prognosis), the development of hydrops, severity of pulmonary hypoplasia on the unaffected side, timing of diagnosis and early planned intervention.

There were two cases of congenital cystic adenomatoid malformation listed in the primary position.

Q3380	CCAM ® Middle Lobe	Pre-natal diagnosis; Live-birth
Q3380	CCAM (L)	Pre-natal diagnosis; Live-birth

A third case was seen in association with spina bifida.

4.4.4. Neuroenteric Cysts, Q341
Neuroenteric cysts represent a failure of complete separation of the notochord from the foregut during the 3rd week of embryogenesis. They are rare and usually located in the posterior mediastinum but can be intracranial. Neuroenteric cysts are frequently associated with vertebral anomalies including hemi-vertebrae. As a consequence of the significant lung hypoplasia symptoms of respiratory distress are usually evident at birth. Ultrasound shows a large cyst in the posterior mediastinum that typically displaces the heart and causes an irregularity of the thoracic spine.

Q341	FOREGUT DUPLICATION CYST POSTERIOR MEDIASTINUM

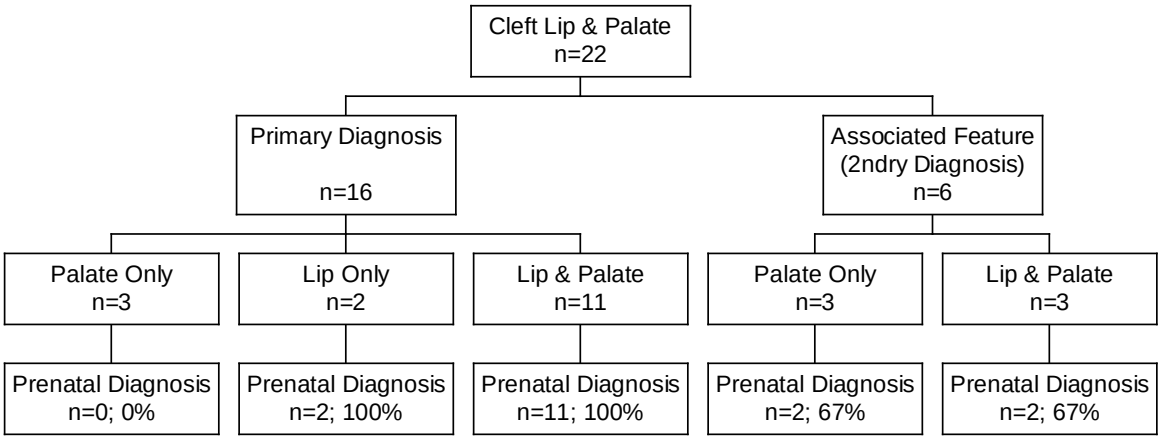
A single case is described in a male infant delivered at 36 weeks gestation following prenatal diagnosis. There was an associated malformation of the spine.

4.5. Face & Neck
Congenital malformations of the head and neck are a wide and heterogeneous group that range in importance and severity from purely cosmetic defects to lethal anomalies. They can be isolated or occur as a component of a sequence, or chromosomal disorder.

4.5.1. Cleft Lip & Palate, (Q 352, Q3539, Q3599, Q3690, Q3699, Q378, Q3799)
Cleft lip and palate are among the more common congenital malformations. Clefts are mainly isolated lesions but are also found in association with various s and chromosomal abnormalities, particularly Trisomy 13 and 18. Cleft lip and palate can be diagnosed on prenatal ultrasound scan in a coronal or sagittal scan through the face or in a transverse scan at the level of the maxilla. Large clefts are fairly conspicuous but a small cleft may be easily overlooked: with a small lip cleft the coronal scan shows only a narrow defect in the upper lip.

A total of 22 cases are recorded with cleft lip, cleft palate or both, (Figure 4.8).

Figure 4.8: Overview of Cleft Lip & Palate



Sixteen cases of cleft lip were listed overall, (either isolated or associated with cleft palate or other abnormality). Prenatal diagnosis was achieved in 15 cases of these cases.

Cleft palate, (with or without cleft lip), was seen in 20 cases. Of these, cleft palate was recorded as a secondary diagnosis in six cases.

Q688	FLEXION CONTRACTURES ALL LIMBS	Palate only
Q8708	PIERRE ROBIN SEQUENCE	Palate only
	UNBAL TRANSLOC: 10q24 DUPLICATION & 4q13	Cleft lip & palate
Q998	DELETION	
Q300	CHOANAL ATRESIA - BILAT	Palate only
Q914	TRISOMY 13	Cleft lip & palate
Q914	TRISOMY 13	Cleft lip & palate

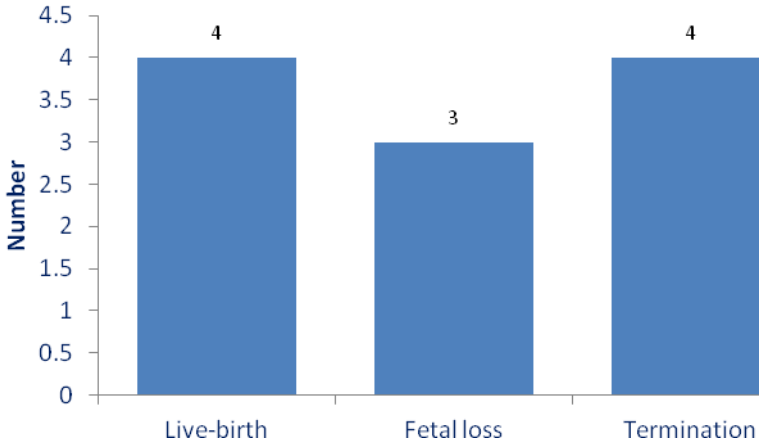
Where prenatal diagnosis of cleft palate was achieved it was typically in association with another anomaly such as cleft lip or a chromosomal . None of the 3 cases of isolated cleft palate were diagnosed on antenatal scan they were all diagnosed at birth.

4.5.2. Congenital Cavernous Lymphangioma, 'Cystic Hygroma', (D181, D1810).
The presence of a congenital cavernous lymphangioma is recorded for 11 cases. Typically the data only records the presence of a congenital lymphangioma - it does not record location. The presumption is made from the data provided that a 'cystic hygroma' is seen at the neck but lymphangioma may present at other locations such as the limbs.

Lymphangioma was a primary isolated finding in two cases and a secondary abnormality in the remaining nine. Cystic hygroma was associated with chromosomal abnormality in eight cases, (72.7%). The majority of cases, (n=10, 90.9%), were identified prenatally. The remaining case, an 'extensive lymphangioma of the left neck' was diagnosed at preterm delivery of a live male infant.

Four cases were terminated following prenatal diagnosis, all in association with other abnormality. There were four live births and three fetal losses. The fetal losses were all associated with fetal aneuploidy, (Figure 4.9).

Figure 4.9: Outcome of pregnancies associated with cystic hygroma, (n=11)



4.5.3. Pierre-Robin Sequence, (Q870)

There was one case recorded of Pierre Robin Sequence, (severe micrognathia with a secondary cleft palate).

Q8708	PIERRE ROBIN SEQUENCE	Prenatal diagnosis; Female; Live-birth at term

4.5.4. Congenital Cataracts, (Q120)

Approximately one third of congenital cataracts are a component of a more extensive or disease. However the origin a good 30% are unexplained. Metabolic disease tends to be associated with bilateral cataracts. Typical associations include Alports , Marfan , Down Syndrome , Myotonic dystrophy, Galactosaemia, Trisomy 13 and congenital infections such as Rubella, Toxoplasmosis, CMV and Herpes Simplex.

There were three cases of bilateral cataracts with the abnormality recorded in the primary position on two occasions.

Q120	CONGENITAL CATARACT - BILAT	No associated abnormality
Q120	CONGENITAL CATARACT - BILAT	Hearing loss; Congenital deformity of skull

Cataracts were also seen in association with Congenital Varicella , (Part 4.2.3, Page 31).

P358	CONGENITAL VARICELLA	Pre-term delivery at 30 weeks

4.5.5. Other Face & Neck

Solitary Median Maxillary Central Incisor (SMMCI) , (Q878)

This is a complex disorder consisting of multiple, mainly midline, defects of development resulting from unknown factors operating in utero at 25th to 38th day post conception[12]. Routine mid-trimester prenatal ultrasound should detect a small head and abnormalities in position of the eyes and nose.

Q878	Solitary Median Maxillary Central Incisor	Prenatal diagnosis; Live-birth at 36 weeks

A single case is described in the current data. Associated features included microphathalmos, encephalocoele, lissencephaly, chonal atresia, agenesis of the corpus callosum and hypoplasia of the spinal cord.

Goldenhar , (Q8704)

The ICD10 code Q870 refers to congenital malformation s that predominantly affect facial appearance. It is a broad category that includes cyclopa, acrocephalopolysyndactyly, 'whistling face' and Goldenhar .

Goldenhar is also known as oculo-auriculo-vertebral and presents as incomplete development of the ear, nose, soft palate, lips and mandible. Goldenhar is believed to arise as a consequence of anomalous development of the 1st and 2nd branchial arches late in the first trimester.

Q8704	GOLDENHAR	Live-birth; Male; Diagnosed at birth

A single case is seen in a male infant delivered at term. Associated features included congenital malformation of the ears, accessory auricle, accessory periauricular skin tags and hypospadias.

Moebius , (Q8706)

This is another congenital malformation predominantly affecting the face. A single case was recorded in a male twin, (Part 1.5, Page 12).

4.6. Gastrointestinal Abnormalities

The gastrointestinal tract is formed from anatomically and functionally distinct regions that may be subject to a variety of errors of embryological development. Patterns of malformation include abnormal lumenization, (stenosis and atresia), duplications, abnormal rotation and fixation and abdominal wall defects.

4.6.1. Oesophageal Atresia, (Q391)

Oesophageal atresia is an anomalous closure of the oesophagus that may or may not be associated with tracheo-oesophageal fistula. It arises from an error in the differentiation of the foregut into the oesophagus, trachea and lung at around 4-6 weeks gestation. A low tracheo-oesophageal fistula is present in around 90% of cases. Diagnosis is difficult with prenatal ultrasound but polyhydramnios and absence of the fetal stomach are helpful signs. However the presence of a fluid-filled gastric bubble does not exclude the abnormality if a low fistula is present. The reported ultrasound detection rate of oesophageal atresia is ranges from 12 to 42%.

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[12] Hall RK. Orphanet. J. Rare. Dis. 2006: 1; 12. The name originally given was 'Solitary median maxillary central incisor, short stature, chonal atresia, mid-nasal stenosis ' and was also known as 'mono-superoincisivodontic dwarfism'. The use of the single incisor tooth in the name emphasises the unique form and position of this tooth.

One case is described with the abnormality in the primary position. The diagnosis was made at birth. Associated abnormalities included horseshoe kidney and VSD.

Q391	OESOPHAGEAL ATRESIA WITH TRACHEO-OESOPHAGEAL FISTULA	

A further case is seen as part of the VACTERL association, a non-random relationship of birth defects that affects multiple organ systems [13].

Q8726	VACTERL ASSOCIATION	Female; Live-birth at term

4.6.2. Imperforate Anus, Anal Stenosis & Anorectal Atresia, (Q4200, Q421, Q4290)

These abnormalities are associated with a variety of perineal appearances including complete absence of the anus or anterior stenosis and anal fistula. They are often seen in association with abnormalities of the renal tract.

Q4200	IMPERFORATE ANUS/RECTO-PROSTATIC URETHRAL FISTULA	Post. urethral valves
Q421	IMPERFORATE ANUS	Horseshoe kidney
Q4290	COLONIC ATRESIA	

Imperforate anus is recorded as a secondary diagnosis in five cases.

Q600	ABSENT KIDNEY (L)	Prenatal diagnosis; Live-birth
Q606	POTTER'S SEQUENCE	Prenatal diagnosis; Termination
Q688	FLEXION CONTRACTURES ALL LIMBS	Prenatal diagnsosis; Termination
Q900	TRISOMY 21	Prenatal diagnosis; Live-birth
Q213	TETRALOGY OF FALLOT	Live-birth; Diagnosis at birth

Prenatal sonographic diagnosis has been achieved following the identification of abnormal large bowel dilatation. Tables are available of normal lumen diameters across gestation. It is probable that any prenatal diagnosis achieved and listed above was of the primary abnormality rather than imperforate anus/anorectal atresia.

4.6.3. Malrotation of Bowel, (Q433)

In ICD10 this is technically ‘Congenital Malformations of Intestinal fixation’ and includes a variety of conditions of small and large bowel.

Q433	MALROTATION	Live birth; Diagnosed in 1st week

Malrotation of the gut is also documented as a secondary diagnosis in a further seven cases

Q601	RENAL AGENESIS - BILAT	Termination
Q878	FRYNS	Termination
Q893	SITUS INVERSUS	Fetal loss
Q899	UNDIAGNOSED GENETIC	Live-birth
Q900	TRISOMY 21	Live-birth

[13] The term VACTERL is an acronym where V=vertebral abnormality; A=anal atresia; C=cardiac defects; T=tracheal anomalies including tracheo-oesophageal fistula; E=oesophageal atresia; R=renal and /or radial abnormality and L= other limb abnormalities.

	ISOMERISM (L) w BILAT SVCs & PAIRED AZYGOUS	
Q206	CONTIN TO SVCs	Live-birth
Q431	HIRSCHSPRUNG'S DISEASE	Live-birth

4.6.4. Other Gastrointestinal Abnormalities

Hirschsprung's Disease, (Q431)

Hirschsprung's disease is due to an absence of parasympathetic ganglion cells in the myenteric submucosal plexus of the rectum. This disorder sometimes extends to the colon. It occurs predominantly males with an incidence of 1:5000 births. Hirschsprung's disease typically presents with abdominal distension and failure of passage of meconium within the first 48hrs. Recognized associations include multiple endocrine neoplasia, Wardenburg's & Down Syndrome .

Two cases were defined as primary disorders.

Q431	HIRSCHSPRUNG'S DISEASE	Male; Live-birth at term; Diagnosed 1- 4 weeks
Q431	HIRSCHSPRUNG'S DISEASE	Male; Live-birth at term; Diagnosed 1- 4 weeks

Foregut Duplication Cysts, (Q434)

Foregut duplication cysts are rare congenital anomalies of enteric origin. In majority of the patients, the diagnosis is made in infancy.

Q434	DUPLICATION CYST	Live birth; Prenatal diagnosis

Duodenal Atresia, (Q410)

Duodenal atresia is seen in approximately 1:10,000 pregnancies. The classic 'double bubble' is due to dilatation of both stomach and the first part of the duodenum proximal to the obstruction. In 30% of cases it is associated with other disorder and in particular there is a well recognized association with Trisomy 21, (Down Syndrome).

Two cases are described as isolated lesions in the primary position.

Q410	DUODENAL ATRESIA	Prenatal diagnosis; Live-birth;
Q410	DUODENAL ATRESIA	Prenatal diagnosis; Live-birth

Three further cases of duodenal atresia are recorded in association with chromosomal abnormality.

Q900	TRISOMY 21	Prenatal diagnosis; Live-birth
Q900	TRISOMY 21	Prenatal diagnosis; Live-birth
Q935	DELETION 1p22	Prenatal diagnosis; Live-birth

4.7. Renal & Urinary System

Renal tract abnormalities may be isolated or components of a recognizable s. The ICD10 classification divides the abnormalities into renal agenesis and reduction defects, cystic kidney disease and congenital obstruction defects. Fetal renal tract anomalies will usually be detected at routine 20 week scan.

4.7.1. Renal Agenesis and Other Reduction Defects, (Q600, Q601, Q602)

These are typically the result of failure of the ureteric bud to develop so that the ureter and kidney are absent. If unilateral the child will live a full and healthy life provided the other kidney is normal. Bilateral agenesis is lethal and is usually diagnosed when profound oligohydramnios is seen on antenatal scan.

Bilateral Renal Agenesis, (Q601)

There were six cases recorded of bilateral renal agenesis. In each case prenatal diagnosis was achieved and the pregnancy terminated.

Q601	RENAL AGENESIS - BILAT	
Q601	RENAL AGENESIS - BILAT	
Q601	RENAL AGENESIS - BILAT	Agenesis of uterus, bladder and ureter.
Q601	RENAL AGENESIS - BILAT	Potter's Sequence
Q601	RENAL AGENESIS	
Q601	RENAL AGENESIS - BILAT	

Potter's Sequence is the result of oligohydramnios leading to pulmonary hypoplasia, low set ears, broad flattened nose and limb abnormalities. This deformation sequence can result from a number of pathological processes including pre-term rupture of membranes, polycystic or multicystic renal disease, and agenesis or obstruction of the ureter, but was initially intended to only refer to cases resulting from Bilateral Renal Agenesis, (the 'Classic' form).

