

# **Public Health Screening Programme**

Annual Report

1 April 2016 to 31 March 2017

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Public Health – Health Services

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# Introduction

This annual report presents information about the following screening programmes period 2016/17:

- 1. Pregnancy Screening:
  - Antenatal Haemoglobinopathies screening
  - Communicable Diseases in Pregnancy
  - Down's syndrome and other congenital anomalies
- 2. Newborn Screening:
  - Newborn Bloodspot
  - Universal Newborn Hearing
- 3. Child Vision Screening
- 4. Aortic Abdominal Aneurysm Screening
- 5. Bowel Screening
- 6. Breast Screening
- 7. Cervical Screening
- 8. Diabetic Retinopathy Screening

The report includes analysis of uptake among people with learning disabilities and uptake by ethnicity.

The purpose of screening is to detect early disease or risk factors among people who have not yet developed symptoms. Early management should result in better outcomes. Screening programmes do not detect all cases of disease and will be positive among some people who are healthy. They therefore contribute to early detection but do not obviate the need for detecting and treating symptomatic patients.

# **Section 1**

# Pregnancy & Newborn Screening

# **Chapter 1 - Pregnancy Screening**

# **Summary**

During 2016/17, of 15,998 women booked to attend antenatal clinics in NHSGCC 13,278 (83%) were NHSGGC residents.

9,451 women (71.2%) were White British, 1009 (7.6%) Asian, 192 (4.1%) Chinese and 496 (3.7%) of any other ethnic origin.

10,394 (86%) of first antenatal booking appointments were offered within 12 weeks gestational age.

#### Gestational Diabetes Mellitus (GDM) and Obesity

Within NHSGGC, the assessment of pregnant women and risks associated with GDM are based on a BMI>= 35, previous macrosomic baby (weighing >4kg at birth), family history of diabetes, previous gestational diabetes and mother's ethnic origin. 3,912 (24%) of bookers were recorded as having 'any risk 'of GDM and were offered an OGTT at 24-28 weeks gestation.

Only 5,832 (43.9%) of pregnant women had a normal weight at the time of their first antenatal booking appointment. 3,700 (27.9%) pregnant women were overweight and 1861(14%) obese and 1168 (8.8%) severely obese (35<=BMI >=45).

## Haemoglobinopathies Screening

Of the 13,278 women booked for their first antenatal booking, 12,995 (97.9%) consented to haemoglobinopathies screening, 18 declined and 265 were not asked.

The Family Origin Questionnaire (FOQ) is completed as part of routine early antenatal risk assessment. For low prevalence areas like NHSGGC, it provides the basis for testing for haemoglobin variants and in the interpretation of results and the need for partner testing. 12,840 (98.8%) women had a completed FOQ.

The samples tested for haemoglobinopathies identified 35 as sickle cell carriers (HbAS), 7 women as Hb D carriers (HbAD) and 6 women as HbE carriers (HbAE).

11,188 women were screened for antenatal haemoglobinopathies and 117 men had to be offered partner testing as they were either from a high risk area or due to the women's test results.

Less than 5 women were identified with a foetus 'at high risk' for major haemoglobinopathy.

The screening for thalassaemia showed that there were 50 (0.44%) Beta thalassaemia carriers and 740 possible alpha zero thalassaemia carriers and/or iron deficiency.

#### Communicable diseases

Uptake was greater than 99% for all of the communicable diseases in pregnancy screening tests.

Screening identified 15 women infected with HIV (13 were previously known); 48 women were infected with hepatitis B (22 were previously known) and 5 women infected with syphilis. 579 (22.4%) women were identified as susceptible to rubella and were offered immunisation with MMR vaccine after delivery.

# Down's syndrome and other congenital anomalies screening

Of the 13,278 women booked at antenatal clinics, 10,887 (82%) consented for either a 1<sup>st</sup> or 2<sup>nd</sup> Trimester Down's syndrome screening. Of these 7053 (64.8%) of samples were taken in the 1<sup>st</sup> Trimester and 1832 (16.8%) in the 2<sup>nd</sup> Trimester. There were 240 (2.7%) high risk results recorded for Down's syndrome for both Trimesters.

198 amniocentesis samples were analysed and 32 abnormalities detected (16.1%) and of these 21 (10.6%) had a diagnosis of trisomy 21 (Down's syndrome).

91 chorionic villus biopsies were analysed and 28 abnormalities detected (30.7% of tests) and 19 of those (20.9% of tests) had a diagnosis of trisomy 21(Down's syndrome).

## Congenital anomalies screening

9,929 (76.6%) fetal anomaly scans were performed and 163 anomalies detected; 50 were confirmed postnatally and the outcomes for 53 are not known.

The phrase *less than five* has been used in line with NHS Scotland information governance which is intended to protect privacy and avoid identifying individuals.

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

## 1.2. Eligible Population

The pregnancy screening programmes are offered universally to all pregnant women during antenatal visits.

#### 1.3. The Screening Tests

**Appendix 1.1** illustrates the gestational age when pregnancy tests are carried out. All pregnant women are offered pregnancy screening for the following conditions.

#### Antenatal haemoglobinopathies screening

The pregnant woman and her partner are asked to complete a family origin questionnaire (**see appendix 1.10**). 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 the 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 1.2.** 

Screening for sickle cell disorders and thalassaemia should be offered to all women as early as possible in pregnancy, and ideally by 10 weeks for women to make a decision on whether to continue with the pregnancy.

#### 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 1.3 – 1.8**.

# Down's syndrome and other congenital anomalies

Screening for **Down's 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's syndrome. The full screening pathway is shown in **Appendix 1.9**. Ultrasound scanning is used to look for other **congenital anomalies** between 18 and 21 weeks.

The decision to accept screening for Down's syndrome and other congenital anomalies raises particular moral and ethical issues for women. Uptake of Down's syndrome or other congenital anomalies screening depends on whether women would wish further investigation or management.

# 1.4. Delivery of NHSGGC Pregnancy Screening Programmes

Each NHS Board has a statutory requirement to submit data on antenatal activity. In NHSGGC, there were 15,998 women booked to attend antenatal clinics and 13,278 (83%) were local residents and 2,720 (17%) were from outwith the Health Board area **(Table 1.1).** 

Table 1.1 Number of women booked for their first antenatal appointments in NHSGGC 1 April 2016 to 31 March 2017

Maternity Unit	Appointed Referrals Not NHSGGC	Appointed Referrals NHSGGC	Appointed Referrals Total	Bookers Not NHSGGC	Bookers NHSGGC Residents	Bookers Total
	Residents	Residents		Residents		
Not assigned	506	217	723	506	217	723
to a unit						
Princess	1,530	4,610	6,140	1,353	4,080	5,433
Royal						
Maternity						
Hospital						
(PRM)						
Queen	602	6,447	7,049	531	5,798	6,329
Elizabeth						
University						
Hospital						
Royal	364	3,551	3,915	330	3,183	3,513
Alexandra						
Hospital						
(RAH)						
Total	3,002	14,825	17,827	2,720	13,278	15,998

Source: Pregnancy & Newborn Screening System, July 2016

Using Onomap software we identified the ethnic origin of pregnant women as follows White British 9451 (71.2%), Asian 1009 (7.6%), Chinese 192 (1.4%) and 496 (3.7%) of any other ethnic group **(Table 1.2).** 

Table 1.2 Number of NHSGGC residents booked for their first antenatal appointment by ethnic origin during 1 April 2016 to 31 March 2017

2001 Census Ethnic Group	Number	%
White – British	9451	71.2
White – Irish	833	6.3
White - any other white background	894	6.7
Asian or Asian British	1009	7.6
Black or Black British	197	1.5
Other ethnic groups - Chinese	192	1.4
Other ethnic groups - any other ethnic group	496	3.7
Unclassified	206	1.6
Total	13,278	

Source: Pregnancy & Newborn Screening System, OnoMap, July 2017

In NHSGGC, 10,394 (86%) of first antenatal booking appointments were offered within 12 weeks gestational age. Only 83.1% of pregnant women living in the most deprived areas booked by 12 weeks and 6 days compared to 90% of women living in the least deprived areas. Work continues to engage with and support women from more deprived areas to book earlier **(Table 1.3).** 

Table 1.3 Gestational age at first antenatal booking appointment by deprivation categories for period 1 April 2016 to 31 March 2017

SIMD 2012 Quintile	<=12 weeks 6 days	% <= 12 weeks 6 days	>12 weeks 6 days	% > 12 weeks 6 days	Total
1 (Most	2,512	83.1	512	16.9	3,024
Deprived)					
2	2,225	85.0	392	15.0	2,617
3	2,074	85.5	352	14.5	2,426
4	1,858	88.3	245	11.7	2,103
5 (Least	1,725	90.0	191	10.0	1,916
Deprived)					
Total	10,394	86.0	1,692	14.0	12,086

Source: SMR02, June 2016

#### 1.5. Gestational Diabetes Mellitus (GDM)

Within NHSGGC, the assessment of pregnant women and risks associated with GDM are based on a BMI>= 35, previous macrosomic baby, (weighing >4 kg at birth) family history of diabetes, previous gestational diabetes and mother's ethnic origin. 3,912 (24%) of bookers were recorded as having 'any risk' of GDM and were eligible to be offered an OGTT at 24-28 weeks gestation (Table 1.4).

Women with gestational diabetes are at increased risk of having a large baby, a stillborn baby or a baby who dies shortly after birth.

Table 1.4 Number of women booked for their first antenatal appointments in NHSGGC 1 April 2016 to 31 March 2017 and GDM risk factors

Maternity Unit	BMI >=35	Previous Macrosomic Baby	Family History Diabetes	Previous Gestational Diabetes	Origin Mother Risk	Any Risk*	Bookers Total
Not assigned to	33	2	39	4	28	92	542
a unit						17%	
Princess Royal	563	13	295	37	606	1322	5702
Maternity						23%	
Hospital (PRM)							
Queen	416	19	438	36	1069	1665	6326
Elizabeth						26%	
University							
Hospital							
(QEUH)							
Royal	390	22	422	62	113	833	3462
Alexandra						24%	
Hospital (RAH)							
Total	1402	56	1194	139	1816	3912	16032
						24%	

Source: Pregnancy & Newborn Screening System, July 2017

#### 1.6. Body Mass Index (BMI) and Pregnant Women

Only 5,832 (43.9%) of pregnant women had a normal weight at the time of their first antenatal booking appointment. 3,700 (27.9%) pregnant women were overweight and 1861(14%) obese and 1168 (8.8%) severely obese (35<=BMI >=45) (**Table 1.5**).

Obesity is a risk factor for gestational diabetes. Within NHSGGC, we are offering support to obese pregnant women by allowing them to access the Live Active Programme. Staff have been trained to support pregnant women by providing information on suitable diet and exercise options during pregnancy

<sup>\*</sup> Summed individual risks may exceed any risk total

Table 1.5 Number and percentage of women booked for their first antenatal appointments by body mass index and by maternity unit from 1 April 2016 to 31 March 2017

				Materni	ty Unit					
BMI Category	Not Assigned to a Unit	%	Princess Royal Maternity Hospital (PRM)	%	Queen Elizabeth University Hospital (QEUH)	%	Royal Alexandra Hospital (RAH)	%	Total	%
BMI Not Recorded	38	17.5	132	3.2	124	2.1	20	0.6	314	2.4
Underweight BMI<18.5	8	3.7	119	2.9	198	3.4	78	2.5	403	3.0
Normal 18.5<=BMI<25	76	35.0	1,660	40.7	2,789	48.1	1,307	41.1	5,832	43.9
Overweight 25<=BMI<30	42	19.4	1,172	28.7	1,588	27.4	898	28.2	3,700	27.9
Obese 30<=BMI<30	33	15.2	593	14.5	718	12.4	517	16.2	1,861	14.0
Severely Obese 35<=BMI<40	10	4.6	253	6.2	270	4.7	254	8.0	787	5.9
Severely Obese 40<=BMI<45	9	4.1	102	2.5	79	1.4	82	2.6	272	2.0
Severely Obese BMI>=45	1	0.5	49	1.2	32	0.6	27	0.8	109	0.8
Total	217		4,080		5,798		3,183		13,278	

Source: PNBS

## 1.7. NHSGGC Antenatal Haemoglobinopathies Screening Programme

## Haemoglobinopathies

The haemoglobinopathies are a large group of inherited blood disorders which affect the haemoglobin (oxygen carrying) component of blood. They fall into two main groups – the haemoglobin variants (such as sickle cell disorders) which are associated with the production of abnormal forms of haemoglobin, and the Thalassaemias in which there is an abnormality in the amount of haemoglobin produced.

Sickle cell disorders, caused by a haemoglobin variant, often result in severe life threatening clinical symptoms. Those with beta thalassaemia major require regular blood transfusions to maintain life. All pregnant women will be offered screening for thalassaemia based on a low prevalence screening model.

# Consent for haemoglobinopathies screening

Of the 13,278 women booked for their first antenatal booking, 12,995 (97.9%) consented to haemoglobinopathies screening, 18 declined and 265 were not asked (Table 1.6).

Table 1.6 NHSGGC Number of women who consented for haemoglobinopathies screening from 1 April 2016 to 31 March 2017

	Haemoglo	binopathy Sci			
Maternity Unit	Consent	Declined	Not	Total	% Consented
			Asked		
Not assigned to a unit	178	2	37	217	82.0
Princess Royal Maternity	3,970	7	103	4,080	97.3
Hospital					
Queen Elizabeth University	5,686	4	108	5,798	98.1
Hospital					
Royal Alexandra Hospital	3,161	5	17	3,183	99.3
Total	12,955	18	265	13,278	97.9

Source: Pregnancy & Newborn Screening System, June 2017

The Family Origin Questionnaire (FOQ) is completed as part of routine early antenatal risk assessment. For low prevalence areas like NHSGGC, it provides the basis for testing for haemoglobin variants and in the interpretation of results and the need for partner testing. 12,840 (98.8%) women had a completed FOQ (Table 1.7).

Table 1.7 Number of women who completed FOQ from 1 April 2016 to 31 March 2017 in NHSGGC

	Family Origin	Questionnaire		
Maternity Unit	Completed	Not	Total	%
		Completed		Completed
Not assigned to a unit	171	7	178	96.1
Princess Royal Maternity Hospital	3898	72	3970	98.2
(PRM)				
Queen Elizabeth University Hospital	5618	68	5686	98.8
(QEUH)				
Royal Alexandra Hospital (RAH)	3153	8	3161	99.7
Total	12840	155	12995	98.8

Source: Pregnancy & Newborn Screening System, June 2017

11,188 women were tested for antenatal haemoglobinopathies screening, Less than 5 women were identified with a foetus 'at high risk' for major haemoglobinopathy. Partner testing should have been offered to 117 men as they were either from a high risk area or due to the women's test results (**Table 1.8**).

Table 1.8 Antenatal Haemoglobinopathy screening outcome by Maternity hub, for the period 1 April 2016 to 31 March 2017

Antenatal Haemoglobinopathies Screening Outcome	Not assigned to a unit	Princess Royal Maternity Hospital (PRM)	Queen Elizabeth University Hospital (QEUH)	Royal Alexandra Hospital (RAH)	Total
Foetus at risk for major haemoglobinopathy.	0	0	<5	0	<5
Foetus not at risk for major haemoglobinopathy.	0	1	14	0	15
None Recorded	2	181	22	9	214
Partner testing not required as woman from a low risk area.	<5	67	142	16	228
Partner testing not required.	115	3182	4600	2714	10611
Partner testing should be offered if from high risk area.	<5	<5	9	<5	15
Partner testing should be offered.	<5	45	48	6	102
Total	124	3479	4838	2747	11188

Source: Pregnancy & Newborn Screening System, June 2017

The samples tested for haemoglobinopathies identified 35 as sickle cell carriers (HbAS), 7 women as Hb D carriers (HbAD) and 6 women as HbE carriers (HbAE) (Table 1.9).

Table 1.9 Outcomes of Haemoglobinopathy screening for Hb variant outcomes among NHSGGC residents, for the period 1 April 2016 to 31 March 2017

	Hub					
Hb Variant Outcomes	Not assigned to a unit	Princess Royal Maternity Hospital (PRM)	Queen Elizabeth University Hospital (QEUH)	Royal Alexandra Hospital (RAH)	Total	
Carrier of Hereditary Persistence of Foetal	0	<5	<5	0	<5	
Haemoglobin Hb D carrier (HbAD)	<5	<5	5	0	7	
Hb E carrier (HbAE)  No evidence of sickle haemoglobin	11	<5 236	<5 462	0 84	793	
None Recorded	30	987	1245	340	2602	
Not tested for Hb variants as mother from low risk area	81	2240	3099	2323	7743	
Sickle cell carrier (HbAS)	<5	11	23	0	35	
Total	124	3479	4838	2747	11188	

Source: Pregnancy & Newborn Screening System, June 2017

Hb D (Hb AD) is one of the haemoglobinopathies carrier traits. The person has inherited haemoglobin A from one parent and haemoglobin D from the other. They will not have an illness, not experience symptoms but the carrier status is important for future reproduction.

Hb E (HbAE) is another haemoglobinopathies carrier traits. The person has inherited haemoglobin A from one parent and haemoglobin E from the other. They will not have an illness, not experience symptoms but the carrier status is important for future reproduction.

The outcomes for thalassaemia screening identified 50 women as Beta Thalassaemia carriers and 740 as possible Alpha Zero Thalassaemia carrier and/or iron deficiency (**Table 1.10**).