Unilateral Renal Agenesis, (Q600)

A total of nine cases of unilateral renal agenesis were listed with a Male:Female ratio of 2:1. In all cases renal agenesis is given as the primary diagnosis. A prenatal diagnosis was made in eight cases. In the remaining case the diagnosis was made between 1 and 4 weeks.

Q600	ABSENT KIDNEY (L)	Live-birth; Male; Congenital uretheroceole; Imperforate anus
Q600	RENAL AGENESIS (L)	Live-birth; Male
Q600	ABSENT KIDNEY ®	Live-birth; Female
Q600	RENAL AGENESIS (L)	Live-birth; Male; Diagnosis 1-4 weeks
Q600	ABSENT KIDNEY ®	Live-birth; Male
Q600	ABSENT KIDNEY (L)	Live-birth; Female
Q600	ABSENT (L) KIDNEY	Live-birth; Female
Q600	ABSENT KIDNEY ®	Live-birth; Male
Q600	ABSENT KIDNEY (L)	Live-birth; Male

Unilateral renal agenesis is not usually of any major health consequence provided that the other kidney is healthy. However it is associated with an increased incidence of abnormality of the development of the female reproductive tract which may present as infertility.

4.7.2. Cystic Kidney Disease (Q611, Q614, Q6141)

Dysplastic kidneys contain abnormally differentiated parenchyma. They are commonly associated with obstruction and other abnormalities of the urinary tract. Eleven disorders are listed in the primary position. Prenatal diagnosis was achieved for all listed cases.

Q613	MULTICYSTIC KIDNEY (L)	Duplex kidney
Q613	POLYCYSTIC KIDNEY ®	
Q614	RENAL DYSPLASIA ®	Congenital hydronephrosis
Q6140	MULTICYSTIC DYSPLASTIC KIDNEY (L)	Congenital uretherocoele
Q6140	MULTICYSTIC DYSPLASTIC KIDNEY ®	
Q6140	MULTICYSTIC DYSPLASTIC KIDNEY (L)	
Q6140	MULTICYSTIC DYSPLASTIC KIDNEY (L)	
Q6140	MULTICYSTIC DYSPLASTIC KIDNEY (L)	Cardiac abnormalities; Single umbilical artery
Q6140	MULTICYSTIC DYSPLASTIC KIDNEY (L)	Ectopic kidney
Q6140	MULTICYSTIC DYSPLASTIC KIDNEY ®	
Q6140	MULTICYSTIC DYSPLASTIC KIDNEY (L)	

The majority of cases were live births but there was one stillbirth at 33 weeks gestation associated with multiple cardiac abnormalities including malposition of the heart, coarctation of the aorta and VSD.

Dysplastic renal disease was a secondary diagnosis in five further cases.

Q606	POTTER'S SEQUENCE	Multicystic Dysplastic Kidney
Q630	DUPLEX KIDNEY ®	Multicystic Dysplastic Kidney; Live-birth
Q6431	CONGENITAL URETHRAL STRICTURE	Multicystic Dysplastic Kidney; Live-birth
Q758	POOR DEVELOPMENT OF MID-FACE	Renal dysplasia; Multiple abnormalities
Q318	LARYNGEAL STENOSIS	Renal dysplasia; Multiple abnormalities

In all five cases prenatal diagnosis was achieved. Three cases were terminated following prenatal diagnosis.

4.7.3. Congenital Obstructive Defects of Renal Pelvis & Malformation of Ureter, (Q62)

This ICD10 category includes a variety of abnormalities of the renal and urinary system including, congenital hydronephrosis, atresia and stenosis of the ureter, agenesis of ureter and congenital PUJ obstruction.

Congenital Hydronephrosis, (Q620)
Hydronephrosis is a common congenital condition that is usually first diagnosed on prenatal ultrasound. While there can be many conditions that lead to hydronephrosis, the most common causes are obstructions that reduce the ability of urine to flow out of the kidney and into the bladder. Many children who are diagnosed with hydronephrosis before they are born will have the condition resolve on its own without medical intervention.

Q620	CONGENITAL HYDRONEPHROSIS	Male; Prenatal diagnosis; Megaloureter
Q620	HYDRONEPHROSIS (L)	Male; Prenatal diagnosis; Ureterocoele
Q620	CONGENITAL HYDRONEPHROSIS (L)	Male; Prenatal diagnosis
Q620	CONGENITAL HYDRONEPHROSIS	Male; Prenatal diagnosis
Q620	CONGENITAL HYDRONEPHROSIS	Male; Prenatal diagnosis; Megaloureter
Q620	CONGENITAL HYDRONEPHROSIS (L)	Male; Prenatal diagnosis
Q620	CONGENITAL HYDRONEPHROSIS (L)	Male; Prenatal diagnosis

Congenital PUJ Obstruction, (Q6210)[14]
The most common cause of obstruction (blockage) in the urinary tract in children is a congenital obstruction at the point where the ureter joins the renal pelvis – the ureteropelvic junction, (UPJ or PUJ). Most PUJ obstructions are identified long before birth by prenatal scan. Urine is produced by the fetus at a rate that exceeds the amount able to drain out of the renal pelvis into the ureter. This causes accumulation of urine within the kidney and dilatation of the renal pelvis which is clearly visible on scan.

Although 'renal pyelectasis' a very common prenatal observation, congenital PUJ obstruction was only formally diagnosed in four cases.

Q6210	PUJ OBSTRUCTION ®	Male; Prenatal diagnosis
Q6210	PUJ OBSTRUCTION (L)	Male; Prenatal diagnosis
Q6210	PUJ OBSTRUCTION/HYDRONEPHROSIS ®	Male; Prenatal diagnosis
Q6210	PUJ OBSTRUCTION (L)	Female; Prenatal diagnosis

Where Congenital PUJ Obstruction appears as the primary abnormality prenatal diagnosis was always achieved.

Other obstructive Abnormalities of the Urinary System
Congenital obstructive defects are listed as secondary diagnoses in a further ten cases with a primary renal or urinary abnormality. The most common of these is the congenital ureterocele, (n=6). An ureterocele is a ballooning of the terminal ureter as it enters the bladder. It occurs when the inner part of the Wolffian duct is incompletely absorbed into the trigone. An ureterocele may also occur in an ectopic ureter or present as a 'cyst' near the external meatus in female infants. This most often occurs at the lowermost ureteric orifice in duplex systems, (see below).

[14] In previous reports the ICD10 code Q623 was used to define these abnormalities.

4.7.4. Other Congenital Malformations of the Kidney, (Q63)

Duplex Kidney and Collecting System, (Q630)

Duplex kidneys are a relatively common abnormality. Duplex kidneys may be associated with ureterocele, ectopic ureter insertion or vesicoureteric reflux. The terminology surrounding duplex kidneys has, however, been conflicting. *A true duplex kidney* has two separate pelvi-calyceal systems. Most of the clinical problems relate to the way the ureters insert into the bladder: the ureter from the upper pole of a duplex kidney will have a more distal/ medial insertion into the bladder than the ureter from the lower pole. In general, the lower pole ureter of a complete duplex inserts more laterally into the bladder and will have a shorter and less oblique intramural course through the bladder wall than a normal ureter and this makes it more prone to reflux. Duplex kidney is listed as a primary diagnosis in ten cases, all live-births.

Q630	DUPLEX KIDNEY (L)	
Q630	DUPLEX KIDNEY ®	Congenital ureterocoele
Q630	DUPLEX KIDNEY ®	
Q630	DUPLEX (L) KIDNEY	
Q630	DUPLEX KIDNEY ®	
Q630	DUPLEX KIDNEY ®	Multicystic dysplastic kidney
Q630	DUPLEX SYSTEM (L)	Anomaly of ureter
Q630	DUPLEX KIDNEY (L)	Congenital ureterocoele
Q630	DUPLEX KIDNEY ®	Congenital ureterocoele
Q630	DUPLEX KIDNEY (L)	Duplication of ureter; Preterm delivery

Duplex kidney is also described as a secondary abnormality in two cases of posterior uretheral valves, (see below).

Abnormally Sited Kidney, (Q631, Q6310, Q632)

Renal ectopia describes a kidney that is not located in its usual position. It is a fairly common abnormality that is often discovered incidentally. Ectopic kidneys can be located anywhere along the path of their usual ascent from the pelvis to the upper abdomen.

Abnormal renal situs is recorded as a primary abnormality on one occasion.

Q632	ECTOPIC KIDNEY	Prenatal diagnosis; Live-birth; Female

Renal ectopia is often associated with congenital abnormalities of other organ systems and is described as a secondary abnormality in a further four cases, all live-births at term.

Q6140	MULTICYSTIC DYSPLASTIC KIDNEY (L)	Ectopic kidney;
Q899	UNDIAGNOSED GENETIC	Accessory kidney
Q391	OESOPHAGEAL ATRESIA WITH TOF	Horseshoe kidney; VSD
Q421	IMPERFORATE ANUS	Horseshoe kidney

As the kidneys rise from the fetal pelvis they may fuse at the lower end or base forming a ‘U’ shape or ‘horseshoe’ kidney. The horseshoe kidney is malrotated and so the ureters leave the kidney from its ventral rather than medial aspect.

4.7.5. Other Congenital Anormalities, (Q64)

Bladder Exstrophy, (Q641)
The exstrophy epispadis complex is a spectrum of disorder ranging in severity from epispadis through bladder extrophy to cloacal extrophy.

Q641	EXSTROPHY BLADDER	Male; Prenatal diagnosis; Epispadias

Posterior Urethral Valves, (Q642)
Posterior urethral valves are the most common cause of lower urinary tract obstruction in the male neonate. The disorder is of variable severity. The condition arises around the 4th week of gestation as the Wolffian ducts fuse with the developing cloaca. A pair of sail-shaped valves develops adjacent to the verumontanum with appearances not unlike valves in a vein. Consequences are bilateral hydronephrosis and hydroureter, hypertrophy of the bladder detrouser and a dilated prostatic urethera.

Two cases are listed in the primary diagnostic position. Prenatal diagnosis of urinary tract obstruction was made in both cases.

Q642	POSTERIOR URETHRAL VALVES	Duplex kidney; Male; Live-birth
Q642	POSTERIOR URETHRAL VALVES	Duplex kidney; Male; Live-birth

A further two diagnoses are recorded as secondary abnormalities

I471	SVT	Live-birth
Q4200	IMPERFORATE ANUS/RECTO-PROSTATIC URETHRAL FISTULA	Live-birth

4.7.6. Hypospadias, (Q540, Q541, Q542, Q549)
Hypospadias describes an abnormality of male infants where the urethra opens on the ventral aspect of the penis at a point proximal to the normal site. The frenulum is almost always affected being imperfectly formed and this deformity may be more obvious than the hypospadias itself. Hypospadias is the commonest abnormality of the male genitalia and was the third commonest abnormality listed in the 2012-2013 data series.
However there are only eight cases where hypospadias was recorded as the primary diagnosis in the current data. It is listed as a secondary diagnosis in a further four cases.

Q564	INDETERMINATE SEX	Live-birth at term
Q8704	GOLDENHAR	Live-birth at term
Q8710	AARSKOG-SCOTT	Live-birth at term
D821	DI GEORGE	Live-birth at term

4.8. Musculo-Skeletal Abnormalities

The congenital musculo-skeletal abnormalities vary greatly in extent and severity. They may be localized, (e.g. TEV, DDH), or generalized, (e.g. achondroplasia).

4.8.1. Developmental Dysplasia of the Hip, (Q6580, Q6581)

Dislocated hips are associated with joint laxity and acetabular dysplasia. Postural features often play a role in their causation. They are commonest in female infants, term deliveries, breech presentation and the left hip. Diagnosis is made at birth by specifically testing the hips.

A total of 10 cases of Congenital Dislocation of the Hip are listed. In nine cases DDH is the main diagnosis and in the remaining case is noted as a secondary abnormality in VACTERL association. In eight cases the abnormality is recorded as unilateral with the right hip more commonly affected than the left.

The majority of cases were diagnosed in the first week of life, (n=6, 60%). Two cases were not diagnosed until after one month.

All ten cases observed were in live-born female infants delivered at term.

4.8.2. Achondroplasia, (Q774)

Achondroplasia is a non-lethal short limb dysplasia which may not be apparent until the time of birth. A single cases of achondroplasia was diagnosed on scan at 37 weeks gestation.

Q774	ACHONDROPLASIA	Live birth at term of male infant

4.8.3. Talipes Equino Varus, (Q660)

Minor degrees of talipes are common at birth, resulting from mechanical pressure *in utero*. The commonest deviation is one in which there is plantar flexion, (equinus), and foot adduction, (varus), at the mid-tarsal joint. The birth incidence is commonly stated as 1:1000. For the year 2013-2014 talipes equino varus, (TEV), is recorded in the primary diagnostic position on eleven occasions with a Male:Female ratio of 4.5:1. The majority of cases, (n=9, 81.8%) were diagnosed on antenatal scan.

Talipes equino varus is also coded as a secondary diagnosis in a further six cases. A prenatal diagnosis is recorded in five of these cases but this may relate to the primary diagnosis rather than the finding of talipes. However, prenatal detection of talipes is known to improve when bilateral or associated with other malformation.

	ARTHROGRYPOSIS MULTIPLEX	
Q743	CONGENITA	Live-birth
Q748	HYPEREXTENDED LEGS	Termination
Q792	EXOMPHALOS	Fetal loss at 15 weeks
Q8706	MOEBIUS	Live-birth
E840	CYSTIC FIBROSIS	Live-birth; Diagnosis at 1 – 4 weeks
Q234	HYPOPLASTIC (L) HEART	Termination

A related case of talipes calaneovarus, (Q661), was also seen in female infant delivered at term.

4.8.4. Limb Reduction Defects, (Q71, Q72).

Limb reduction defects are defined by the absence or severe hypoplasia of limb skeletal structures. They are rare and in their milder presentations frequently missed antenatally. Three cases are listed as primary limb reduction abnormalities. All were live-births at term.

Q710	ABSENT UPPER LIMBS ABSENT (L) HAND - FINGER	Prenatal diagnosis
Q713	BUDS ONLY	Prenatal diagnosis
Q7131	HYPOPLASTIC (L) THUMB	Diagnosis at birth

One or more limb reduction defects are listed as secondary abnormalities in a further four cases.

Q935	DELETION 1p22	Multiple abnormalities
D610	FANCONI'S ANAEMIA	Prenatal diagnosis; Termination
Q220	PULMONARY ATRESIA	
Q758	POOR DEVELOPMENT OF MID-FACE	

Fetal forearm defects are often associated with underlying genetic s or aneuploidy, particularly when bilateral. Limb reduction defects are also associated with certain common medications including clomiphene and SSRI's .

A female infant with a deletion of 1p22 was delivered at 37 weeks gestation following the demonstration of multiple fetal abnormalities at sixteen weeks gestation. The most striking feature was of bilateral symmetrical reduction and flexion deformities of both radius and hands. The differential diagnosis was of TAR , Holt-Oram , Duane-radial Ray anomaly and Fanconi's anaemia. Amniocentesis was performed and karyotype confirmed[15]. Chromosome breakage studies for Fanconi's anaemia were normal. Other features included duodenal atresia and plagiocephaly. Excellent 3D ultrasound images proved to be invaluable in counselling and management of this case.

4.8.5. Craniosynostosis (Q750)

Craniosynostosis is due to the premature closure of one or more of the skull sutures. It affects about 1:2500 children. Craniosynostosis causes distortion of the shape of the skull owing both to failure of bone growth at the prematurely closed suture site and to compensatory overgrowth at the sutures that remain open. The different types of craniosynostosis are classified by which sutures have closed prematurely. One primary case is described.

Q750	CRANIOSYNOSTOSIS	Male; Diagnosis at birth

4.8.6. Other Musculo-Skeletal Abnormalities

Arthrogryposis, (Q743)

Arthrogryposis is not really a diagnosis but a description that refers to a number of pathological processes resulting in limb immobilization and multiple congenital joint contractures. It is therefore a rather heterogenous grouping of conditions both syndromic, (e.g. Larsen , Freeman-Shelden and Multiple Pterigium) and non-syndromic.

[15] Other data associated with this case confirms that the karyotype was actually reported as 46, XX, t(1:12)(p13; q22).

Two cases were described, both in the primary diagnostic position.

Q743	ARTHROGRYPOSIS ARTHROGRYPOSIS MULTIPLEX	Prenatal diagnosis; Termination
Q743	CONGENITA	Prenatal diagnosis; Live-birth

Features associated with arthrogryposis included talipes, cystic hygroma and micrognathia.

Congenital Malformations of the spine not associated with scoliosis, (Q764)
This is a broad classification under ICD10 and includes fusion of the spine, absence of vertebrae, hemi-vertebrae, malformation of the lumbo-sacral joint and supernumerary vertebrae. Congenital malformation of the spine was an associated feature in three cases.

Q8726	VACTERL ASSOCIATION FOREGUT DUPLICATION CYST POSTERIOR
Q341	MEDIASTINUM IMPERFORATE ANUS/RECTO-PROSTATIC
Q4200	URETHRAL FISTULA

4.9. Abdominal Wall Defect

ICD10 Codes Q790-Q799 are ‘Congenital malformations of the musculoskeletal system, NEC’ and includes Congenital Diaphragmatic Hernia, Exomphalos, Gastroschisis and Amniotic Rupture Sequence - collectively considered here as ‘Abdominal Wall Defects’.

4.9.1. Congenital Diaphragmatic Hernia, (Q790, Q791)

Diaphragmatic hernia, a unilateral or bilateral diaphragmatic defect allowing abdominal viscera to herniate into the chest, is relatively common and occurs in 1:2500 live births. It is a consequence of deficient closure of the pleuroperitoneal duct. Pre-natal diagnosis is typically based on the ultrasound finding of fluid-filled stomach or bowel within the thoracic cavity. Prognosis depends on the size of the defect, the presence of accompanying anomalies and preparation for intervention following early diagnosis.

A total of four cases were described in 2013-2014. In two cases a ‘straightforward’ diaphragmatic hernia was the primary diagnosis.

Q790	DIAPHRAGMATIC HERNIA (L)	Prenatal diagnosis; Live-birth
Q790	DIAPHRAGMATIC HERNIA	Live-birth; Diagnosed between 1 and 12 months

Congenital diaphragmatic hernia was also classified as a secondary diagnosis as part of Fryn’s .

Q878	FRYNS	Prenatal diagnosis; Termination

Fryn’s is typically characterised by a diaphragmatic defect, abnormalities of the fingers and toes and distinct facial features such as hypotelorism, large mouth, small chin, microphthalmia, and cleft lip/palate. It is said to be the most common autosomal recessive condition associated with diaphragmatic hernia and accounts for 1-10% of all cases of CDH. The case described above was associated with hypotelorism, micrognathia, and malrotation of the gut.

A further case involving a congenital anterior diaphragmatic hernia was recorded.

Q897	PENTALOGY OF CANTRELL	Prenatal diagnosis; Termination at 13 weeks

Pentalogy of Cantrell, (or more accurately Cantrell-Haller-Ravich), is exceptionally rare[16]. The describes a spectrum of midline thoraco-abdominal defects typically involving the supra-umbilical wall, lower sternum, anterior diaphragm and diaphragmatic pericardium. These can results in exomphalos, parietal herniation of the heart and other cardiothoracic abnormalities such as sternal clefts and VSD. The case described above included ectopia cordis with the fetal heart located partially outside of the thorax[17].

4.9.2. Gastroschisis, (Q793)

Gastroschisis is an open, sporadically occurring, abdominal wall defect with extruded loops of bowel. It develops between the 5th and 6th week of embryonic development. Instead of the physiological herniation of bowel into the umbilical cord a rupture forms in the ventral abdominal wall lateral to the umbilical cord insertion allowing the free extrusion of bowel loops. It is likely that the rupture is a consequence of the premature obliteration of the right umbilical vein creating a weakness in the abdominal wall.

Four cases of gastroschisis were diagnosed on antenatal scan. There were no associated abnormalities; gastroschisis was an isolated lesion in all cases. They were all live-births with a mean gestation at delivery of 35 weeks. Looking at the data from previous reports pre-term delivery seems to be a feature of these cases. It is difficult to know from the data if this is iatrogenic. Gastroschisis is certainly associated with a young maternal age and it is said that mother's under the age of 20 years are twelve times more likely to have an infant with gastroschisis than the general obstetric population. In this small series the mean maternal age was 26 years, (range 20 – 32 years).

4.9.3. Exomphalos, (Q792)

Exomphalos is the result of the physiological herniation of the gut into the umbilical cord and the failure of the intestinal loops to return to the fetal abdomen. Typically membrane covered, it is often seen with associated malformations.

Only two cases of exomphalos are coded in the data for 2013-2014. It is given as the primary diagnosis in one case which was associated with a mosaic whole chromosome monosomy and talipes equinovarus.

Q792	EXOMPHALOS	Prenatal diagnosis at 12 weeks; Fetal loss at 15 weeks

Exomphalos was an associated feature in a case of Trisomy 18.

Q910	TRISOMY 18	Prenatal diagnosis; Termination at 13 weeks

[16] Cantrell JR, Haller JA, Ravich MM. Surg. Gynecol. Obstet. 1957; 107(5): 602-614

[17] This is a presumption made from the use of the ICD10 code Q248 as a secondary diagnosis. Ectopia cordis certainly maps to this code but Q248 can also be used for any 'Other Specified Malformation of the Heart' including (for example) diverticulum of the left ventricle or even Uhl disease.

4.9.4. Amniotic Band Sequence, (Q7980)

The commonly accepted view is that amniotic band sequence is a consequence of amniotic rupture without injury to the chorion. Fibrous bands of the ruptured amnion 'float' and can encircle and trap fetal parts. Later as the fetus grows but the bands do not, the bands become constricting. In some cases a complete amputation of a digit or limb may occur. Amniotic bands can also attach to the face or neck causing deformities such as cleft lip and palate.

A single case of Amniotic Band Sequence is listed and was associated with abnormalities of the skull and face.

Q7980	AMNIOTIC BAND	Prenatal diagnosis; Termination at 11 weeks

4.10. Chromosomal Abnormality

A chromosomal abnormality is recorded in the primary or secondary position for 82 cases, (25.2%). They account for 14.7% of all abnormalities detected in the 2013-2014 cohort. The majority, (n=77, 94%), are recorded as the primary diagnosis, (Figure 4.10). The majority of cases were diagnosed prenatally, (Figure 4.11). Termination was the predominant pregnancy outcome, (Figure 4.12).

Figure 4.10: Overview of Primary Chromosomal Abnormality, (Simplified)

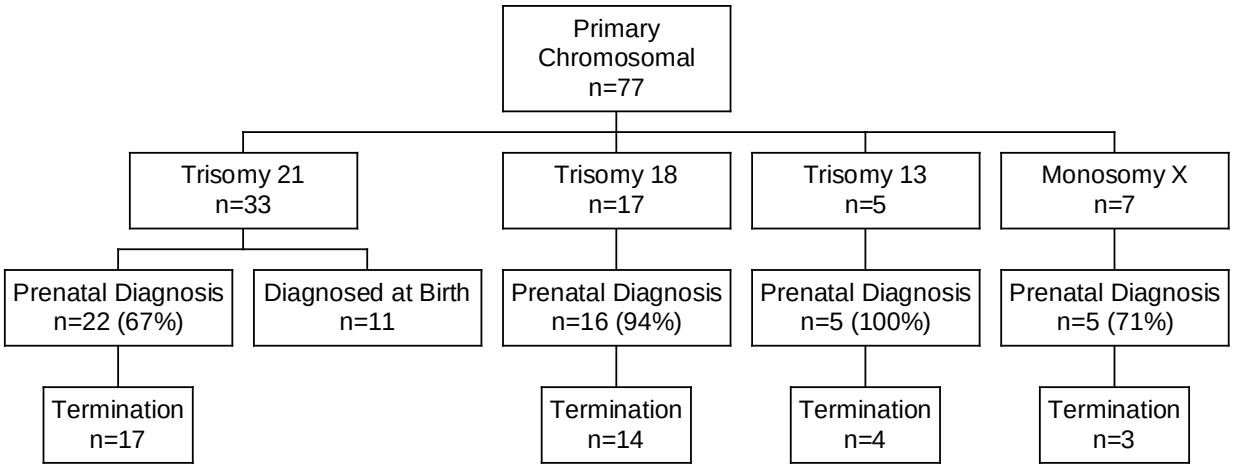


Figure 4.11: Point of Diagnosis of Primary Chromosomal Abnormality, (n=77)

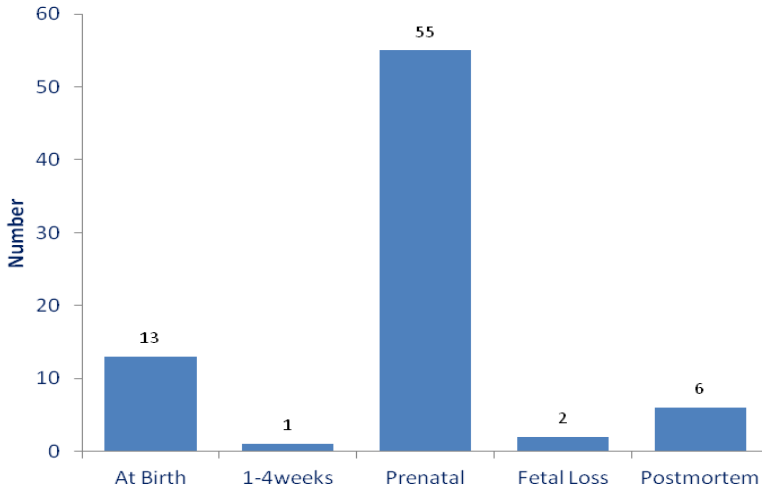
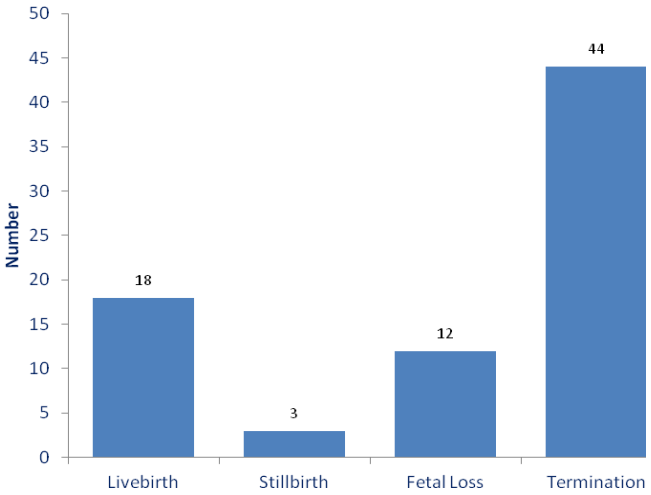


Figure 4.12: Outcome of Pregnancy with Primary Chromosomal Abnormality, (n=77)



4.10.1. Trisomy 21 (Down Syndrome), (Q900, Q909)

A total of 33 cases were associated with Trisomy 21, (incidence of 1:403 maternities). Trisomy 21 was always recorded as a primary abnormality. Forty-two percent of cases, (n=14), were live born. There were two stillbirths following prenatal diagnosis, both at 32 weeks gestation. The remaining seventeen cases were terminated following prenatal diagnosis, (Figure 4.13).

Figure 4.13: Outcome of pregnancies associated with Trisomy 21, (n=33)

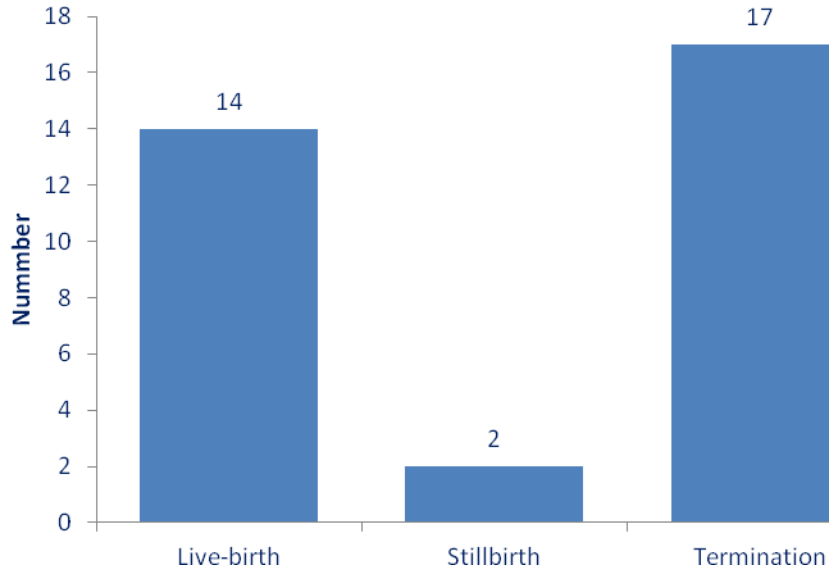
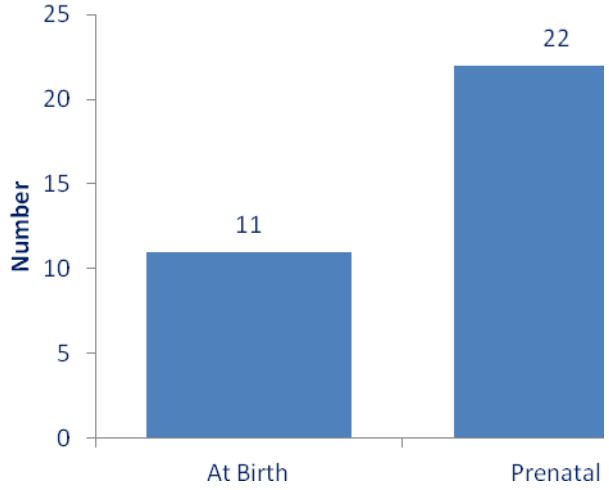


Figure 4.14: Point of diagnosis of Trisomy 21, (n=33)



With regards to the diagnoses made at birth,(Figure 4.14), some data is available from the Pregnancy & Newborn Screening system on whether or not women were offered antenatal screening for Down Syndrome . It emerges that eight women did elect to have screening for Down Syndrome - six cases were low risk on screening but two cases were high risk and declined invasive testing. There were two further cases where an offer of screening was made but declined and one late booker.

4.10.2. Trisomy 18, (Q910)

There were 17 cases of Trisomy 18 (Edward's) listed in the data. The majority, (n=16, 94%), were diagnosed antenatally. Trisomy 18 was diagnosed in a fetal loss at 11 weeks, (prior to any prenatal diagnosis).

Q910	TRISOMY 18	Prenatal diagnosis; Termination
Q910	TRISOMY 18	Cystic hygroma; Cardiac abnormality; Prenatal diagnosis; Termination
Q910	TRISOMY 18	Prenatal diagnosis; Termination
Q910	TRISOMY 18	Prenatal diagnosis; AVSD; Stillbirth at 35 weeks
Q910	TRISOMY 18	Prenatal diagnosis; Termination
Q910	TRISOMY 18	Prenatal diagnosis; Termination
Q910	TRISOMY 18	Cystic hygroma; Holoprosencephaly; Prenatal diagnosis; Termination
Q910	TRISOMY 18	Prenatal diagnosis; Exomphalos; Termination
Q910	TRISOMY 18	Prenatal diagnosis; VSD; Termination
Q910	TRISOMY 18	Prenatal diagnosis; Termination
Q910	TRISOMY 18	Prenatal diagnosis; Termination
Q910	TRISOMY 18	Anencephaly; Prenatal diagnosis; Termination
Q910	TRISOMY 18	Prenatal diagnosis; Termination
Q910	TRISOMY 18	Cystic hygroma; Prenatal diagnosis at 11 weeks; Fetal loss at 16 weeks
Q910	TRISOMY 18	Prenatal diagnosis; Termination
Q910	TRISOMY 18	Fetal loss at 11 weeks
Q910	TRISOMY 18	Prenatal diagnosis; Termination

Cardiac abnormalities are commonly associated with Trisomy 18 yet are seen in only three cases, (17.6%) in this series.

4.10.3. Trisomy 13, (Q914, Q917)

There were 5 listed cases of Trisomy 13, (Patau's). All were diagnosed antenatally. Holoprosencephaly was an associated feature in one case.

Q914	TRISOMY 13	Cleft lip and palate; Prenatal diagnosis; Termination
Q914	TRISOMY 13	Cystic hygroma; Prenatal diagnosis; Fetal loss
Q914	TRISOMY 13	Prenatal diagnosis; Termination
Q914	TRISOMY 13	Prenatal diagnosis; Termination
Q914	TRISOMY 13	Holoprosencephaly; Prenatal diagnosis; Termination

4.10.4. Polyploidy: Triploidy & Tetraploidy, (Q927)

Polyploidy refers to a numerical change in a whole set of chromosomes, (whereas aneuploidy refers to a numerical change in part of a chromosome set). Triploidy, (69 XXY, XXX or XYY), in which the fetus gains a complete extra set of chromosomes, is thought to occur in up to 2% of conceptions and 15% of miscarriages.

Q927	TRIPLOIDY	Prenatal diagnosis; Termination of pregnancy

Triploidy may also result as a consequence of either digyny (the extra haploid set is from the mother) or diandry (the extra haploid set is from the father). Diandry is mostly caused by reduplication of the paternal haploid set from a single sperm or as a result of dispermic fertilization. Digyny is most commonly caused by either failure of one meiotic division during oogenesis leading to a diploid oocyte or failure to extrude one polar body from the oocyte.