Table 1.10 Outcomes of Thalassaemia screening for NHSGGC residents, for the period 1 April 2016 to 31 March 2017

Thalassaemia Outcomes	Not assigned to a unit	Princess Royal Maternity Hospital (PRM)	Queen Elizabeth University Hospital (QEUH)	Royal Alexandra Hospital (RAH)	Total
Beta thalassaemia carrier	1	12	31	6	50
No evidence of abnormal haemoglobin or thalassaemia	30	961	1233	339	2563
No evidence of thalassaemia	82	2253	3117	2318	7770
None Recorded	1	29	29	6	65
Possible alpha zero thal carrier and/or iron deficiency	4	74	154	20	252
Possible iron deficiency and/or alpha + thal carrier	6	150	274	58	488
Total	124	3479	4838	2747	11188

Source: Pregnancy & Screening Newborn Screening System, June 2017

# 1.8. NHSGGC Communicable Diseases in Pregnancy Screening

#### Communicable diseases

These include Hepatitis B, Syphilis and Human Immunodeficiency Virus (HIV): Hepatitis B infection can be passed on from mother to baby during birth. It is a virus that affects the liver. Babies can be immunised at birth to prevent being infected from mothers.

Syphilis is an infection that can damage the health of both mother and baby if not treated with antibiotics.

Human Immunodeficiency Virus (HIV) infected women can pass HIV to their babies during pregnancy, childbirth and through breastfeeding. Many women with HIV will not know that they are infected unless they are tested.

#### Screening tests and results for Communicable diseases

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. Uptake across NHSGGC was greater than 99% for all of the screening tests (Table 1.11).

Table 1.11 NHSGGC Communicable diseases tests and results

1 April 2016 – 31 March 2017						Results			
	Total Number of samples	No. Requesting individual test	No. Not requesting individual test	Uptake	Antibody detected <sup>1,2,3</sup>		Antibody not detected <sup>4</sup>		
	(N)	(N)	(N)	%	(N)	%	(N)	%	
HIV	15768	15746	22	99.9	15 <sup>1</sup>	0.1	15731	99.9	
HBV	15767	15751	16	99.9	48 <sup>2</sup>	0.3	15703	99.7	
Rubella	2586 <sup>3</sup>	2583	3	99.9	2004	77.6	579 <sup>5</sup>	22.4	
Syphilis	15769	15747	22	99.9	5	0.03	15742	99.97	

Sources: West of Scotland Specialist Virology Centre

#### Notes:

- 1. 13 of the 15 HIV infections were previously known about
- 2. 22 of the 48 HBV infections were previously known about
- 3. Rubella screening was discontinued on 1<sup>st</sup> June 2016
- 4. Rubella antibody detected means that the woman is immune to rubella
- 5. No antibody detected means that the woman is susceptible to rubella and should be offered immunisation with MMR vaccine after delivery

# 1.9. NHSGGC Down's syndrome and Other Congenital Anomalies Screening Programme

Down's syndrome is characterised an extra copy of chromosome 21 (trisomy 21) and older mothers are more likely to have a baby with Down's syndrome although it can occur in women of any age.

# 1.10. 1st and 2nd Trimester Down's syndrome Testing

Of the 13,278 women booked at antenatal clinics, 10,887 (82%) consented for either a 1<sup>st</sup> or 2<sup>nd</sup> Trimester Down's syndrome screening. Of these 7053 (64.8%) of samples were taken in the 1<sup>st</sup> Trimester and 1832 (16.8%) in the 2<sup>nd</sup> Trimester. There were 240 (2.7%) high risk results recorded for Down's syndrome for both Trimesters (**Table 1.12**).

Table 1.12 NHS Greater Glasgow & Clyde Residents. Women who gave consent for Down's screening and sample taken either at 1st or 2nd Trimester & Overall Risk

	Booked	Number consented either 1 <sup>st</sup> or 2 <sup>nd</sup> trimester	% consented either 1 <sup>st</sup> or 2 <sup>nd</sup> trimester	Number sample taken 1 <sup>st</sup> or 2 <sup>nd</sup> trimester	Number sample taken 1 <sup>st</sup> trimester	% sample taken 1 <sup>st</sup> trimester	Number sample taken 2 <sup>nd</sup> trimester	% sample taken 2 <sup>nd</sup> trimester	Number high risk results	% high risk results
Not assigned to a unit	217	150	69.1	98	75	50.0	24	16.0	2	2.0
Princess Royal Maternity Hospital (PRM)	4080	3607	88.4	2982	2364	65.5	632	17.5	81	2.7
Queen Elizabeth University Hospital (QEUH)	5798	4853	83.7	3928	3126	64.4	806	16.6	122	3.1
Royal Alexandra Hospital (RAH)	3183	2277	71.5	1854	1488	65.3	370	16.2	35	1.9
Total	13,278	10,887	82.0	8,862	7,053	64.8	1,832	16.8	240	2.7

Source: PNBS

#### 1.11. Amniocentesis

198 amniocentesis samples were analysed by the Cytogenetics Laboratory and 32 abnormalities were detected (16.1%) and of these 21 (10.6%) had a diagnosis of trisomy 21 (Down's syndrome) (Table 1.13).

Table 1.13 Cytogenetics analysis of amniocentesis samples by indication type for the period 1 April 2016 - 31 March 2017

	Biochemical	Maternal	Abnormalities	Other	Total
	Screening	Age	on Scan		
Number of women	91	7	68	32	198
(=number of tests)					
% total referral	46.0%	35%	34.3%	16.2%	100%
reasons					
Number with normal	82	7	49	28	166
results					
Number with	6	0	12	3	21
diagnostic trisomy					
% number with	6.59%	0.00%	17.65%	9.38%	10.6%
diagnostic trisomy					
Number of other non	3	0	7	1	11
trisomy abnormalities					
Total number of	9	0	19	4	32
abnormalities					
% total number of	9.9%	0%	27.9%	12.5%	16.1%
abnormalities					

Source: Cytogenetics Laboratory

# 1.12. Chorionic Villus Biopsies (CVS)

91 chorionic villus biopsies were analysed by the Cytogenetics Laboratory in 2016/17. 28 abnormalities were detected (30.7%) and 19 of those (20.9%) had a diagnosis of trisomy 21 (Down's syndrome) **(Table 1.14).** 

Table 1.14 Cytogenetics analysis outcomes of chorionic Villus Biopsy samples by indication for the period 1 April 2016 - 31 March 2017

	Biochemical	Maternal	Abnormalities on	Other	Total
	Screening	Age	Scan		
Number of	8	3	44	36	91
women					
(= number of					
tests)					
% total referral	8.8%	3.3%	48.4%	39.6%	100
reasons					
Number with	6	3	25	28	62
normal results					
Number with	2	0	14	3	19
diagnostic					
trisomy					
% total with	25.0%	0.0%	31.8%	8.3%	20.9
diagnostic					
trisomy					
Number of other	0	0	4	5	9
non trisomy					
abnormalities					
Total number of	2	0	18	8	28
abnormalities					
% total number	25	0	40.9	22.2	30.7
of abnormalities					

Source: Cytogenetics Laboratory

# 1.13. Other Congenital Anomalies Screening

#### Fetal Anomalies Scan

All women are offered an ultrasound scan between 18 and 21 weeks to confirm the gestation age and identify any possible problems that may require medical intervention during pregnancy or after birth.

The number of women who gave consent for a fetal anomaly scan was 12,967 (97.6%) and 9,929 scans were performed **(Table 1.15).** 

Table 1.15 Uptake rate for other congenital anomalies (fetal anomaly scan) for the period 31 March 2016 to 1 April 2017

Maternity Unit	Number of Bookers	Number of Consents	% Consented	Number of fetal anomaly scans performed	% fetal anomaly scans performed	% Uptake
Not assigned to a unit	217	186	85.71	110	59.1	50.7
Princess Royal Maternity Hospital	4,080	4,038	98.97	3,136	77.7	76.9
Queen Elizabeth University Hospital	5,798	5,673	97.84	4,281	75.5	73.8
Royal Alexandra Hospital	3,138	3,070	96.45	2,402	78.2	75.5
Total	13,278	12,967	97.66	9,929	76.6	74.8

Source: Pregnancy & Newborn Screening System, June 2017

9,929 (76.6%) fetal scans were performed and 163 anomalies were detected. Of these 50 were confirmed postnatally, and 60 had no anomaly detected postnatally. The outcomes for 53 anomalies are not known **(Table 1.16).** 

Table 1.16 Outcome of fetal anomaly scans performed for the period 1 April 2016 to 31 March 2017

Maternity Unit	Fetal Anomaly scan performed	Fetal anomaly detected	% Fetal anomaly detected	Anomaly detected postnatally	No anomaly detected postnatally	Outcome not known
Not assigned to a unit	110	0	1.82	0	0	0
Princess Royal Maternity Hospital	3,136	45	1.43	16	16	13
Queen Elizabeth University Hospital	4,281	81	1.89	23	30	28
Royal Alexandra Hospital	2,402	35	1.46	11	13	11
Total	9,929	163	1.64	50	60	53

Source: Congenital Anomalies Surveillance Tool, Pregnancy & Newborn Screening System, June 2017