Complete tetraploidy, (92XXXX), is more rarely diagnosed than triploidy, but is observed in 1–2% of early miscarriages.

Q927	TETRAPLOIDY	Fetal loss at 11 weeks; Diagnosis on post-mortem

4.10.5. Turner , (Q960, Q969)

Turner is an aneuploidy, and is also known as 'monosomy X', (45XO). The incidence is roughly 1:2500 live-born girls. Fifteen percent of cases demonstrate some mosaicism. Sometimes a lymphangioma, (cystic hygroma), prompts diagnostic investigation. Seven cases were diagnosed prenatally.

Q960	TURNERS	Fetal loss
Q960	TURNER	Prenatal diagnosis; Termination
Q960	TURNER (MONOSOMY X)	Fetal loss
Q960	TURNER	Prenatal diagnosis; Termination
Q960	TURNER	Prenatal diagnosis; Termination
Q960	TURNER	Cystic hygroma; Prenatal diagnosis; Fetal loss
Q969	TURNER	Fetal loss

4.10.6. Klinefelter , (Q980)

Klinefelter , (47, XXY), affects 1:1000 males and is typically diagnosed in early adulthood during investigations of infertility. There are two cases where the diagnosis of Klinefelter is in the primary position.

Q980	KLINEFELTER	Live-born at 38 weeks gestation; Diagnosis at birth
Q980	KLINEFELTER	Prenatal diagnosis; Termination of pregnancy

However two further cases of Klinefelter are classified in association with other aneuploidy.

Q998	TRISOMY 15	Fetal Loss; Diagnosis at post-mortem examination
Q900	TRISOMY 21	Live-birth at term; Indeterminate sex

4.10.7. Other Specified Chromosome Abnormalities, (Q998)
This is an ICD10 'place-holder' for chromosomal abnormalities that are 'not elsewhere categorized'. A total of seven cases are seen, all in the primary position.

Q998	PERICENTRIC INVERSION CHROM 11 & TERMINAL DEL CHROM 7	Termination
Q998	TRISOMY 16	Fetal loss
Q998	UNBAL TRANSLOC: 10q24 DUPLICATION & 4q13 DELETION	Live-birth
Q998	UNBALANCED TRANSLOCATION	Termination
Q998	TRISOMY 15	Fetal loss
Q998	TRISOMY 15	Fetal loss
Q998	TRISOMY 15	Fetal loss

Pericentric inversion of chromosome 11 with terminal deletion of chromosome 7 was detected on amniocentesis at 15 weeks gestation. The indication for amniocentesis is not recorded. Termination of pregnancy was undertaken at 18 weeks gestation. No associated abnormalities are listed.

The diagnosis of an unbalanced translocation: 10q24 duplication & 4p13 deletion was made following the live-birth of a male infant with both congenital pulmonary valve stenosis and cleft lip & palate. There had been no suggestion of abnormality on prenatal scan.

Termination of pregnancy was performed for an unbalanced translocation at 12 weeks gestation. The diagnosis had been made at 11 weeks, presumably following chorionic villus sampling. No associated abnormalities are listed. The indication for invasive testing is not given.

The case of Trisomy 16 was a spontaneous pregnancy loss at 11 weeks gestation. Diagnosis was made at post-mortem. Trisomy 16 is said to be the second most common cause of spontaneous pregnancy loss after monosomy X, (Turner).

Chromosome 15 spans more than 102M base pairs and alone accounts for more than 3% of the total DNA in the human genome. Complete Trisomy 15 is therefore lethal and indeed the three cases listed above were associated with 1st trimester spontaneous pregnancy loss. One case was a male fetus with an additional X chromosome – essentially Trisomy 15 with Klinefelter – and has already been mentioned above.

Appendix 1

NHS Greater Glasgow & Clyde Maternities 1st April 2013 – 31st March 2014
Source: Pregnancy & Newborn Screening System, June 2014

	Appointed Referrals Non-NHSGGC Residents	Appointed Referrals NHSGGC Residents	Total Appointed Referrals	Bookers Non-NHSGGC Residents	Bookers NHSGGC Residents	Total Bookers
Princess Royal Maternity	1154	5920	7074	1016	5188	6204
Royal Alexandra Hospital	376	3415	3791	338	3166	3504
Southern General Hospital	379	6851	7230	333	6011	6344
Not recorded	78	182	260	78	182	260
Total	1987	16368	18355	1765	14547	16312

Appendix 2

Case Prevalence Comparison, (per 10,000 births) ‡.

Abnormality	Prevalence in Primary Position	Prevalence in any Position	EUROCAT Prevalence Data*
Amniotic Band Sequence, (Q7980)	0.75	0.75	0.51
CCAM,(Q338)	1.50	2.25	0.95
Bilateral Renal Agenesis, (Q602)	4.50	4.50	1.18
Congenital cataract, (Q120)	1.50	2.25	1.23
Hirschsprung's Disease, (Q431)	1.50	1.50	1.24
Turner , (Q914-917)(Q960-969)	2.25	2.25	2.24
Craniosynostosis, (Q750)	0.75	0.75	2.39
Hypoplastic Left Heart, (Q234)	2.25	2.25	2.66
Congenital Diaphragmatic Hernia, (Q790)	1.50	2.25	2.76
Gastroschisis, (Q793)	3.00	3.00	2.85
Exomphalos, (Q792)	0.00	0.75	3.00
Fallot's Tetralogy, (Q213)	6.00	6.75	3.45
Transposition of Great Arteries, (Q203)	0.75	3.00	3.52
Coarctation of the aorta, (Q251)	2.25	3.75	3.85
Atrioventricular septal defect, (Q212)	N/A	5.25	4.09
Edwards , (Q910-913)	11.26	12.76	5.13
Hydrocephalus, (Q030-039)	N/A	N/A	5.77
Hip dislocation and/or dysplasia, (Q651)	6.75	7.51	8.07
Cleft Lip/Palate, (Q352-3799)	12.01	16.52	8.77
NTD's, (Q000,Q010-019, Q051-059)	14.26	16.52	9.66
Hypospadias, (Q549)	6.00	9.00	18.01
Down Syndrome , (Q900-909)	24.77	24.77	22.1

‡Denominators: The congenital anomaly surveillance tool that has been used to compile the data within this report is restricted to mothers' resident within the geographically defined area of NHS GG&C at the time of birth. In order to allow comparison with the EUROCAT prevalence data the appropriate denominator for the prevalence data is therefore the total live births and stillbirths for that area between 1st April 2013 and 31st March 2014 which is 13,321, (13,265 live births and 56 stillbirths). Data was extracted on 9th July 2014. EUROCAT prevalence data excludes fetal losses/deaths less than 20 weeks gestation i.e. four cases of Turner are excluded from the data.

*Source for comparison data: EUROCAT Website Database. The EUROCAT prevalence data quoted is for 2007-2011.

Appendix 3

Prenatal Detection Rates: Comparison with 'established' data

Abnormality	Observed Prenatal Detection Rate	Expected Detection Rate*
Anencephaly	100%	98% (96.7%)
Spina Bifida	90%	90% (82.9%)
Diaphragmatic Hernia (Q790)	67%	60% (58.0%)
Cleft Lip ◊	93.8%	75% (50.7%)
Gastroschisis	100%	98% (91.6%)
Exomphalos	100%	80% (83%)
Serious Cardiac Abnormalities (EUROCAT defined)	60.0%	50%
Transposition of Great Vessels (Q203)	100%	(41.4%)
Atrioventricular septal defect (Q212)	57.1%	
Fallot's Tetralogy (Q213)	67%	
Ebstein's Anomaly (Q225)	N/A	
Hypoplastic Left Heart (Q234)	100%	(71.9%)
Hypoplastic Right Heart (Q226)	100%	
Coarctation of Aorta (Q251)	80%	
Bilateral Renal Agenesis	100%	84% (88.1%)
Talipes Equino-varus	82%	(39.8%)
Trisomy 21	67%	95% (63.8%)
Trisomy 18	94%	95% (90.9%)
Trisomy 13	100%	95% (90.9%)

◊ Figures vary depending on whether or not looking at cleft lip alone, in combination with palate defect, or as part of a complex or . Figure given is for any cleft lip, (primary or secondary abnormality, isolated or in association with cleft palate).

*Ward P & Soothill P. Fetal Anomaly ultrasound scanning: the development of a national programme for England. TOG 2011; 13: 211-217. Figures in brackets relate to EUROCAT observed Prenatal Detection Rates.

SUMMARY

CHAPTER 5: NEWBORN SCREENING

- 13,332 babies were eligible for newborn bloodspot screening in NHS Greater Glasgow and Clyde. 13,332 were screened, that is 97.2% of the total eligible population.

- Results were not available for the 378 (1.7%) babies that moved into the NHSGGC Board area.

- Live births have gradually increased year on year from 12,409 in 2002/03 to 13,792 in 2012/2013. This represents an increase of 10**%.**

- Following screening, five babies were diagnosed with congenital hypothyroidism, four babies with cystic fibrosis; seven babies with sickle cell disease, 1 baby with MCADD and 91 babies were identified as carriers for haemoglobinopathies. All babies received appropriate management within the timescale of the set NHSQIS standards.

- 73% of babies screened had white UK ancestry, 6.9% had South Asian ancestry and 3.7% had mixed background ancestry.

- 205 (1.4%) 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.

- 120 (0.8%) samples received had taken more than seven days to arrive at the laboratory.

- 13,657 babies were eligible for newborn hearing screening. 13,215 were screened for hearing loss giving an uptake of 96.8%.

- 442 (3.2%) 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.

- 1,105 (9.2%) babies required a second stage follow up and, of these, 162 (1.2%) babies were referred to audiology.

- 55 babies were confirmed with a hearing loss (0.4% 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 (MCCAD).

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 MCCAD 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 (MCCAD).

Detailed pathway is shown in **Appendix 5.1**.

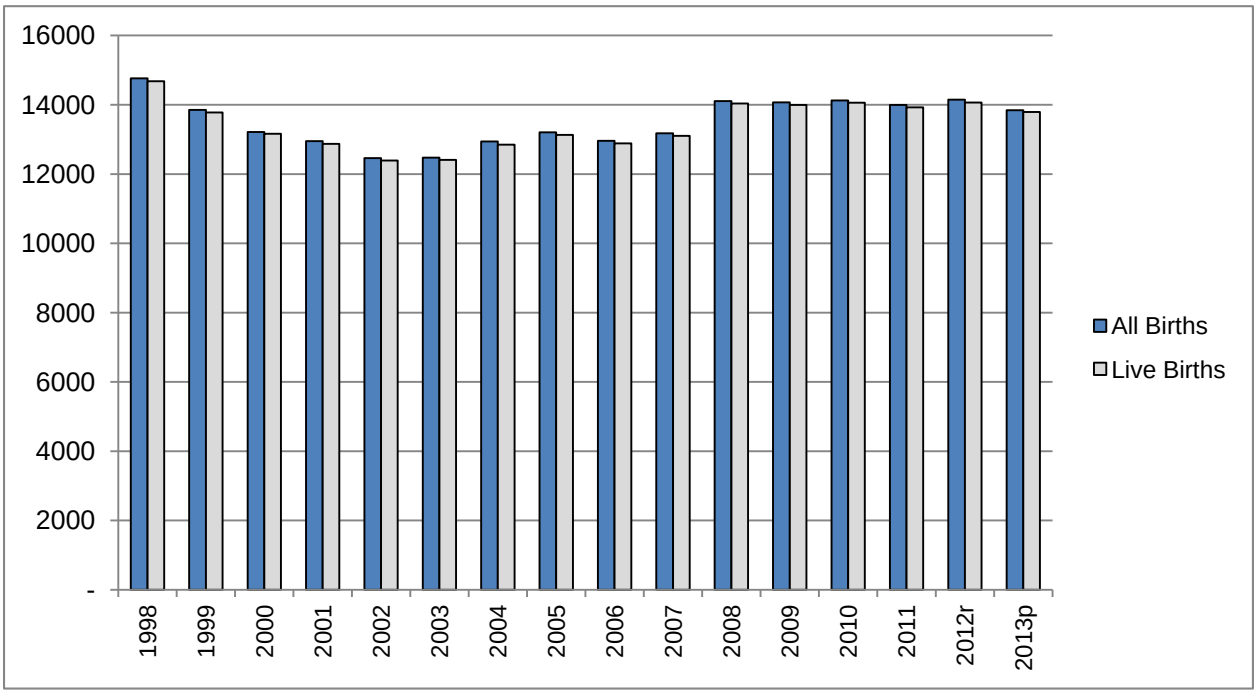
Universal Newborn Hearing screening: Hearing tests are carried out on all babies born in NHS Greater Glasgow and Clyde using the Automated Auditory Brainstem Response (AABR).

Detailed screening pathway is shown in **Appendix 5.2**

Delivery of NHSGGC Newborn Bloodspot Screening programmes

Figure 5.1 shows that number of live births have gradually increased year on year from 12,409 in 2002/03 to 13,792 in 2012/2013. This represents an increase of 10**%.**

Figure 5.1 Number of live and still births across NHS Greater Glasgow and Clyde over a 16 year period from 1998 to 2013



Source: SMR02, ISD Scotland

1 - Excludes home births and births at non-NHS hospitals.
2 - Where four or more babies are involved in a pregnancy, birth details are recorded only for the first three babies delivered.

3 - Scotland data includes births where NHS board of residence is unknown or outside Scotland.

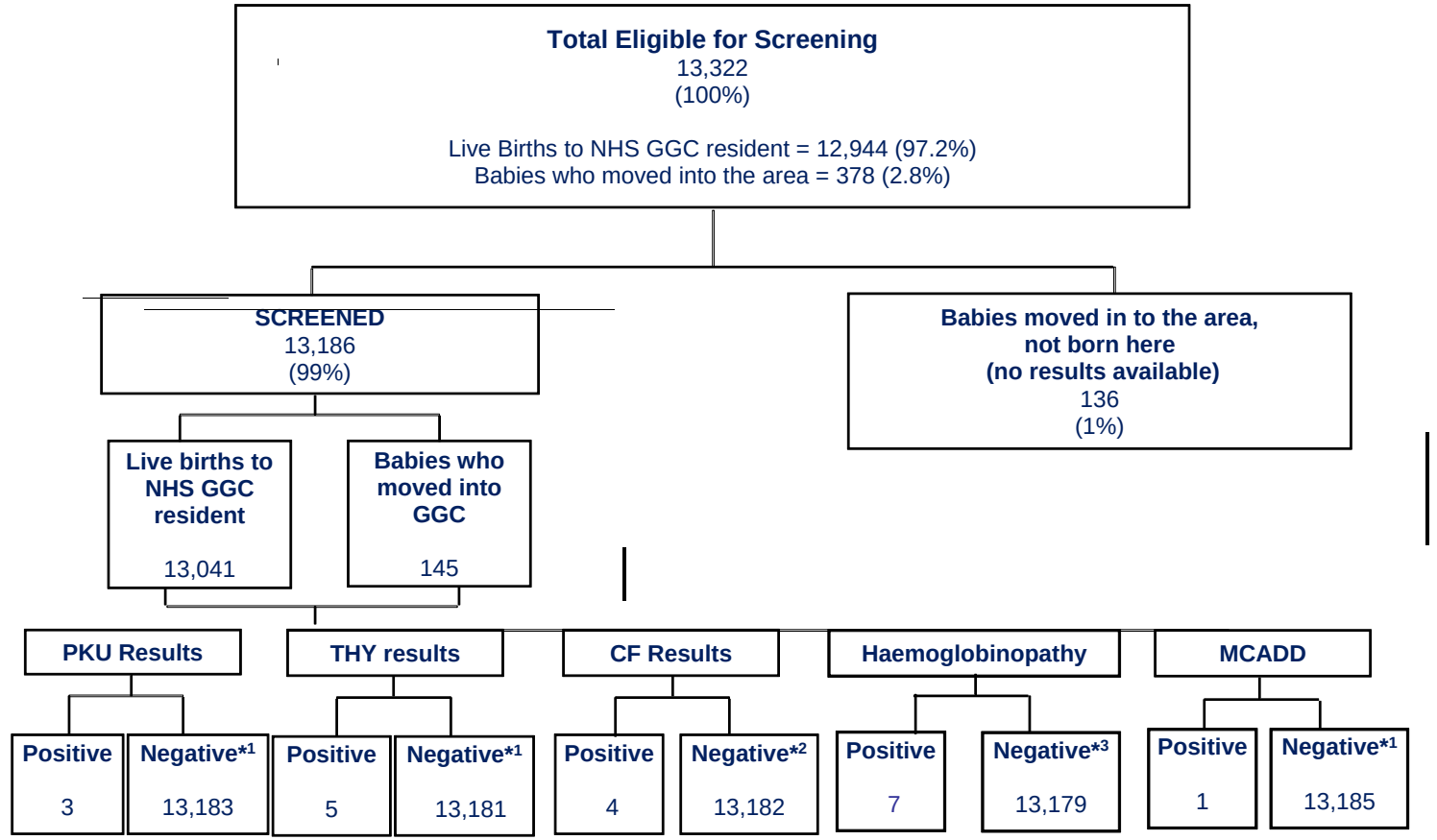
p - Provisional.

r revised

Figure 5.2 illustrates newborn bloodspot uptake rates and the results of the screening programme from 1 April 2013 to 31 March 2014.