## 1.14. Information Systems

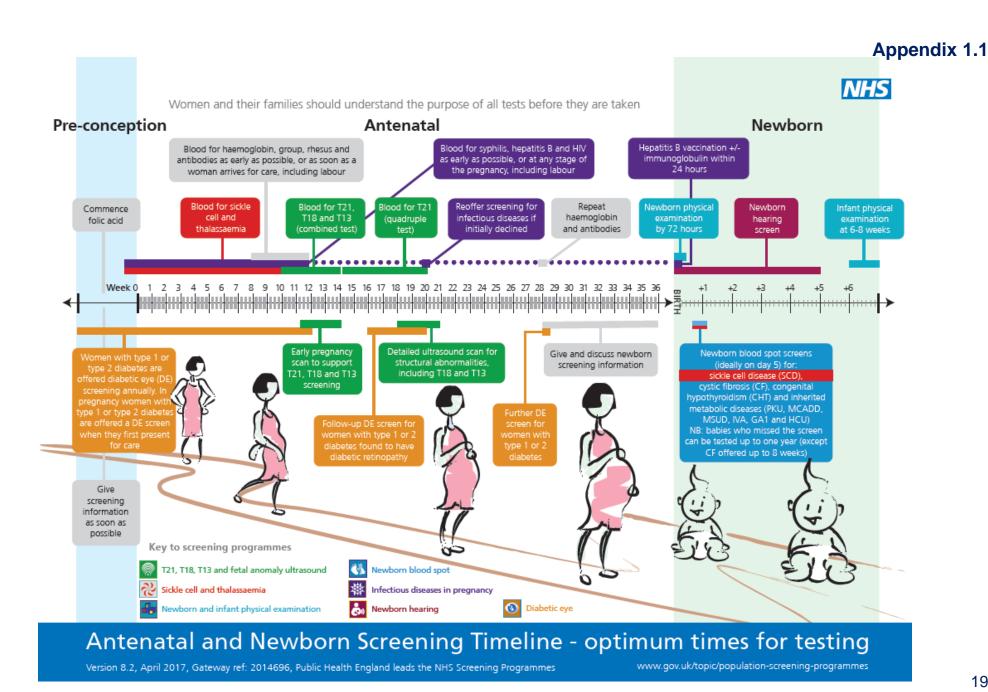
PNBS IT application is used to support all pregnancy and newborn screening programmes. The application brought improvements in both the reporting and management of cases identified through the screening programme and introduced additional failsafe mechanisms into the screening programmes.

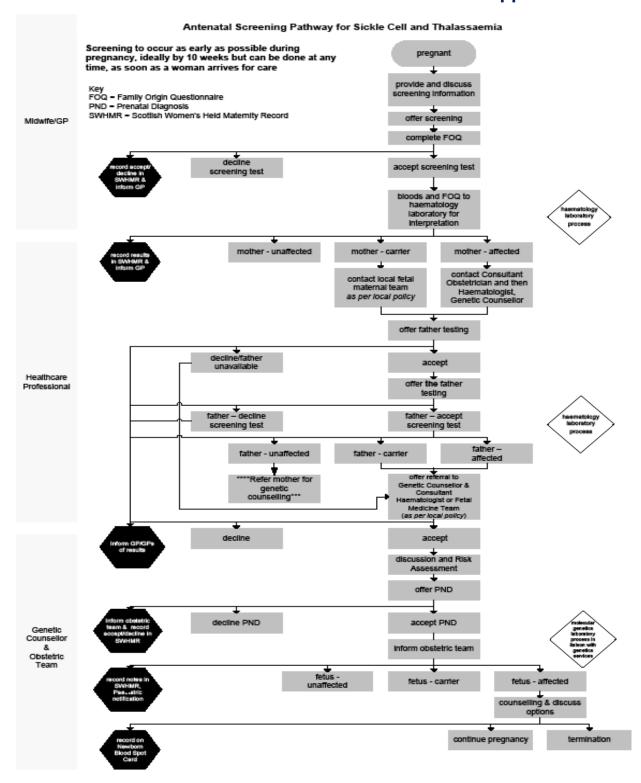
The NHSGGC Maternity Services are commissioning a new IT system – BadgerNet which will record all future pregnancy screening programmes.

NHSSS has decommissioned the Prenatal Screening Laboratory in Glasgow from November 2016. The sample analysis and reporting for 1<sup>st</sup> Trimester Down's syndrome screening will be at the NHS Lothian Laboratory and the 2<sup>nd</sup> Trimester samples at the Bolton Laboratory.

# 1.15. Challenges and Priorities

- Meeting testing and reporting timelines for pregnancy screening programmes
- Recording full pregnancy screening programmes pathway data electronically including data collection on BadgerNet
- Improving uptake of partner screening for haemoglobinopathies
- Re-engineering of 1<sup>st</sup> and 2<sup>nd</sup> Trimester Down's syndrome screening





#### Offering Routine Antenatal Communicable Disease Screening Tests The primary aim of screening women for these conditions is to ensure a plan for treatm management for affected individuals and their babies". NHS QIS Clinical Standards, Pregnancy and Newborn Screening On confirmation of pregnancy woman is referred for antenatal care Woman requests Woman issued with information pack detailing more information or expected care and routine tests, at least 48 hours in refuses one or more advance of booking visit (Standard 3b.3) screening tests Health care worker confirms woman has read information leaflet, offers blood tests, obtains Relevant information, which outlines the benefits and consent and informs woman when and how she will receive her risks of screening should be provided in a user-friendly results manner so that women and their partners can make an informed choice. This information should be provided by her midwife with additional support from appropriate (within 21 days, Standard 3c.1,2,4,5) specialists as necessary. Contact details below. Blood is taken and tests ordered for those tests Woman declines one or more screening tests. where consent is given Consent for tests accepted, and decision about Is it imperative that the Pregnancy and those declined, is documented Newborn Screening IM&T system is used to ensure tests can be tracked and failsafes are in place. The PNBS system should be updated if a Women who decline one or more tests, should be previously declined test is later accepted. re-offered testing early in the third trimester, between 28-31 weeks Women who book late should be offered screening at the first opportunity. Test is indeterminate or unsatisfactory. See Appendix 1 for Late Booking Protocol. ing and/or further tests provided with All test results for a woman should be known prior 5 days of any indeterminate/unsatisfactory test. to delivery and definitely before discharge (Standard 3d.1) SIGNIFICANT TEST RESULTS The laboratory sends result to a named person Carrier of hepatitis B who will make arrangements to recall women to site for repeat blood test within 5 days (Standard3d.1) Positive syphilis serology Positive for HIV infection REFER TO SIGNIFICANT TEST Test is negative. Woman informed by letter of negative screening RESULT CARE PATHWAY FOR EACH INFECTION tests within 21 days (Standard 3c5). Confirmation that woman has

N.B. If a woman feels she has been/continues to be at risk of exposure to HIV, she should be offered re-testing 3 monthly in pregnancy If a woman develops symptoms of hepatitis or an STI she should be referred to the relevant professional (hepatologist/SHA) for appropriate assessment.

Special Needs in Pregnancy (SNIPs) -RAH - 0141 314 6199 or 0141 887 9111 then page 56311 VOL - 01389 817 270 IRH – 01475 504 833 Glasgow - 0141 221 5267 or 0141 211 5366 or 0141 211 5337 (secretary)
Sexual Health Advisors, Sandyford – 0141 211 8634
Counselling and Support Team (CAST), Brownlee Centre 0141 211 1089

received screening tests results should be recorded at subsequent antenatal visits.

Version No Revised: Approved by: Date Approved: Next revision date: V5.3 24 May 2016 Communicable Diseases in Pregnancy Steering Group April 2011

# 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 <u>no immediate risk of delivery:</u>
- Seek informed consent for screening (HIV, Syphilis, hepatitis B)
- Fill one 9ml purple topped EDTA bottle and complete a virology request form, clearly indicating which tests (HIV, 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 <u>risk of delivery is high</u>:
- 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, 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 Amended Protocol Ordering and Use of Taxis and Couriers October 2011)

http://www.staffnet.ggc.scot.nhs.uk/Corporate%20Services/Communications/Briefs/Documents/amen\_ded%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 in labour:
- 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,).
- Fill one 9ml purple topped EDTA bottle and complete a virology request form, clearly indicating which tests (HIV, 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/amen\_ded%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.

# Protocol for Significant Laboratory Results **SYPHILIS** Microbiologist detects positive syphilis serology from booking blood. All screen positive samples undergo confirmatory tests and results issued to named clinician within 15 days. (Standard 3e2) Microbiologist telephones outpatient manager (or Microbiologist telephones Sexual Health Advisors deputy) at maternity unit responsible for woman's at Sandyford (GUM Services) on antenatal care, and sends hard copy of report. 0141 211 8634 All results are confirmed to requesting clinician in And writing within 21 days of screen being performed. Sends hard copy of the labatory report to Sandyford Initative FAO Sexual Health Advisors (Standard 3c.2) Clinician/midwife recalls woman, explain result, and repeats blood to confirm identity, with support from sexual health advisor from Woman seen at GUM services for Sandyford within 5 days of mother receiving treatment and care of syphilis infection. test result (Standard 3d 1), and within 21 days of GUM services arrange follow up of any blood test. (Standard 3c 4) contacts as required. Mother receives antenatal care as per appropriate pregnancy pathway. Healthcare worker ensures appropriate instructions for follow-up of baby are documented in relevant place in mother's notes. Paediatrician reviews and arranges follow Maternity staff contact paediatrician at delivery up of baby at birth.

Communicable Diseases in Pregnancy Steering Group Lead Author Dr Gillian Penrice added 6.1.2016 December 2011 Checked 1 2016

Version No:

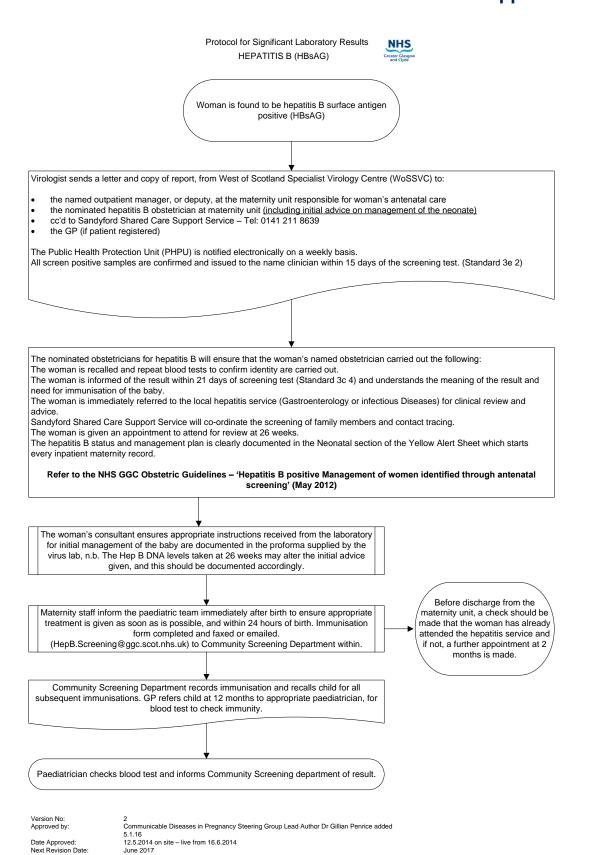
Approved by: Date Approved:

Next Revision Date

V4.2

December 2014 Next Review 31/01/2017

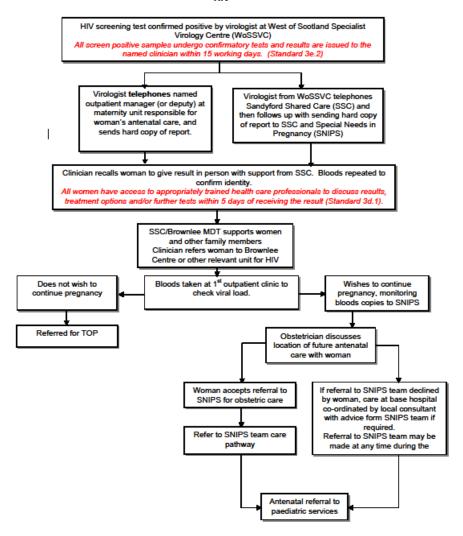
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## **Protocol for Significant Laboratory Results**

HIV



vo.1 Communicable Diseases in Pregnancy Steering Group Lead Author - Dr Gillian Penrice added 5.1.2016 On site 12.6.14 Live from 16.6.14 June 2017

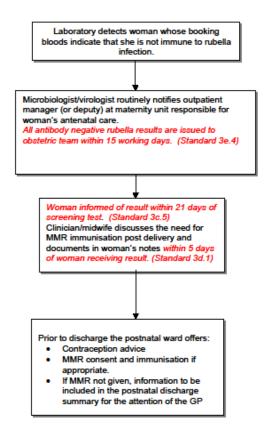
Approved by: Date Approved: Next revision date:

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#### **Protocol for Significant Laboratory Results**

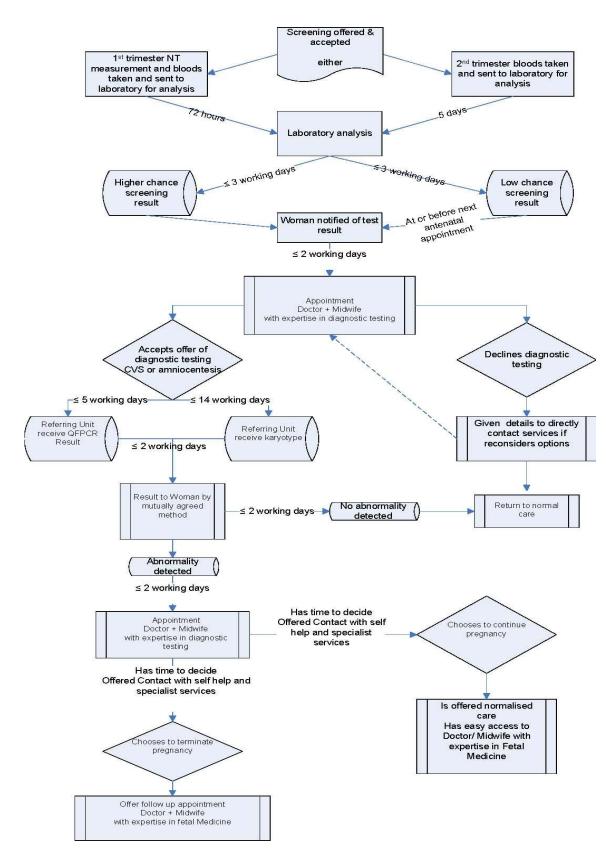
#### NOT IMMUNE TO RUBELLA INFECTION



V4.2 Communicable Diseases in Pregnancy Steering Group Lead Author Dr Gillian Penrice added 5.1.16 December 2011 Checked 1.2016 December 2012 Next Review 1.2017

Note: Antenatal immunisation against rubella infection ceased from June 2016.

# Down's syndrome screening pathway for women accepting screening





# Family Origin

# NHS

Baby's father

Questionnaire Screening Programmes Sickle Cell & Thalassaemia If using a pre-printed label please attach one to each copy Hospital Name ..... Screening test declined Hospital No ..... Do you want to give a reason why NHS No. declined? Estimated Delivery Date ...... Surname..... Forename ..... Add1,.... Add2 Post Code REPORT DESTINATION (og Community Midwife, GP, Anternatal Clinic, Obstetrician),...... What are your family origins? Please tick all boxes in ALL sections that apply to the woman and the baby's father A. AFRICAN OR AFRICAN-CARIBBEAN (BLACK) Baby's father Caribbean Islands Africa (excluding North Africa) ŏ Any other African or African-Caribbean family origins (please write in...) B. SOUTH ASIAN (ASIAN) Woman Baby's father India or African-Indian Pakistan, Bangladesh Sri Lanka Baby's father C. SOUTH EAST ASIAN (ASIAN) Woman China including Hong Kong, Taiwan, Singapore Thailand, Indonesia, Burma ## # Malaysia, Vietnam, Philippines, Cambodia, Laos **-** # - 4 Any other Asian family origins (please write in...) (e.g. Caribbean-Asian) D. OTHER NON-EUROPEAN (OTHER) Woman Baby's father North Africa, South America etc Middle East (Saudi Arabia, Iran etc) Any other Non-European family origins (please write in...) E. SOUTHERN & OTHER EUROPEAN (WHITE) Woman Baby's father # # Sardinia - # # Greece, Turkey, Cyprus Italy, Portugal, Spain Any other Mediterranean country Albania, Czech Republic, Poland, Romania, Russia etc Baby's father F.\* UNITED KINGDOM (WHITE) refer to chart at the back England, Scotland, N Ireland, Wales G. NORTHERN EUROPEAN (WHITE) refer to chart at the back Baby's father Austria, Belgium, Ireland, France, Germany, Netherlands Scandinavia, Switzerland etc П П Any other European family origins, refer to chart (please write in) (e.g. Australia, N America, S Africa) \* Hb Variant Screening Requested by (F) and/ or (G) # Higher risk for alpha zero thalassaemia 

H. DON'T KNOW adoption/unknown ancestry donor egg/sperm bone marrow transplant I. DECLINED TO ANSWER J. ESTIMATED DELIVERY DATE (please write in if not above) ECTATION AT TIME OF TH

ESTATION AT TIME OF	IESI		
women need to be informed that a moglobin variant screening to all v moglobin variant screening to all v	routine analysis of blood may women if they or the baby's women irrespective of answe	tidentify them as a thelessemia carrier. In low father have answers in any yellow box. In high m, ic. If they or the baby's father have answer	e prevalence areas OFFER h prevalence areas OFFER is in white and yellow boses A
ned	Print Name	Job Title	Date

laboratory with the antenatal hospital notes or where appropriate. tenatal booking request form and sent to the notes, third (yellow) copy to go into hospital i to the laboratory antenatal in the patient's maternity notes, screening programme for sickle the screening programme The TOP (white) copy of this form must be attached securely blood samples, the second (pink) copy is to be retained in the The completion of this form is an ESSENTAL part of the scree

# Members of Pregnancy Screening Steering Group (as at March 2017)

Dr Emilia Crighton
Ms Sally Amor
Dr Catriona Bain
Ms Donna-Maria Bean
Head of Health Services Section (Chair)
Health of Health Improvement, NHS Highland
Clinical Director, Obstetrics and Gynaecology
Lead Sonographer (Obstetrics & Gynaecology)