12,944 babies resident in NHS Greater Glasgow and Clyde were screened, that is 97.2% of the total eligible population of 13,332. Results were not available for the 378 (1.7%) babies that moved into the NHSGGC Board area.

Figure 5.2 Newborn bloodspot uptake rates and the results for babies born 1 April 2013 to 31 March 2014



Source: Child Health (CH2008); Date extracted: 25th April 2014

Notes:

*1 Total includes 13 verifications

*2 Total includes 4 carriers and 1 late test; 14 verifications

*3 Total includes 91 carriers; 14 verifications

Following screening, five babies were diagnosed with congenital hypothyroidism, four babies with cystic fibrosis; seven babies with sickle cell disease, 1 baby with MCADD and 91 babies were identified as carriers for haemoglobinopathies. All babies 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 rate of bloodspot screening by CH(C)P and deprivation categories

	Most Deprived				SIMD				Least Deprived			
	1		2		3		4		5		Total	
CHP/CH(C)P	Screened	% uptake	Screened	% uptake	Screened	% uptake	Screened	% uptake	Screened	% uptake	Screened	% uptake
East Dunbartonshire	47	100.0	175	100.0	74	100.0	137	99.3	443	99.8	878	99.8
East Renfrewshire	96	100.0	82	100.0	66	100.0	145	99.3	463	99.1	854	99.4
Glasgow North East	1,432	99.2	275	98.6	157	98.1	134	97.1	42	97.7	2,042	98.8
Glasgow North West	1,023	98.9	269	98.9	318	95.2	244	95.7	332	97.1	2,187	97.7
Glasgow South	1,210	99.1	754	98.3	391	99.2	293	98.7	156	100.0	2,809	98.9
Inverclyde	385	100.0	110	100.0	83	100.0	111	100.0	68	98.6	759	99.9
North Lanarkshire	45	100.0	33	97.1	72	100.0	84	100.0	5	100.0	240	99.6
Renfrewshire	604	99.2	250	100.0	396	99.2	181	100.0	303	99.7	1,743	99.5
South Lanarkshire	223	98.2	72	98.6	136	100.0	182	98.9	62	100.0	677	99.0
West Dunbartonshire	396	99.5	268	100.0	186	100.0	76	100.0	35	100.0	962	99.8
NHSGGC	**5,461**	**99.2**	**2,288**	**99.0**	**1,879**	**98.7**	**1,589**	**98.6**	**1,909**	**99.1**	**13,186**	**99.0**

Source: Child Health (CH2008);
SIMD=Scottish Index of Multiple Deprivation 2012

Note: 60 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. 73% of babies had white UK ancestry, 6.9% had South Asian ancestry and 3.7% had mixed background ancestry.

Table 5.2 NHSGGC Newborn Bloodspot screening – ancestry of the babies tested 2013 – 2014

	Clyde		Glasgow		Total	
Ancestry Group	**N**	**%**	**N**	**%**	**N**	**%**
A African or African Caribbean	36	1.1	322	3.2	358	2.7
B South Asian (Asian)	57	1.7	879	8.6	936	6.9
C South East Asian (Asian)	19	0.6	250	2.5	269	2.0
D Other non-European (Other)	7	0.2	146	1.4	153	1.1
E Southern & Other European (White)	69	2.1	430	4.2	499	3.7
F United Kingdom (White)	2,808	85.1	7,051	69.1	9,859	73.0
G North Europe (White)	16	0.5	82	0.8	98	0.7
H Don't Know	3	0.1	27	0.3	30	0.2
I Decline to Answer	1	0.0	4	0.0	5	0.0
J Any Mixed Background	103	3.1	507	5.0	610	4.5
Z Not Stated	181	5.5	499	4.9	680	5.0
Total	**3,300**		**10,197**		**13,497**	

Source: National Newborn Screening Laboratory

Table 5.3 illustrates the laboratory outcomes of blood spot tests (data could not be separated for Clyde and Argyll and Bute). In 2013/14, of the 14,182 bloodspot samples received, 14,057 were normal. 205 (1.4%) 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. 120 (0.8%) 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 2013 and 31 March 2014

Specimen Test - Outcomes	Clyde	Glasgow	Total
Refused all tests	1	2	3
Partial refused	0	0	0
Insufficient blood to perform all tests	48	157	205
Unsatisfactory >14 days in transit	0	6	6
Unsatisfactory Other	18	97	115
Updated info	24	133	157
IRT tested late (total)	0	1	1
IRT tested late (Born in Scotland)	0	1	1
>7 days in transit	33	87	120
Ref PKU	0	3	3
Ref CHT	1	4	5
Ref CF	1	3	4
Ref CF Carrier	2	4	6
Ref MCADD	0	1	1
Ref SCD	0	2	2
Ref SCD Carrier	5	71	76
Ref HbV	0	5	5
Ref HbV Carrier	2	21	23
Number of Normal results	3,441	10,616	14,057
Pre-TF	23	95	118
Sent for SCD DNA	3	18	21
Total Specimens received	**3,452**	**10,730**	**14,182**
Insufficent as % of Total	1.4	1.5	1.4
Unsatisfactory as % of Total	0.52	0.96	0.85
IRT tested late as % of Total	0.00	0.01	0.01
IRT tested last (born in Scotland) as % of Total	0.00	0.01	0.01
>7 days in transit as % of Total	1.0	0.8	0.8

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 = baby 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.

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.

Table 5.4 Percentage Uptake for newborn hearing screening by CH(C)P

CHP/CH(C)P	Eligible	Screened	% Uptake
East Dunbartonshire	903	876	97.0
East Renfrewshire	864	847	98.0
Glasgow North East	2,138	2,020	94.5
Glasgow North West	2,270	2,175	95.8
Glasgow South	2,924	2,836	97.0
Inverclyde	758	752	99.2
North Lanarkshire[1]	237	233	98.3
Renfrewshire	1,795	1,771	98.7
South Lanarkshire[1]	671	640	95.4
West Dunbartonshire	978	958	98.0
Unassigned[2]	119	107	89.9
NHSGGC	**13,657**	**13,215**	**96.8**

Source: Scottish Birth Record (SBR) Extracted: June 2014

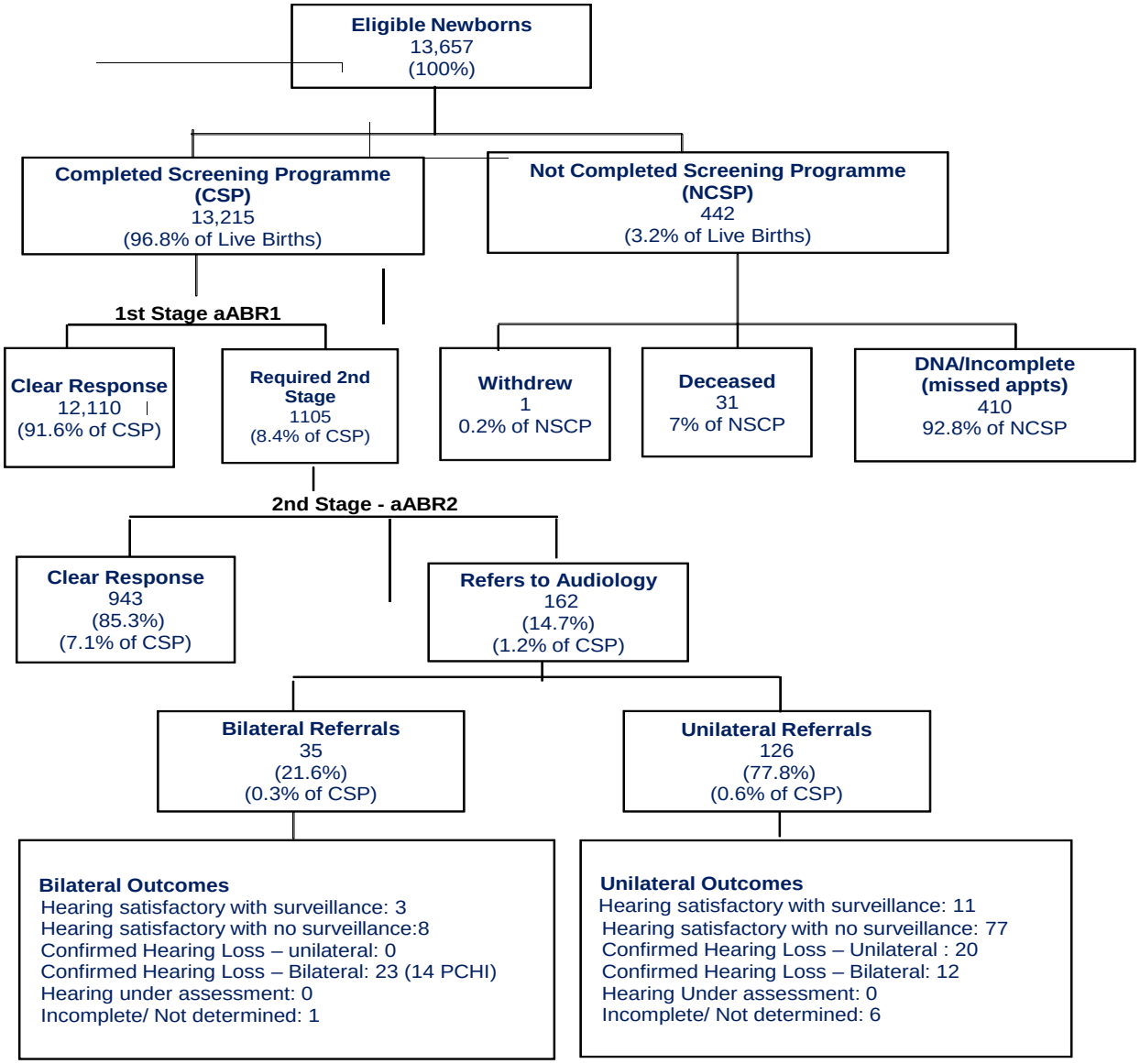
Notes

[1] NHS Greater Glasgow and Clyde residents only

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

Figure 5.3 illustrates the hearing screening activity. Of the 13,657 eligible babies, 13,215 were screened for hearing loss giving an uptake of 96.8% (**Figure 5.3 and Table 5.4**).

Figure 5.3 Summary of NHS Greater Glasgow and Clyde Universal Newborn Hearing Screening Programme



Source: Scottish Birth Record (SBR); Extracted June 2014

Definitions - Screening

1st Stage aABR1- is first first screen

2nd Stage aABR2 - is the second screen

Not Completed - all babies who did not complete screen process but had a final outcome set on SBR includes DNA, deceased, moved away. Babies who are still screening process either waiting 1st or 2nd stage screen are also included

Definitions - Outcomes

Hearing under assessment - all babies referred from the screening programme but have not attended diagnostic testing at the time the report was compiled.

Incomplete - patient did not attend appointment for diagnostic testing

Not yet determined - the severity and type of loss was not finalised at time of reporting. Will be followed up by Audiology.

PCHI - all babies who were diagnosed with permanent Childhood hearing loss in both ears - better ear responses at 40dB and deceased and pendings etc.

1,105 (9.2%) babies required a second stage follow up and, of these, 162 (1.2%) babies were referred to audiology. 55 babies were confirmed with a hearing loss (0.4% of the screened population).

442 (3.2%) 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 results 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 deliver hearing screening.

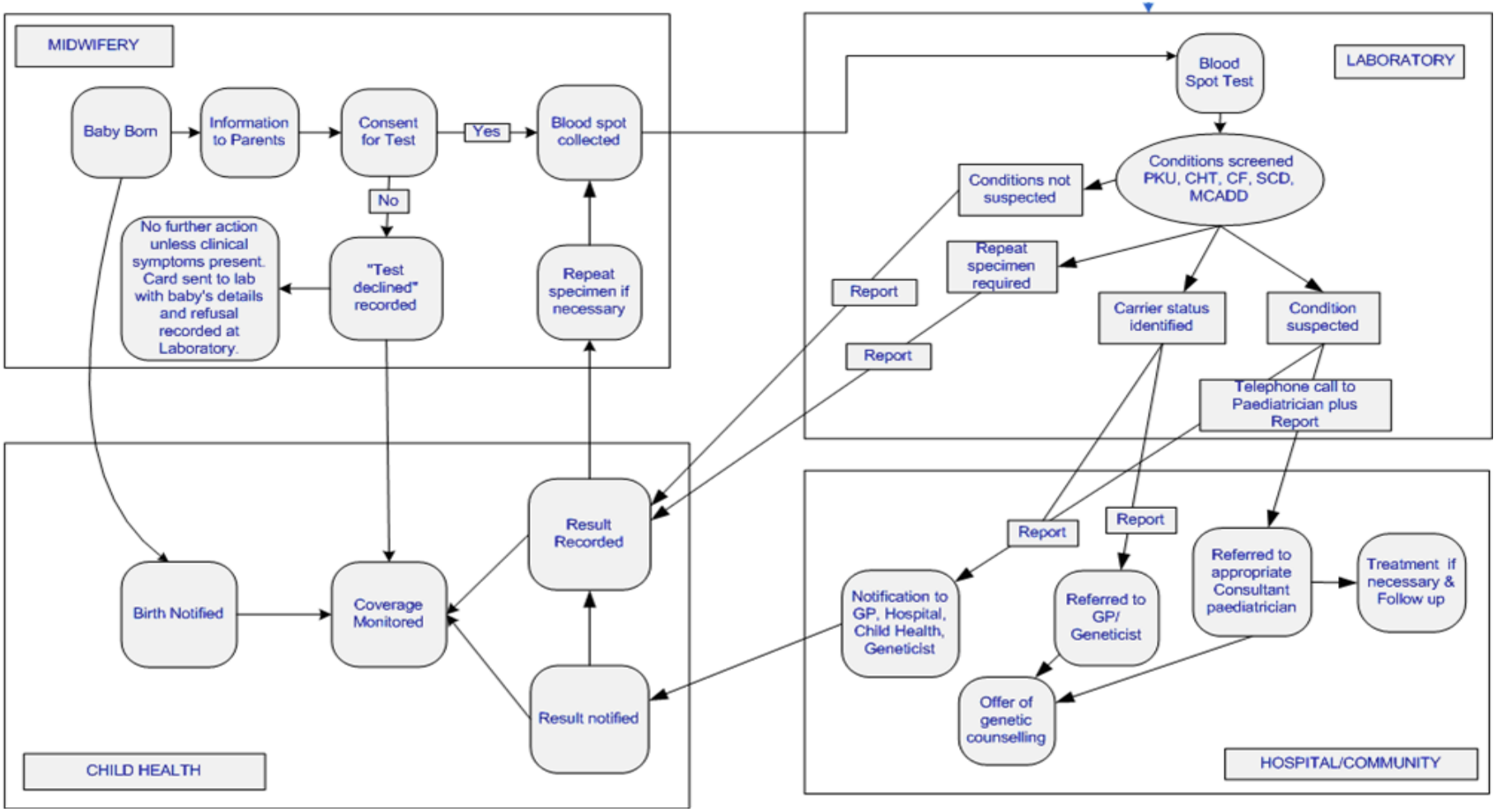
The Child Health Surveillance Programme Pre-School system (CHSP-PS) is holding screening outcomes and is used as a failsafe to ensure all babies are offered hearing screening.

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.