Ms Vicki Brace Consultant Obstetrician

Ms Louise Brown West of Scotland Pregnancy Laboratory

Mr Paul Burton Information Manager

Mrs Lin Calderwood HI&T Screening Service Delivery Manager

Ms Pam Campbell Site Health Records Manager Ms Margaret Cartwright Sector Laboratory Manager

Mrs Diana Clark Lead Midwife

Dr Rosemarie Davidson Consultant Clinical Geneticist

Ms Helen Devlin Senior Charge Midwife

Mr Ian Fergus Site Technical Manager, Diagnostics

Ms Dorothy Finlay Lead Midwife Ms Evelyn Frame Chief Midwife

Mrs Elaine Garman Public Health Specialist, NHS Highland

Mrs Jaki Lambert Lead Midwife (Argyll and Bute)
Dr Robert Lindsay Associate, Glasgow University

Ms Karen McAlpine Lead Midwife Miss Denise Lyden Project Officer

Ms Marie-Elaine McClair Interim Clinical Service Manager

Dr Louisa McIlwaine Consultant Haematologist
Mrs Michelle McLauchlan General Manager, Obstetrics
Ms Barbara McMenemy Acute Addiction Manager

Dr Gillian Penrice Consultant in Public Health Medicine
Mrs Uzma Rehman Public Health Programme Manager
Mrs Elizabeth Rennie Screening Programmes Manager
Dr Jim Robins Consultant Obstetrician, Clyde
Ms Margaretha Van Mourik Consultant Genetic Counsellor
Dr Nicola Williams Head of Molecular Genetics

# Members of Communicable Diseases Steering Sub Group (As at March 2017)

Dr Gillian Penrice Public Health Protection Unit (Chair)

Dr Tamer Abdelrahman Honorary Virology Registrar Ms Hilary Alba Charge Midwife SNIPS team

Ms Donna Athanasopoulos Information & Publications Manager

Ms Catrina Bain Clinical Director Obstetrics and Gynaecology

Ms Elizabeth Boyd Clinical Effectiveness Co-ordinator

Mr Paul Burton Information Manager

Mrs Lin Calderwood National Portfolio Programme Manager

Mrs Louise Carroll Programme Manager HIV/STIs
Mrs Diana Clark Lead Community Midwife
Ms Helen Devlin Senior Charge Midwife

Ms Flora Dick Special Needs (SNIPS) Midwife Ms Rose Dougan Special Needs (SNIPS) Midwife

Ms Elizabeth Ellis Staff Grade
Ms Dorothy Finlay Lead Midwife

Ms Catherine Frew Data Analyst, Specialist Virology Centre

Mrs Fiona Gilchrist Assistant Programme Manager

Ms Claire Glover Clinical Nurse Specialist

Ms Louise Jack Midwife

Mrs Jaki Lambert Lead Midwife

Mr Sam King Sexual Health Advisor

Miss Denise Lyden Project Officer

Ms Victoria Mazzoni Senior Community Midwife

Ms Karen McAlpine Lead Midwife

Ms Valerie McAlpine Senior Charge Midwife

Ms Marie-Elaine McClair Interim Clinical Service Manager

Mrs Katie McEwan Clinical Service Manager
Ms Michelle McLaughlan General Manager, Obstetrics

Ms Jane McOwan Technical Manager, Specialist Virology Centre

Ms Elizabeth Rennie Programme Manager

Dr Jane Richmond Obstetrician and Gynaecologist
Ms Linda Rhodick Medical Secretary/Data Co-ordinator
Dr James Robins Consultant Obstetrician & Gynaecologist

Ms Samantha Shepherd Clinical Scientist

Ms Claire Stewart Clinical Service Manager

Dr Andrew Thomson Consultant Obstetrician & Gynaecologist

# **Chapter 2 - Newborn Bloodspot Screening**

# **Summary**

- 12,108 babies resident in NHSGGC were screened, that is a total of 98.8% of the total eligible population of 12,257. The uptake of screening ranged from 98.1% to 99.0% across HSCP geographical areas.
- 8,575 (70.1%) of babies screened were White UK, 900 (7.4%) South Asian and 589 (4.8%) were of Southern or Other European ethnicity.
- Following screening, eight babies were diagnosed with congenital hypothyroidism (CHT). Less than five babies were diagnosed with PKU (phenylketonuria) or MCADD.
- The cystic fibrosis results showed less than five babies tested positive, and less than 5 were carriers. For Haemoglobinopathy, although less than five were diagnosed with sickle cell disease, 74 babies were identified as haemoglobinopathy carriers.
- The phrase *less than five* has been used in line with NHS Scotland information governance which is intended to protect privacy and avoid identifying individuals.

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#### 2.1. Newborn Bloodspot Screening

Newborn bloodspot screening identifies babies who may have rare but serious conditions. Most babies screened will not have any of the conditions but, for the small number that do, the benefits of screening are enormous. Early treatment can improve health and prevent severe disability or even death. Every baby born in Scotland is eligible for and routinely offered 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, medium chain acyl-CoA dehydrogenase deficiency (MCADD), maple syrup urine disease (MSUD), isovaleric acidaemia (IVA), glutaric aciduria type 1 (GA1), homcystinuria (pyridoxine unresponsive (HCU).

#### 2.2. Eligible Population

Newborn Bloodspot screening is offered to all newborns. Eligible babies is the total number of babies born within the reporting period (2016-17), excluding any baby who died before the age of 8 days.

#### 2.3. The Screening Test

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 MCADD 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 Queen Elizabeth University Hospital for analysis.

Detailed pathway is shown in **Appendix 2.1**.

#### 2.4. Delivery of NHSGGC Newborn Bloodspot Screening Programmes

There were 12,233 live births and 33 stillbirths recorded for NHSGGC residents during 2016/17 **(Table 2.1).** 

Table 2.1 Number of live and still births across NHSGGC by council area, 1 April 2016 to 31 March 2017

	Numbers			Rate pe women ag	-	Rate per 1,000 births
	All births	Live births	Stillbirths	All births	Live births	Stillbirths
West Dunbartonshire	909	907	<5	54.2	54.1	2.2
East Dunbartonshire	1001	1000	<5	58.0	58.0	1.0
East Renfrewshire	855	854	<5	54.1	54.0	1.2
Glasgow City	7037	7012	25	49.7	49.6	3.6
Inverclyde	701	699	<5	50.1	49.9	2.9
Renfrewshire	1763	1761	<5	54.5	54.5	1.1
Greater Glasgow & Clyde	12,266	12,233	33	51.6	51.4	2.7

Source: http://www.isdscotland.org/Health-Topics/Maternity-and-Births/Births/

**Figure 2.1** illustrates newborn bloodspot uptake rates and the results of the screening programme from 1 April 2016 to 31 March 2017.

The total number of babies eligible for screening were 12,257 and of these 12,108 (98.8%) babies were screened. Results were not available for the 76 (0.6%) babies that moved into the NHSGGC Board area.

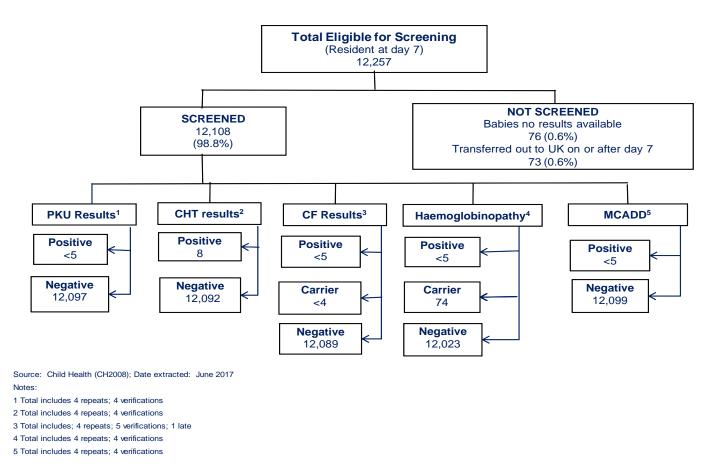
Following screening, eight babies were diagnosed with congenital hypothyroidism (CHT). Less than five babies were diagnosed with PKU (phenylketonuria) and MCADD.

The cystic fibrosis results showed less than five babies tested positive, and less than 5 were carriers. For Haemoglobinopathy, although less than five were diagnosed with sickle cell disease, 74 babies were identified as haemoglobinopathy carriers.

All babies received appropriate management within the timescale of the set national standards.

In this report the phrase less than 5 has been used in line with NHS Scotland information governance standards to protect the privacy of individuals.

Figure 2.1 Newborn bloodspot uptake rates and the results for babies born 1 April 2016 to 31 March 2017



The percentage uptake rate of Newborn Bloodspot screening was greater than 96% across all HSCP areas and deprivation categories is in **Table 2.2**.

Table 2.2 Percentage uptake rate of bloodspot screening by HSCP and deprivation categories, 1 April 2016 to 31 March 2017

	Most De	eprived			SIMD 2016	Quintile			Least De	prived		
HSCP	1		2		3		4		5		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
	Screened	uptake	Screened	uptake	Screened	uptake	Screened	uptake	Screened	uptake	Screened	uptake
East	51	100.0	181	98.4	44	100.0	170	100.0	528	99.4	974	99.4
Dunbarton- shire												
East Renfrew- shire	67	98.5	77	98.7	82	98.8	137	99.3	490	98.8	852	98.8
Glasgow North East	1,368	98.9	244	98.4	208	98.1	200	97.1	8	100.0	2,013	98.6
Glasgow North West	1,104	99.1	247	99.2	224	99.6	217	98.6	385	98.7	2,167	99.0
Glasgow South	1,323	98.8	589	99.0	416	98.6	271	97.8	201	99.0	2,784	98.7
Inverclyde	360	99.2	94	100.0	67	97.1	93	100.0	60	100.0	671	99.3
Renfrewshire	582	99.1	325	97.6	279	98.2	282	97.9	255	96.6	1,718	98.1
West Dunbarton- shire	416	99.0	268	98.9	140	99.3	76	98.7	33	100.0	929	99.0
Total	5,271	99.0	2,025	98.7	1,460	98.6	1,446	98.4	1,960	98.7	12,108	98.8

Source: Child Health (CH2008); Date extracted: June 2017

#### 2.5. Ethnicity of babies born in 2016/17

The breakdown of the ethnicity groups for babies tested within NHSGGC shows that 8,575 (70.1%) of babies screened were White UK, 900 (7.4%) South Asian and 589 (4.8%) had Southern and Other European ethnic group (**Table 2.3**).

Table 2.3 NHSGGC Newborn Bloodspot screening – ethnicity of the babies tested 1 April 2016 – 31 March 2017

	Clyde		Glas	gow	Tot	al
Ethnicity Group	N	%	N	%	N	%
African or African	26	0.8	319	3.5	345	2.8
Caribbean (Black)						
South Asian (Asian)	76	2.4	824	9.1	900	7.4
South East Asian (Asian)	14	0.4	207	2.3	221	1.8
Other non-European	6	0.2	206	2.3	212	1.7
(Other)						
Southern & Other	106	3.4	483	5.3	589	4.8
European (White)						
United Kingdom (White)	2,605	82.6	5,970	65.8	8,575	70.1
North Europe (White)	34	1.1	79	0.9	113	0.9
Don't Know	4	0.1	16	0.2	20	0.2
Decline to Answer	2	0.1	1	0.0	3	0.0
Any Mixed Background	124	3.9	523	5.8	647	5.3
Not Stated	157	5.0	444	4.9	601	4.9
Total	3,154		9,072		12,226	

Source: Scottish Newborn Screening Laboratory - Newborn Bloodspot Screening Report 2016/17 Note: Scottish Newborn Screening Laboratory figures cannot be mapped to NHS GGC new boundary and may include Lanarkshire, Highland patients, etc

#### 2.6. Ethnicity of Babies 2011/12 to 2016/17

Across NHSGGC the changes in population and migration from other countries is illustrated when data is compared for ethnicity using the Bloodspot card. For African and African Caribbean residents the percentage has decreased from 1.6% in Clyde to 0.8% but has remained steady for Glasgow areas. For the South Asian community there is an increase of 0.9% for Clyde and of 0.5% for Glasgow areas. The South East Asian community remained steady for the last six years. There was an increase of 1.2% to 2.3% for other non-Europeans in the Glasgow areas for 2016/17 **(Table 2.4).** 

Table 2.4 NHSGGC Newborn Bloodspot screening – ethnicity of the babies tested 1 April 2011 – 31 March 2017

	2011/12		2012/13		2013	/14	2014	2014/15		5/16	2016/	2017
	Glasgow	Clyde	Glasgow	Clyde	Glasgow	Clyde	Glasgow	Clyde	Glasgow	Clyde	Glasgow	Clyde
African or African Caribbean (Black)	3.6%	1.6%	3.4%	0.8%	3.2%	1.1%	2.7%	1.2%	3.2%	0.7%	3.5%	0.8%
South Asian (Asian)	8.6%	1.5%	8.2%	2.3%	8.6%	1.7%	8.6%	1.6%	8.9%	1.9%	9.1%	2.4%
South East Asian (Asian)	2.4%	0.6%	2.7%	0.4%	2.5%	0.6%	2.6%	0.5%	2.3%	0.5%	2.3%	0.5%
Other non- European	1.2%	0.2%	1.3%	0.2%	1.4%	0.2%	1.5%	0.2%	1.4%	0.2%	2.3%	0.2%

Source: Scottish Newborn Screening Laboratory data from 2011/12 to 2016/17

The laboratory outcomes of Newborn Bloodspot tests shows that in 2016/17, of the 12,791 bloodspot samples received, 12,890 test results were normal. There are several tests carried out on each specimen (**Table 2.5**).

185 (1.4%) specimens could not be analysed due to insufficient amounts of blood on the bloodspot card and required a repeat test. Avoidable repeat samples can cause anxiety for parents, distress to babies and delays in the screening process.

Five samples received had taken more than 14 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 for 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 2.5 Specimen test outcomes for NHSGGC for period 1 April 2016 and 31 March 2017

Specimen Test - Outcomes	Clyde	Glasgow	Total
Refused all tests	1	4	5
Partial refused	0	0	0
Insufficient blood to perform all tests	58	127	185
Unsatisfactory >14 days in transit	5	0	5
Unsatisfactory No CHI	13	61	74
Unsatisfactory Other	24	26	50
<3 days post T/F	1	7	8
Updated info	76	222	298
IRT tested late (total)	3	11	14
IRT tested late (Born in Scotland)	2	0	2
Ref PKU	<5	<5	<5
Ref CHT	<5	<5	5
Ref CF	0	<10	<10
Ref CF Carrier	<5	<5	<5
Ref MCADD	<5	0	<5
Ref MSUD*	0	0	0
Ref HCU*	0	0	0
Ref IVA*	0	0	0
Ref GA1*	0	0	0
Ref SCD	0	<5	<5
Ref SCD Carrier	7	45	52
Ref HbV	0	<5	<5
Ref HbV Carrier	<5	<25	23
Number of normal results	3,346	9,544	12,890
Pre-TF	22	59	81
Sent for SCD DNA	3	10	13
Total Specimens received	3,332	9,459	12,791

<sup>\*</sup>screening for these conditions started 20th March 2017

Insufficient as % of Total	1.7	1.3	1.4
Unsatisfactory as % of Total	1.26	0.92	1.01
IRT tested late as % of Total	0.09	0.12	0.11
IRT tested last (born in Scotland) as % of Total	0.06	0.00	0.02

Source: Scottish Newborn Screening Laboratory - Newborn Bloodspot Screening Report 2016/17

#### **Notes**

Scottish Newborn Screening Laboratory figures cannot be mapped to NHS GGC new boundary and may include Lanarkshire, Highland patients, etc

**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 Congenital 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 haemoglobinopathy disorder. These require follow-up for confirmation and some may not be confirmed as cases.

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

#### 2.7. 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.

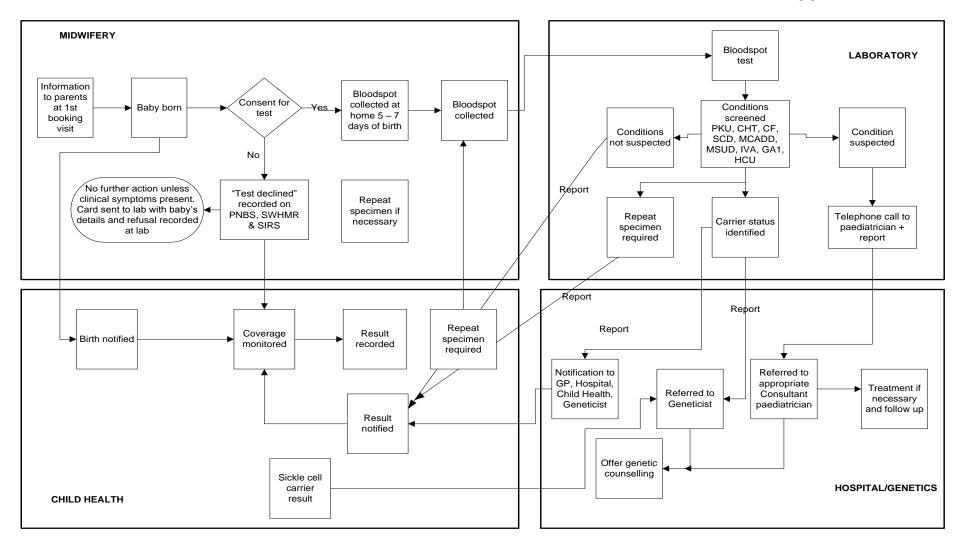
The results of the Bloodspot test are recorded against the individual child's record held within the Scottish Immunisation and Recall System (SIRS) and also in PNBS IT application that supports the failsafe processes for newborn bloodspot screening.

#### 2.8. Challenges and Service Improvements

- 1. Support parents whose children are identified as carriers of Sickle Cell Disease to access genetic counselling.
- 2. Develop a website with information about haemoglobinopathies for staff and parents in accessible formats.