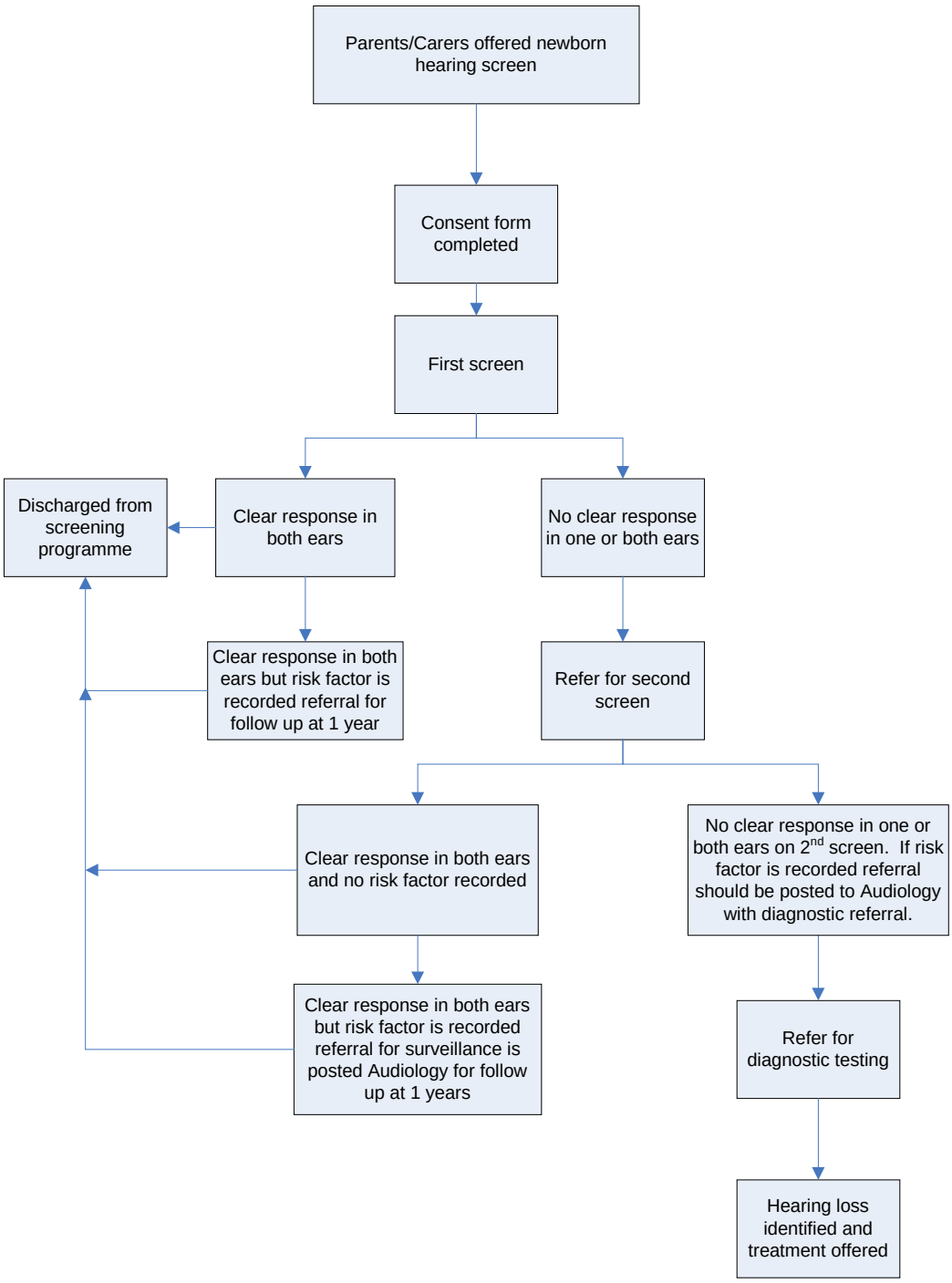
NHSGGC Newborn Bloodspot Screening Pathway

Appendix 5.1



Appendix 5.2

NHSGGC Universal Newborn Hearing Screening Pathway



Appenidx 5.3

Members of Newborn Bloodspot Screening Steering Group
As at March 2014

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 Elizabeth Chalmers	Consultant Paediatric Haematologist
Dr Rosemarie Davidson	Consultant Clinical Geneticist
Dr Anne Devenny	Consultant Paediatrician
Dr Catherine Dorrian	Consultant Clinical Scientist
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 Annette Little	Information Analyst
Miss Denise Lyden	Project Officer
Dr Helen Mactier	Consultant Neonatologist
Mrs Fiona Manwell	Lead Midwife
Mrs Michelle McLauchlan	General Manager, Obstetrics
Mrs Marion McNabb	Clinical Lead Midwife
Mrs Julie Mullin	Assistant Programme Manager, Screening Dept
Dr Peter Robinson	Consultant in Paediatric Metabolic Medicine
Dr Bernd Schwahn	Consultant in Paediatric Metabolic Medicine
Ms Sarah Smith	Principle Scientist, Newborn Screening Laboratory
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 2014)

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 Jan Savage	National Deaf Children's Society
Mrs Jacqueline Truss	Audiologist Team Leader
Dr Madeline White	Consultant Neonatologist
Ms Heather Young	National Deaf Children's Society, Family Support

SUMMARY

CHAPTER 6: PRESCHOOL VISION SCREENING

- 13,638 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 2.2% decrease from previous year 2012/13.

- 39.7% (5,418) of children live in the most deprived areas, with the largest proportion living in the Glasgow area.

- 74.9% (10,215) of children were registered with a nursery. Of the 3,423 (25.1%) children not registered with a nursery, 1,950 (57.9%) were from Glasgow City CHP sectors.

- 11,728 were screened for a visual abnormality, giving an overall uptake of 85.9%.

- 74.1% of children registered with a nursery were screened while only 11.9% of children not registered with a nursery took up screening

- 8,620 (73.5%) had a normal result. 2,290 (19.5%) children were referred for further assessment. 1,041 (23.1%) were from the most deprived areas.

- 294 (2.5%) children were recalled back to be screened due to difficulties screening children's vision during their first screen. 524 (4.5%) children are currently under follow up by ophthalmology service

- Uptake rate for the programme across the CH(C)P areas varied from 80.3% in Glasgow North East to 91.2% in East Renfrewshire.

- The highest proportion of children screened that were referred for further investigation was in Glasgow North East (24.3%) and Glasgow North West (23.5%). The lowest was 14.3% 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 NHS Greater Glasgow and Clyde aged between four and five years 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 2009 and 28 February 2010 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 2013/14

In 2013/14, 13,638 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 2.2% decrease from previous year 2012/13.

Table 6.1 shows that 39.7% (5,418) 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		
CHP/CH(C)P	**1**	**2**	**3**	**4**	**5**	**Unassigned[2]**	**Total**
East Dunbartonshire	42	224	92	173	578	5	1,114
East Renfrewshire	82	90	83	200	656	5	1,116
Glasgow North East	1,405	237	147	150	53	7	1,999
Glasgow North West	1,068	256	224	203	299	8	2,058
Glasgow South	1,213	670	322	326	135	15	2,681
Inverclyde	365	132	108	118	84	3	810
North Lanarkshire	40	26	50	64	11	0	191
Renfrewshire	531	288	419	252	345	26	1,861
South Lanarkshire	244	91	128	170	98	0	731
West Dunbartonshire	428	290	191	98	47	7	1,061
Unassigned[2]						16	16
NHSGGC	**5,418**	**2,304**	**1,764**	**1,754**	**2,306**	**92**	**13,638**
% of NHSGGC Total	**39.7**	**16.9**	**12.9**	**12.9**	**16.9**	**0.7**	

Source: Child Health - Pre-School Date Extracted: September 2014

Notes

1 Scottish index of multiple deprivation 2012

2 Unable to assign SIMD due to incomplete or incorrect postcode

Table 6.2 shows that 74.9% (10,215) of children were registered with a nursery. Of the 3,423 (25.1%) children not registered with a nursery, 1,950 (57.9%) 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

CHP/CH(C)P	Children eligible for screening	Registered with a Nursery	Registered %	Not registered with a nursery	Not Registered %
East Dunbartonshire	1,114	942	84.6	172	15.4
East Renfrewshire	1,116	847	75.9	269	24.1
Glasgow North East	1,999	1,386	69.3	613	30.7
Glasgow North West	2,058	1,492	72.5	566	27.5
Glasgow South	2,681	1,877	70.0	804	30.0
Inverclyde	810	677	83.6	133	16.4
North Lanarkshire	191	148	77.5	43	22.5
Renfrewshire	1,861	1,466	78.8	395	21.2
South Lanarkshire	731	574	78.5	157	21.5
West Dunbartonshire	1,061	795	74.9	266	25.1
Unassigned[1]	16	11	68.8	5	31.3
NHSGGC	**13,638**	**10,215**	**74.9**	**3,423**	**25.1**

Source: Child Health - Pre-School Date Extracted: September 2014

Notes

1 Unable to assign SIMD due to incomplete or incorrect postcode

Table 6.3 shows that of the 74.1% of children registered with a nursery had a screening test while only 11.9% of children not registered with a nursery have been screened.

Table 6.3 The number of children eligible for screening, number and percentage uptake of children registered and not registered with a nursery by CH(C)P

CHP/CH(C)P	No of Eligible children registered with nursery	% Uptake registered with nursery	No of Eligible children not registered with nursery	% Uptake not registered with nursery	Total No of Eligible children	% total uptake
East Dunbartonshire	942	83.6	172	7.6	1,114	91.2
East Renfrewshire	847	74.3	247	14.4	1116	88.7
Glasgow North East	1,386	68.3	605	12.0	1,999	80.3
Glasgow North West	1,492	71.7	550	11.2	2,058	82.8
Glasgow South	1,877	69.2	775	14.7	2681	83.8
Inverclyde	677	83.5	128	9.1	810	92.6
North Lanarkshire	148	77.5	40	11.5	191	89.0
Renfrewshire	1,466	78.3	380	11.7	1,861	90.0
South Lanarkshire	574	77.6	154	12.4	731	90.0
West Dunbartonshire	795	74.7	254	9.8	1,061	84.5
Unspecified[1]	11	68.8	1	25.0	16	93.8
NHSGGC	**10,215**	**74.1**	**3,296**	**11.9**	**13,638**	**86.0**

Source: Child Health - Pre-School

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 2013. Of the 13,638 eligible children, 11,728 were screened for a visual abnormality, giving an overall uptake of 85.9%. 2,290 (19.5%) children were referred for further assessment (Figure 6.1).

Figure 6.1: Summary of NHSGGC Pre-school Vision Screening Activity

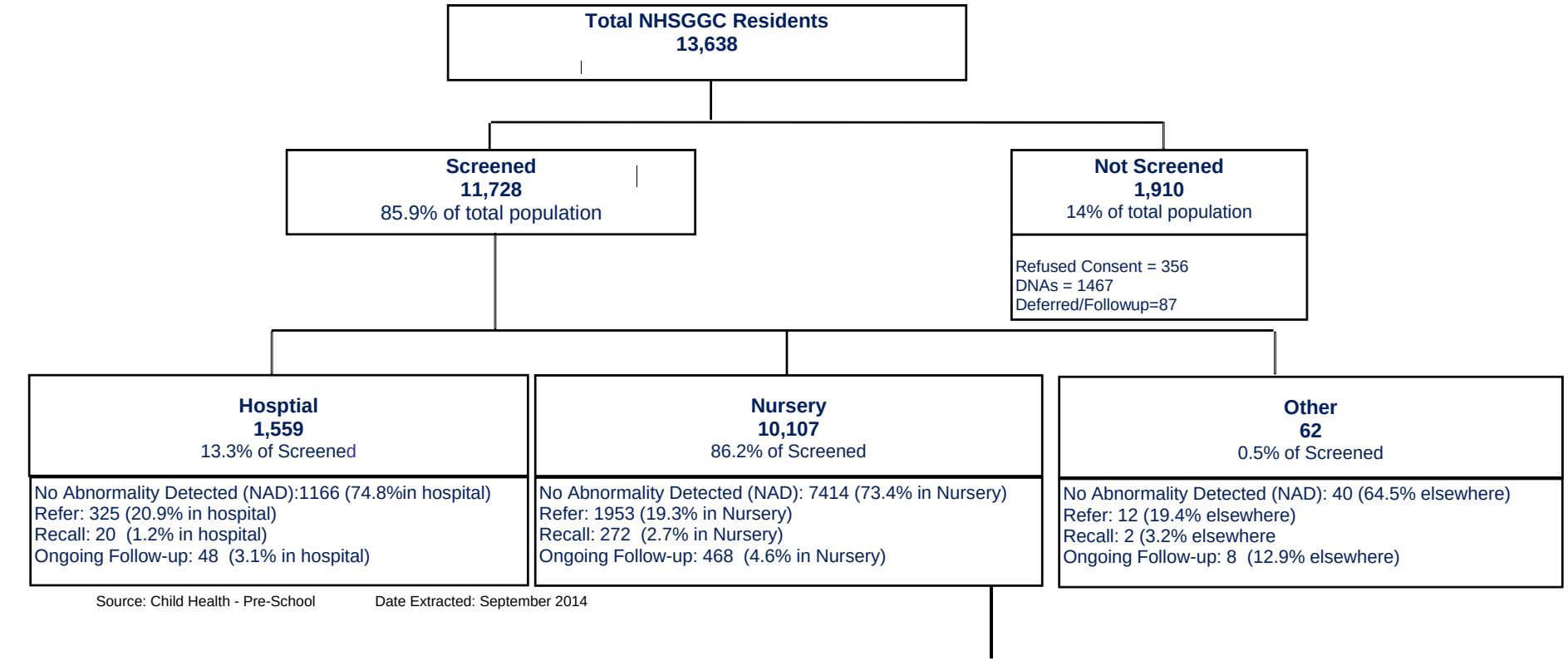


Table 6.4 shows that, of the 11,728 children screened, 8,620 (73.5%) had a normal result. Of the 2,290 (19.5%) children referred for further assessment, 1,041 (23.1%) were from the most deprived areas. 294 (2.5%) children were recalled back to be screened due to difficulties screening children's vision during their first screen. 524 (4.5%) children are currently under follow up by ophthalmology service

Table 6.4 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	4,502	3,086	68.5	1,041	23.1	141	3.1	234	5.2
2	1,959	1,425	72.7	395	20.2	50	2.6	89	4.5
3	1,530	1,169	76.4	263	17.2	31	2.0	67	4.4
4	1,564	1,205	77.0	274	17.5	32	2.0	53	3.4
5	2,088	1,668	79.9	304	14.6	39	1.9	77	3.7
Unassigned[1]	85	67	78.8	13	15.3	1	1.2	4	4.7
Total	**11,728**	**8,620**	**73.5**	**2,290**	**19.5**	**294**	**2.5**	**524**	**4.5**

Source: Child Health - Pre-School Date Extracted: September 2014

Notes

1 Unable to assign SIMD due to incomplete or incorrect postcode

Table 6.5 shows the uptake rate for the programme across the CH(C)P areas varied from 80.3% in Glasgow North East to 91.2% in East Renfrewshire.

The highest proportion of children screened that were referred for further investigation was in Glasgow North East (24.3%) and Glasgow North West (23.5%). The lowest was 14.3% in East Renfrewshire.

Table 6.5 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	1,114	1,016	98	91.2	76.4	17.4	2.0	4.2
East Renfrewshire CHCP	1,116	990	126	88.7	81.7	14.3	2.1	1.8
Glasgow North East	1,999	1,606	393	80.3	66.1	24.3	4.2	5.4
Glasgow North West	2,058	1,705	353	82.8	69.0	23.5	2.5	5.0
Glasgow South	2,681	2,247	434	83.8	72.4	20.8	3.0	3.8
Inverclyde CHP	810	750	60	92.6	73.9	18.1	1.7	6.3
North Lanarkshire CHP	191	170	21	89.0	72.9	22.9	2.4	1.8
Renfrewshire CHP	1,861	1,674	187	90.0	78.4	14.8	1.5	5.3
South Lanarkshire CHP	731	658	73	90.0	77.5	15.5	3.3	3.6
West Dunbartonshire CHP	1,061	897	164	84.5	73.1	20.8	1.1	4.9
Unassigned 1	16	15	1	93.8	80.0	6.7	6.7	6.7
Total	**13,638**	**11,728**	**1,910**	**86.0**	**73.5**	**19.5**	**2.5**	**4.5**

Source: Child Health - Pre-School Date Extracted: September 2014

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 Local Authorities Education Departments to understand taking up nursery places and how to improve this.

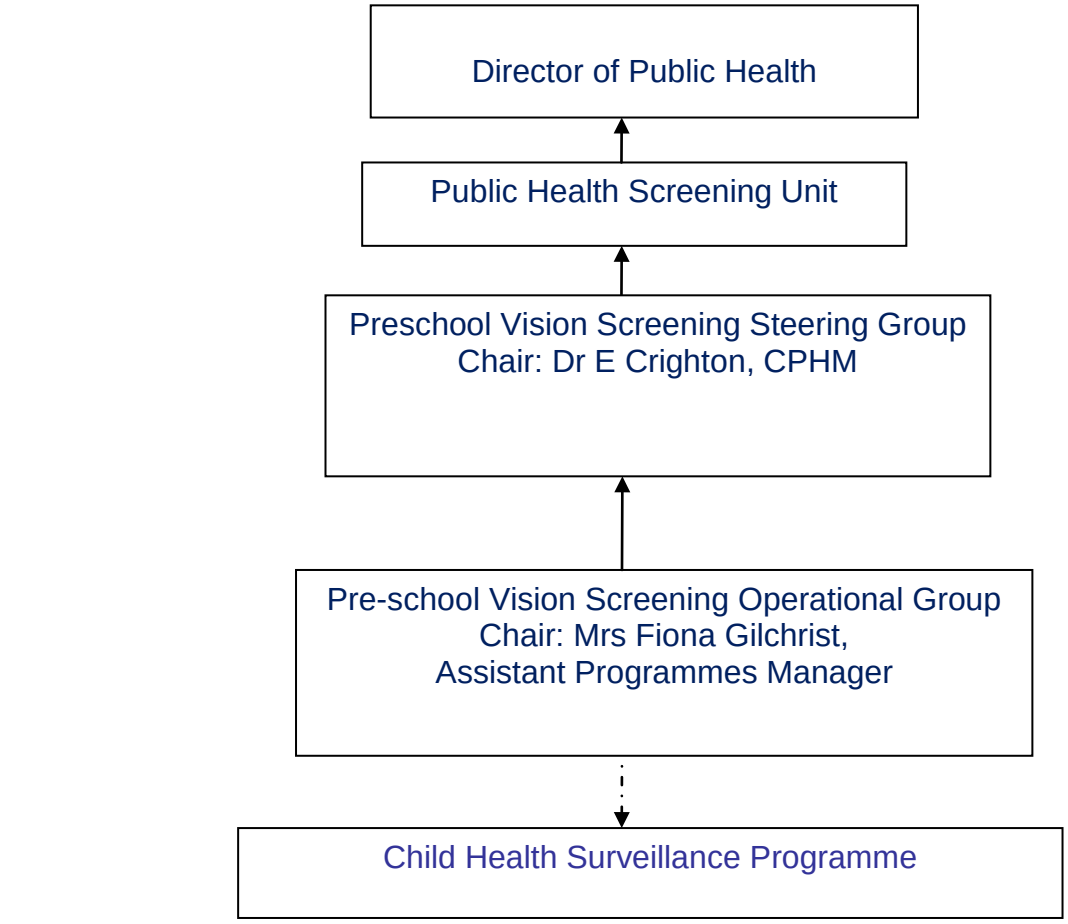
Appendix 6.1

Members of Pre-school Vision Screening Steering Group (As at March 2014)

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 Liz Daniels	Clinical Services Manager, Renfrewshire CHP
Mrs Emma Finlay	Child & Families Team Lead, Renfrewshire CHP
Mrs Fiona Gilchrist	Assistant Programme Manager, Screening Dept
Ms Bernie Hegarty	Deputy Head of Optometry
Ms Nicola McElvanney	Chair Area Optometry Committee
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
Dr Kathy Spowart	Associate Specialist, Community Paediatrics
Mrs Sandra Simpson	Programme Support Officer

Appendix 6.2

Reporting Structure:
Pre-School Vision Screening Steering Group



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

SUMMARY

CHAPTER 7: DIABETIC RETINOPATHY SCREENING

- There were 65,265 NHS Greater Glasgow and Clyde residents with a diagnosis of diabetes in 2013/14, representing an increase of 3.4% from 2012/13.

- The prevalence of diabetes among NHS Greater Glasgow and Clyde adult residents has gradually increased from 4.3% in 2007/08 to 5.7% in 2012/13.

- 26,505 (40.6%) are known to be resident in the most deprived areas compared to 9,273 (14.2%) who live in the least deprived areas.

- The largest proportion of people with diabetes was among the 50 – 79 year olds. This represents 68.9% (44,950) of the total population with diabetes.

- Of the 65,265 patients with diabetes, 55,282 (84.7%) were eligible for screening. Of those, 90.6% (50,070) were screened. This means that 76.6% of the total population with diabetes in NHS GGC was screened in 2013/14.

- 9,983 (15.3%) people were not eligible for screening because they were either permanently or temporarily suspended from the programme.

- Of the total number of residents screened (50,070), 1,911 were referred to Ophthalmology for further investigation.

- All CH(C)P areas exceeded the minimum standard of 80% uptake for diabetic retinopathy screening.

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

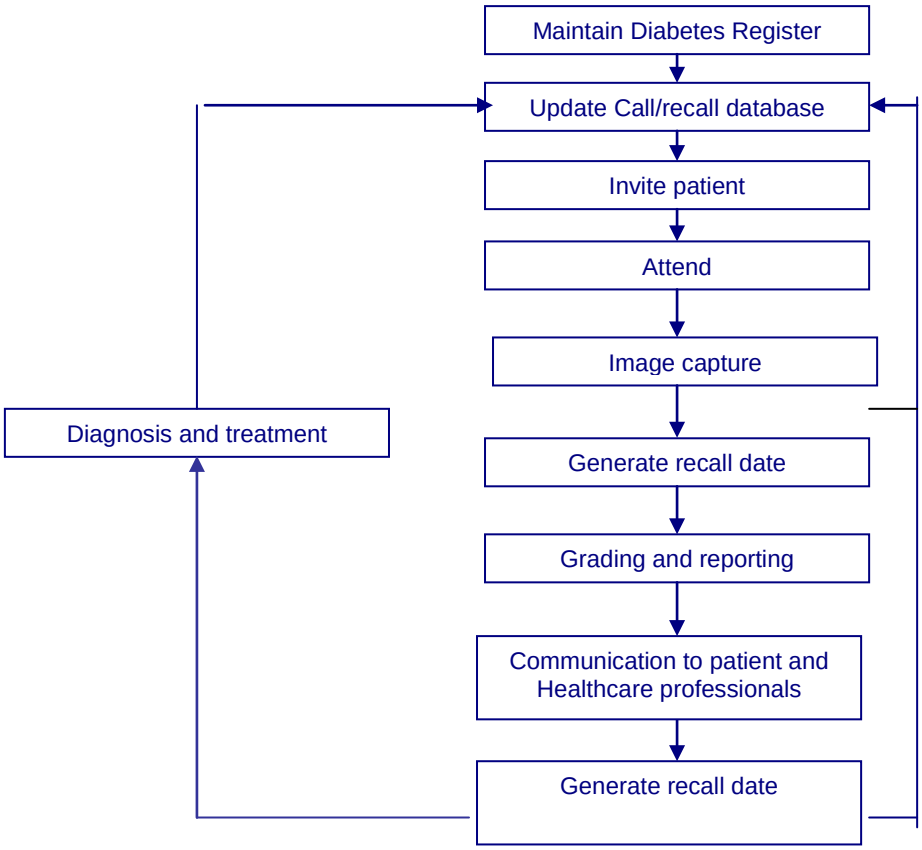
The screening programme takes place in a variety of settings. This can either be at a fixed site or within a mobile screening unit, which visits health centres and other locations around the area. Across Greater Glasgow and Clyde there were six fixed site locations and four mobile screening units.

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

Screening Pathway

Figure 7.1 illustrates the 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 seven year period from 2007/08 to 2013/14. There were 65,265 NHS Greater Glasgow and Clyde residents with a diagnosis of diabetes in 2013/14, representing an increase of 3.4% from 2012/13. 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 5.7% in 2012/13.

Table 7.1 Number of NHSGGC residents with diabetes, type of diabetes and prevalence from 2007/2008 to 2013/2014

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**
2013/2014	1,147,662	6,629	56,170	1,002	1,464	65,265	**5.7**

Source: DRS, Soarian Date Extracted: April 2014

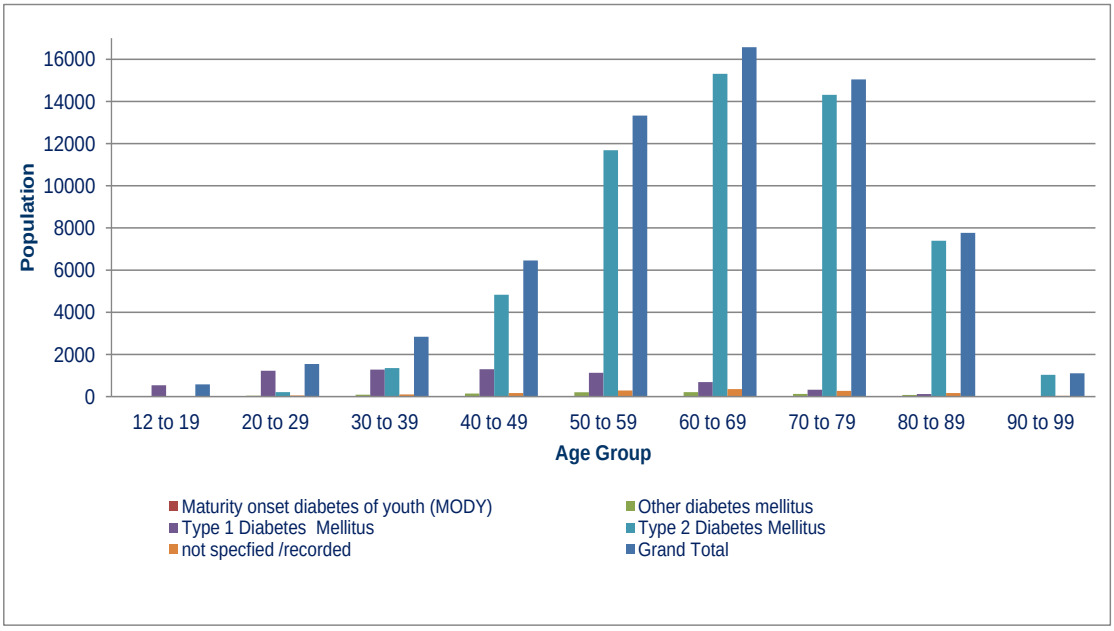
[1] Total Population aged over 12 years old (Source CHI - Jan 08, Jan 09, Jan 10, Jan 11, Jun 12, Aug 13, Mar 14)

[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 July 2014

Table 7.2 shows the prevalence and type of diabetes by CH(C)P. The prevalence of diabetes has continued to increase across all CHCP areas with the exception of Glasgow North West sector which has remained static at 4.6%

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	97,083	548	4,352	67	106	5,073	5.2%
East Renfrewshire	80,903	480	3,656	68	121	4,325	5.3%
Glasgow North East	172,227	978	8,786	201	170	10,135	5.9%
Glasgow North West	203,213	1,065	7,943	161	206	9,375	4.6%
Glasgow South	210,350	1,219	11,396	213	187	13,015	6.2%
Inverclyde	71,458	435	3,898	80	167	4,580	6.4%
North Lanarkshire[3]	17,407	102	852	11	12	977	5.6%
Renfrewshire	158,096	940	8,172	98	321	9,531	6.0%
South Lanarkshire[3]	54,564	323	2,687	21	38	3,069	5.6%
West Dunbartonshire	82,361	518	4,384	71	116	5,089	6.2%
Unassigned[4]	n/a	21	44	11	20	96	
NHSGGC Total	**1,147,662**	**6,629**	**56,170**	**1,002**	**1,464**	**65,265**	**5.7%**

Source: DRS, Soarian Date Extracted: April 2014

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 NHSGGC, 26,505 (40.6%) are known to be resident in the most deprived areas compared to 9,273 (14.2%) who live in the least deprived areas.

The largest proportion of people with diabetes was among the 50 – 79 year olds. This represents 68.9% (44,950) of the total population with diabetes.

28 centenarian residents developed diabetes late on life with average age of diagnosis at 77.

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	215	102	88	69	102	3	579	37.1%
20 to 29	575	274	249	208	222	15	1,543	37.3%
30 to 39	1,269	540	397	330	285	20	2,841	44.7%
40 to 49	2,986	1,263	852	699	618	37	6,455	46.3%
50 to 59	5,623	2,572	1,841	1,536	1,696	61	13,329	42.2%
60 to 69	6,509	3,092	2,220	2,139	2,562	52	16,574	39.3%
70 to 79	5,976	2,881	2,079	1,799	2,265	47	15,047	39.7%
80 to 89	2,958	1,470	1,077	917	1,327	18	7,767	38.1%
90 to 99	384	215	165	142	191	5	1,102	34.8%
100+	10	3	7	2	5	1	28	35.7%
Total	**26,505**	**12,412**	**8,975**	**7,841**	**9,273**	**257**	**65,265**	**40.6%**

Source: DRS, Sorian Date Extracted: April 2014

Notes:

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

Age calculated as at financial year end (ie 31/03/2014)

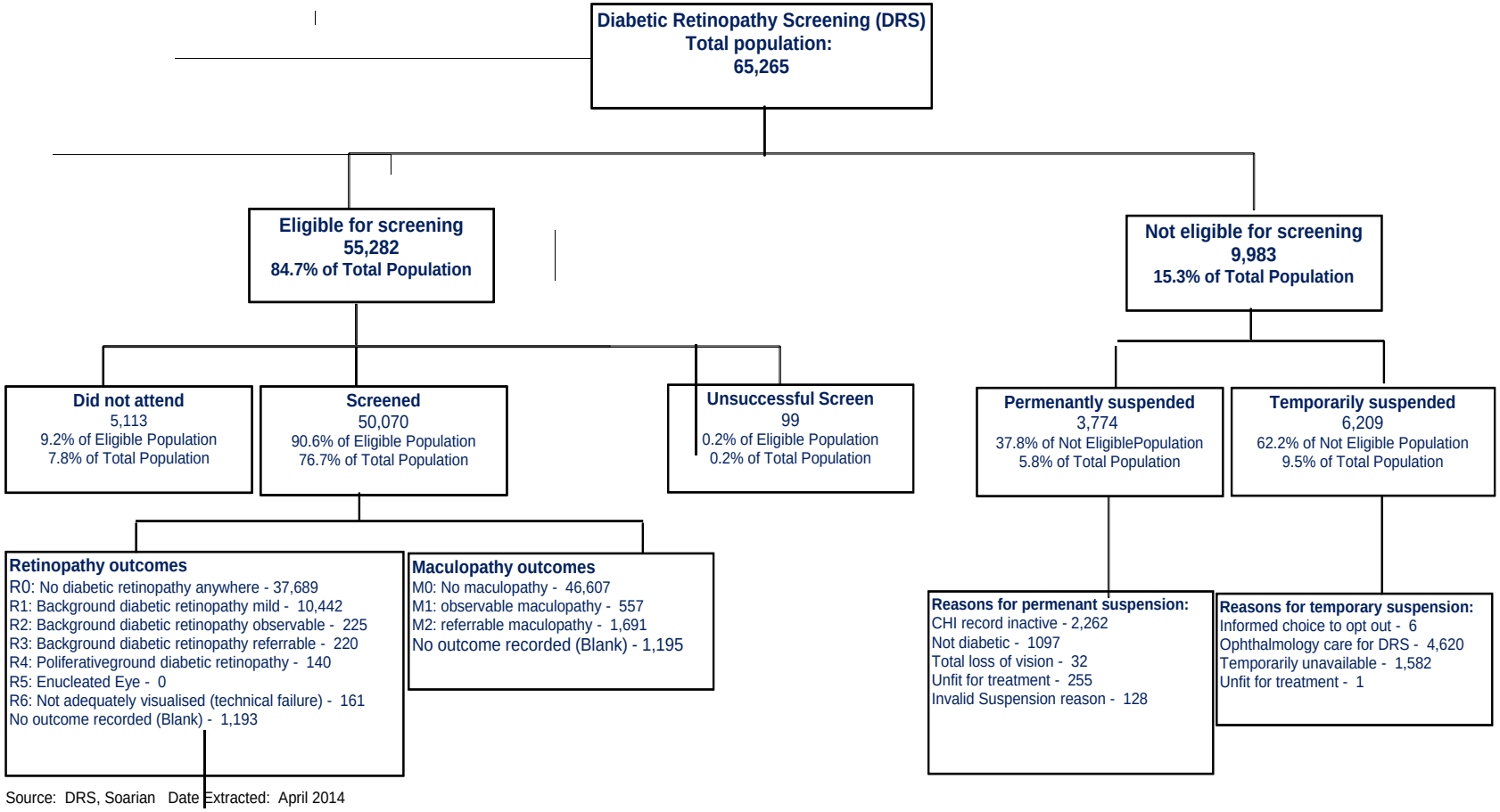
Figure 7.3 illustrates the summary of the NHS Greater Glasgow and Clyde Diabetic Retinopathy Screening programme for the period 1 April 2013 to 31 March 2014.

Of the 65,265 patients with diabetes, 55,282 (84.7%) were eligible for screening. Of those, 90.6% (50,070) were screened. This means that 76.6% of the total population with diabetes in NHSGGC was screened in 2013/14.

9,983 (15.3%) 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 (50,070), 1,911 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 2013 to 31 March 2014



Source: DRS, Soarian Date Extracted: April 2014

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 of 80%.

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	5,073	4290	4057	94.6%
East Renfrewshire	4,325	3610	3403	94.3%
Glasgow North East	10,135	8705	7724	88.7%
Glasgow North West	9,375	7838	7067	90.2%
Glasgow South	13,015	10835	9682	89.4%
Inverclyde	4,580	3831	3490	91.1%
North Lanarkshire[1]	977	870	786	90.3%
Renfrewshire	9,531	8126	7442	91.6%
South Lanarkshire[1]	3,069	2691	2450	91.0%
West Dunbartonshire	5,089	4439	3928	88.5%
Unassigned[2]	96	47	41	87.2%
NHSGGC Total	**65,265**	**55282**	**50070**	**90.6%**

Source: DRS, Sorian Data Extracted: April 2014

Notes

1 NHSGGC residents only

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

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-Diabetes is an essential component for effective Diabetic Retinopathy Screening. It provides both the diabetes population register for the DRS call/recall and the screening results are then feedback to SCI-Diabetes where they can be viewed by clinical staff involved in the care of patients with diabetes.

After being piloted in 2012 and 2013 the use of DRS autograding software is now embedded within the DRS programme

Challenges and future priorities

It is anticipated that the number of people with diabetes will continue to increase, requiring additional screening capacity and resources in the future. At present the current prevalence of diabetes for NHSGGC adult residents is 5.7%.

Work will continue to try and reduce DNAs and increasing the number of people taking up appointments.

Appendix 7.1

Members of Diabetic Retinopathy Screening Steering Group (As at March 2014)

Dr Emilia Crighton	Consultant in Public Health Medicine (chair)
Mr Jim Bretherton	Clinical Service Manager
Mrs Lin Calderwood	HI&T Screening Service Delivery Manager
Mrs Fiona Gilchrist	Assistant Programme Manager, Screening Dept
Mrs Fiona Heggie	Clinical Nurse Co-ordinator, Retinal Screening
Mrs Annette Little	Information Analyst
Miss Denise Lyden	Project Officer
Mr Carsten Mandt	Co-ordinator for MCN for Diabetes
Miss Nicola McElvanney	AOC Chair
Mr Eddie McVey	Optometric Advisor
Mrs Elizabeth Rennie	Programme Manager, Screening Dept
Mr David Sawers	DRS Service Manager
Dr William Wykes	Consultant Ophthalmologist
Dr Sonia Zachariah	Specialty Doctor, Diabetic Retinal Screening

SUMMARY

CHAPTER 8: ABDOMINAL AORTIC ANEURYSM SCREENING

- 5,526 male residents aged 65 in NHS Greater Glasgow and Clyde were invited to participate in the AAA Screening programme.
- 4,486 (81.2%) took up screening.
- The lowest uptake was 74.7% among men resident in the most deprived neighbourhoods compared to all other deprivation areas where uptake was above 80%.
- Lowest uptakes were found in Glasgow North East 74.8%; Glasgow West at 78.6% and Glasgow South at 78.7%.
- 48 men were found to have an aneurysm measuring between 3.00 and 5.4 cm and are currently on surveillance. 5 men had an aneurysm measuring over 5.5 cm that required surgical assessment and intervention. 1.1% required surveillance and 0.1% were referred to secondary care for assessment.

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

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.

Screening test

The screening test involves a single abdominal scan using a portable ultrasound machine.

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 (**Figure 8.1**).

Participants 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.

Sometimes an image cannot be achieved if participants have a high BMI, large abdominal girth, as bowel gas or previous surgery that can cause issues with visualisation of the aorta preventing accurate measurements and image capture.

If an image cannot be achieved after two appointments men will be discharged from the programme and referred to Vascular Services to manage the participants locally (**Figure 8.2**).

Figure 8.1 Positive Abdominal Aortic Aneurysm Screening Pathway

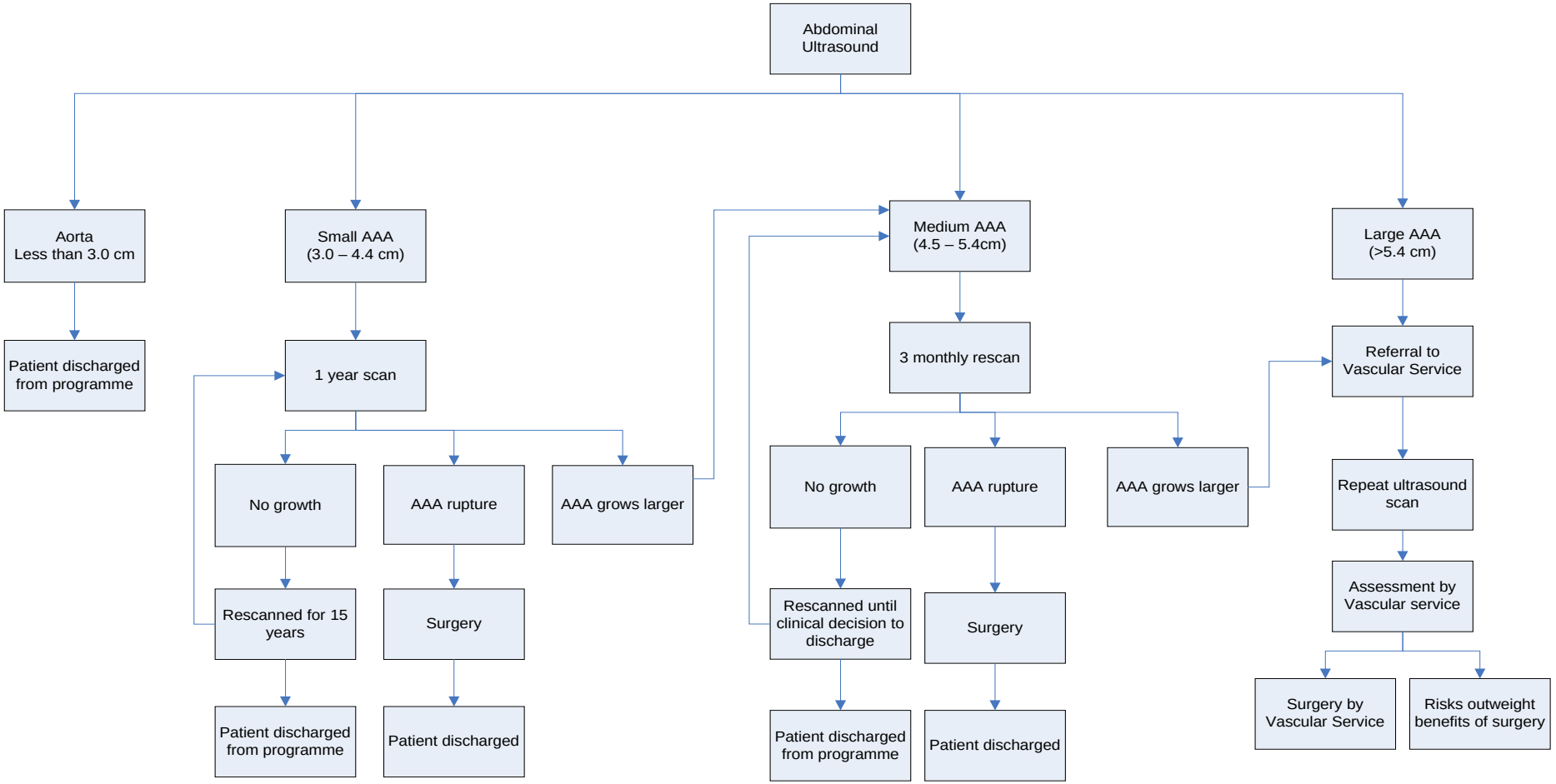
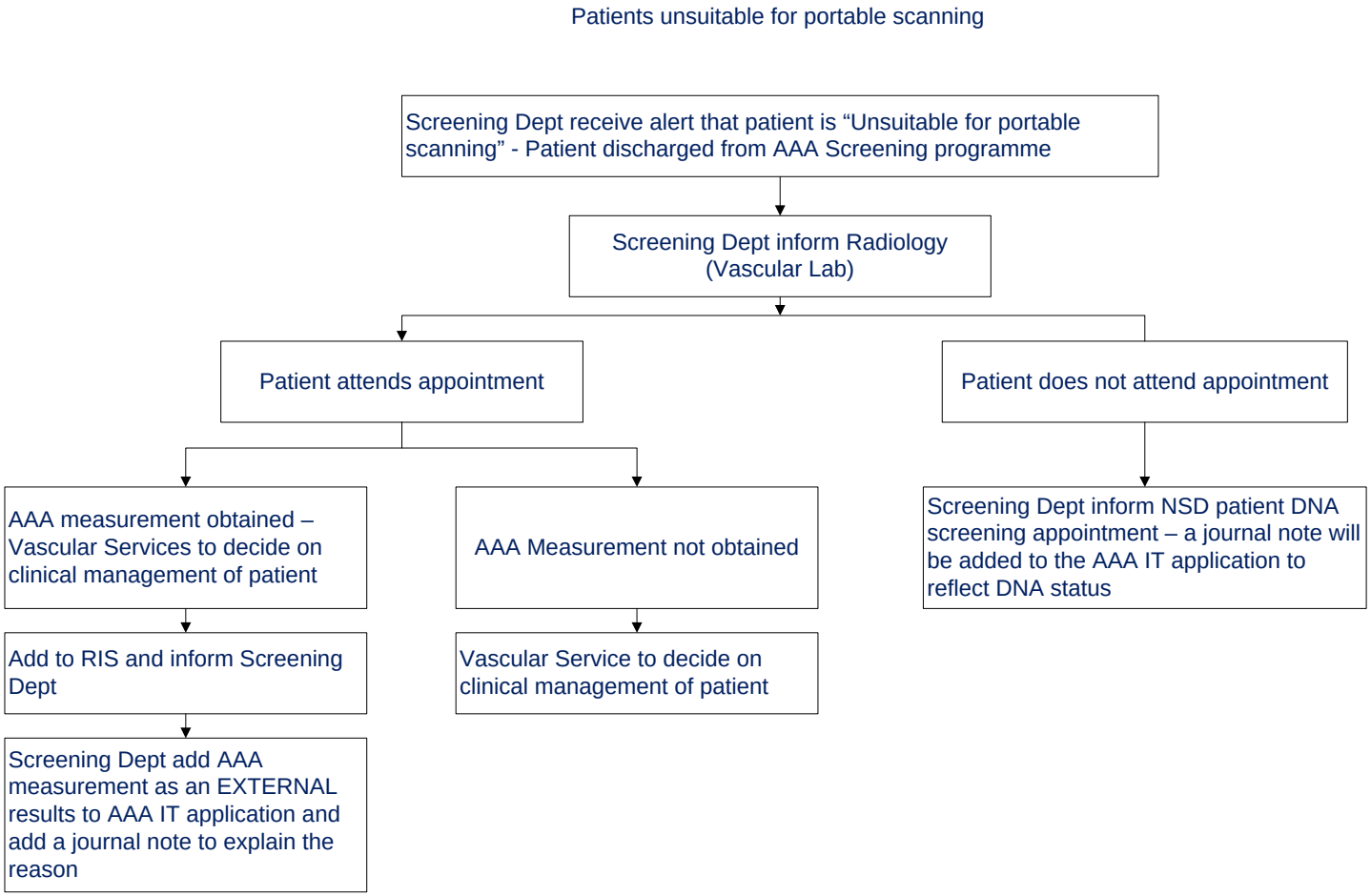


Figure 8.2 Pathway for participants that are unsuitable for portable scanning



Delivery of NHSGGC Abdominal Aortic Aneurysm Screening

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
6,110	5,815	5,691	5,671	5,570	5,907	5,858	6,191	6,398

Source: National Services Division business case (2008)

From 1 April 2013 to 31 March 2014, 5,526 male residents aged 65 in NHS Greater Glasgow and Clyde were invited to participate in the AAA Screening programme. Of the total invited, 4,486 (81.2%) took up screening (**see Table 8.2**).

Table: 8.2 NHS Greater Glasgow and Clyde AAA Screening activity 1 February 2013 – 31 March 2014

Activity	**Total**
Number Invited	5,526
Attended	4,486
Cancelled By Programme	2
Did Not Attend	1,038
% Uptake	**81.2**
% Did not attend	**18.8**

Source: Abdominal Aortic Aneuysm (AAA) BO; extracted May 2014

Table 8.3 shows the abdominal aortic aneurysm screening uptake varied across the different deprivation categories. Lowest uptake was 74.7% among residents in the most deprived neighbourhoods while uptake among residents in the least deprived areas was 89.4%. Lowest uptakes were found in Glasgow North East 74.8%; Glasgow West at 78.6% and Glasgow South at 78.7%.

Table 8.3 NHSGGC Abdominal Aortic Aneurysm Screening uptake by CHP and deprivation category

					% Uptake by SIMD						
CHP/CH(C)P	Number Invited	Number Attended	Did not attend	Did not attend %	1	2	3	4	5	Unassigned[1]	Total[2]
East Dunbartonshire	524	464	60	11.5	86.7	89.3	83.3	85.1	90.2	100.0	88.5
East Renfrewshire	473	412	60	12.7	48.6	83.0	93.8	89.1	91.1	100.0	87.1
Glasgow North East	794	594	200	25.2	72.8	74.3	72.5	84.3	85.0	100.0	74.8
Glasgow North West	637	501	136	21.4	73.4	83.8	78.6	85.9	83.5	50.0	78.6
Glasgow South	859	676	183	21.3	74.7	74.6	79.4	83.5	93.5	100.0	78.7
Inverclyde	338	277	60	17.8	81.9	77.8	88.9	81.0	84.0	50.0	82.0
North Lanarkshire	128	112	16	12.5	90.9	78.3	95.7	80.6	86.7	100.0	87.5
Renfrewshire	319	264	55	17.2	70.9	78.9	84.3	87.3	87.1	0.0	82.8
South Lanarkshire	372	314	58	15.6	80.6	82.5	88.7	88.3	86.3	0.0	84.4
West Dunbartonshire	1,047	847	200	19.1	75.7	82.9	78.0	84.8	96.9	100.0	80.9
Unassigned[1]	35	25	10	28.6						71.4	71.4
Total[2]	**5,526**	**4,486**	**1,038**	**18.8**	**74.7**	**80.5**	**81.7**	**85.0**	**89.4**	**78.9**	**81.2**

Source: Abdominal Aortic Aneuysm (AAA) BO; extracted May 2014

Note:

[1] - due to incomplete/incorrect postcodes uable to assign SIMD

[2] Total includes 2 patients whose appointments where cancelled by the Programme

Table 8.4 shows that 48 men were found to have an aneurysm measuring between 3.00 and 5.4 cm and are currently on surveillance. 5 men had an aneurysm measuring over 5.5 cm that required surgical assessment and intervention. 1.1% required surveillance and 0.1% were referred to secondary care for assessment.

Table 8.4 NHSGGC Abdominal Aneurysm Screening results for the period 1 April 2013 to 31 March 2014

Largest Measure	NHS GGC	Total
<3	4431	98.8%
3.00 - 5.40[1]	48	1.1%
5.5+[2]	5	0.1%
Total	**4484**	

Source: Abdominal Aortic Aneuysm (AAA) BO; extracted May 201

Notes:

1. Requiring surveillance
2. Requiring secondary care follow up

Information Systems

The Abdominal Aortic Aneursym (AAA) IT application is used to appoint and manage the patient through their screening pathway. This application obtains the demographic details of the participants by linking with the Community Health Index (CHI).

The AAA application is used by all of the stakeholders that are listed below:-

- Call and Recall staff
- Screening staff
- Vascular services staff

Challenges

Screening Locations

One of the main challenges is to ensure there are enough screening locations across NHS Greater Glasgow & Clyde to provide participants with a choice of where they can attend for their AAA scan. In order to maximise uptake these screening locations need to be accessible to participants which means they are held within a reasonable radius to their home address or locality.

While significant progress is being made there is still a limited backlog of participants who have still to be offered scanning because there has not been a suitable screening location made available until recently.

Staffing

Once adequate screening sessions are available and delivered on a regular basis to meet the demand of the eligible cohort, the staffing level will need to be maintained and reviewed accordingly.

Future Priorities

- NHS Greater Glasgow and Clyde will work towards offering all eligible participants an appointment to attend for screening when they are aged 65.

- Maintain the screening staffing level and screening locations to ensure stability in the delivery of

APPENDIX 8.2

Members of Abdominal Aortic Aneurysm Screening Implementation Group (as at March 2014)

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 Marie Devine	Radiographer
Dr Richard Edwards	Consultant Radiologist
Mrs Janette Fraser	NHS Forth Valley
Ms Marilyn Horne	Health Records Services Manager
Ms Denise Lyden	Project Officer
Ms Aileen MacLennan	Director, Diagnostics
Mrs Karen McClure	NHS Forth Valley
Mrs Susan McFadyen	General Manager
Mr Nick Pace	Clinical Director, Theatres and Anaesthesia
Mrs Elizabeth Rennie	Programme Manager, Screening Department
Mrs Lynn Ross	General Manager, Diagnostics
Mr Wesley Stuart	Lead Clinician
Mr George Welch	Associate Medical Director

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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.