## **NHSGGC Newborn Bloodspot Screening Pathway**

# Appendix 2.1



### Appendix 2.2

# Members of Newborn Bloodspot Screening Steering Group As at March 2017

Dr Emilia Crighton Head of Health Services Section (Chair)
Ms Sally Amor Health of Health Improvement, NHS Highland

Mr Paul Burton Information Manager

Mrs Lin Calderwood HI&T Service Delivery Manager Dr Elizabeth Chalmers Consultant Paediatric Haematologist

Mrs Diana Clark Lead Midwife
Ms Barbara Cochrane Metabolic Dietician

Ms Alison Cozens Consultant in Inherited Metabolic Medicine

Dr Rosemarie Davidson Consultant Clinical Geneticist
Dr Anne Devenny Consultant Paediatrician
Ms Alison Estell Healthcare Scientist

Mrs Elaine Garman Public Health Specialist, NHS Highland

Mr Ian Fergus Technical Site Manager

Ms Dorothy Finlay Lead Midwife Ms Patricia Friel Lead Nurse

Dr Peter Galloway Consultant Clinical Biochemist

Mrs Jaki Lambert Lead Midwife Miss Denise Lyden Project Officer

Dr Helen Mactier Consultant Neonatologist

Ms Karen McAlpine Lead Midwife

Mrs Marie-Elaine McClair Clinical Service Manager, Community Midwifery

Ms Julie Mullin Assistant Programme Manager
Mrs Uzma Rehman Programme Manager, Public Health

Ms Elizabeth Rennie Programme Manager

Ms Sarah Smith Principle Scientist, Newborn Screening Laboratory

Ms Margaretha van Mourik Consultant Genetics Counsellor Mrs Nicola Williamson Consultant Clinical Scientist

# **Chapter 3 - Universal Newborn Hearing Screening**

# **Summary**

- Universal Newborn Hearing screening can detect early permanent congenital hearing impairment as well as babies with mild and unilateral losses who receive ongoing review.
- Of the 12,206 eligible babies, 12,042 were screened for hearing loss giving an uptake of 98.7%. A second stage follow up was required for 1,385 (11.5%) babies and, of these, 195 (1.6%) were referred to audiology.
- Forty-eight babies were confirmed with a hearing loss (0.3% of the screened population). Twenty-seven babies had confirmed bilateral hearing loss and 21 babies had confirmed unilateral hearing loss.
- 164 (1.3%) babies did not complete the screening programme. These included babies who did not attend for screening, are deceased or have moved away from their current home address or transferred to another Board area.

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#### 3.1. Universal Newborn Hearing Screening

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.

#### 3.2. Eligible Population

Universal Newborn Hearing screening programmes is offered to all newborns by 4 weeks of corrected age (NICU) babies or by 5 weeks corrected age (community programmes). The eligible babies are those whose mothers were registered with a GP practice within the Health Board or resident within the area.

The babies excluded are those who died before screening was complete or have not reached the corrected age for screening.

#### 3.3. Screening Tests

Hearing tests are carried out on all babies born in NHS Greater Glasgow and Clyde using the Automated Auditory Brainstem Response (AABR). The screening is completed prior to discharge from hospital if this is not possible then an appointment is made at an outpatient clinic.

#### 3.4. Repeat Screens

These may be required if the baby was unsettled during the original screen, or if there was fluid or temporary blockage in the ear and for confirmation if the baby has a hearing loss.

Detailed screening pathway is shown in Appendix 3.1

# 3.5. NHSGGC Universal Newborn Hearing Screening Programme across HSCPs

The uptake of Newborn Hearing Screening is high across all areas and ranged from 97.9% in Glasgow South to 99.0% in Inverclyde **(Table 3.1).** 

Table 3.1 Percentage Uptake for newborn hearing screening by HSCP

HSCP	Eligible	Screened	% Uptake
East Dunbartonshire	978	967	98.9
East Renfrewshire	860	853	99.2
Glasgow North East	2,042	2,013	98.6
Glasgow North West	2,169	2,135	98.4
Glasgow South	2,811	2,753	97.9
Inverclyde	674	667	99.0
Renfrewshire	1,744	1,737	99.6
West Dunbartonshire	928	917	98.8
Total	12,206	12,042	98.7

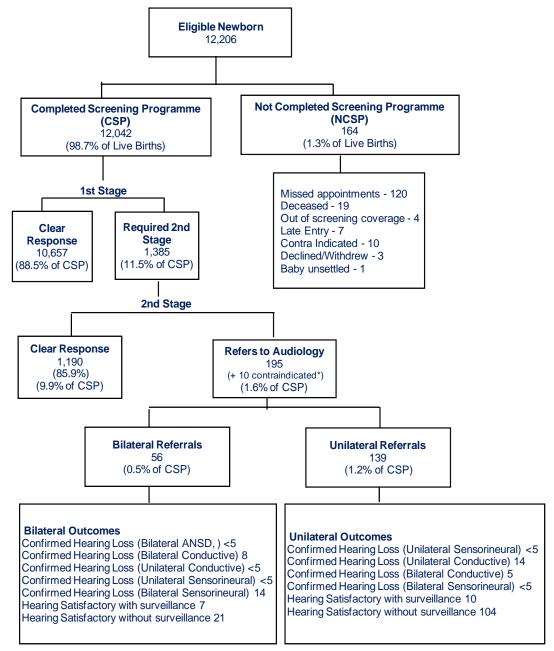
Source: Scottish Birth Record (SBR) Extracted: July 2017

Of the 12,206 eligible babies, 12,042 were screened for hearing loss giving an uptake of 98.7%.

1,385 (11.5%) babies required a second stage follow up and, of these, 195 (1.6%) babies were referred to audiology. Forty-eight babies were confirmed with a hearing loss (0.3% of the screened population). Twenty-seven babies had confirmed bilateral hearing loss and 21 babies had confirmed unilateral hearing loss.

164 (1.3%) babies did not complete the screening programme. These included babies who did not attend for screening, are deceased or have moved away from their current home address or transferred to another Board area (**Figure 3.1**).

Figure 3.1 Summary of NHSGGC Universal Newborn Hearing Screening Programme



Source: Scottish Birth Record (SBR); Extracted July 2017

\* 10 Contraindicated: Confirmed Hearing Loss 5 (Bilateral ANSD 1, Bilateral Conductive & Sensorineural 1, Unilateral Conductive 1, Unilateral Sensorineural 1, Bilateral Sensorineural 1)

#### Definitions - Screening

1st Stage - 1st Screen (AABR1) for Greater Glasgow & Clyde

2nd Stage - 2nd screen (AABR2) for Greater Glasgow & Clyde

Not Completed screening programme- all babies did not completed screen process but have a final outcome set on SBR includes, DNA, Deceased, Moved Away, etc. Babies who are still in screen process either awaiting 1st or 2nd stage screen are also in this data

#### <u>Definitions - Outcomes</u>

**Hearing Under assessement**: all babies who have referred from the screen but have not attended for diagnostic testing at time report was compiled. **Incompleted**: Patient did not attend appointment for diagnostic testing

Not yet determined: the severity and type of loss is not finalised at the time of reporting. Will be followed up in Audiology.

PCHI: all babies who were diagnosed with permanent Childhood Hearing Loss in both ears - better ear responses at 40dB and more.

### 3.6. Information Systems

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) holds screening outcomes and is used as a failsafe to ensure all babies are offered hearing screening.

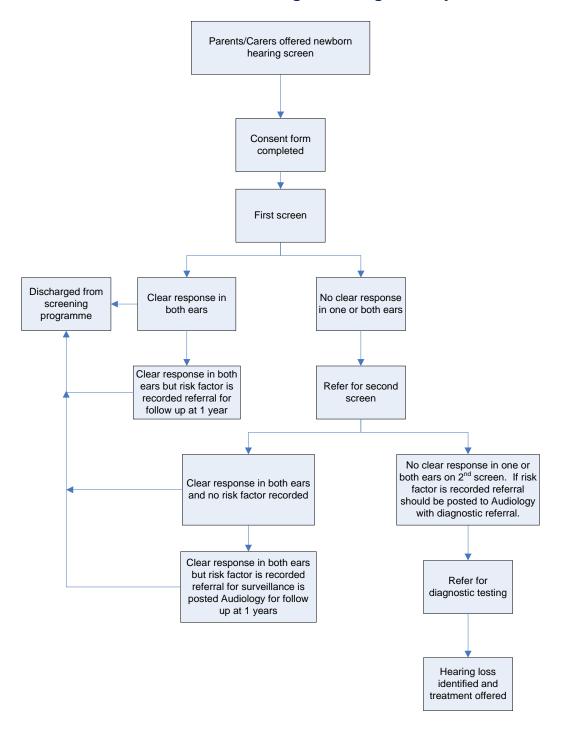
## 3.7. Challenges and Future Priorities

Maintain service performance and ensure that all babies are offered Universal Newborn Hearing Screening to meet national standards and targets.

Replace old testing equipment across all sites.

### Appendix 3.1

# **NHSGGC Universal Newborn Hearing Screening Pathway**



# **Universal Newborn Hearing Screening Programme Steering Group** (As at March 2017)

Dr Emilia Crighton Head of Health Services Section (Chair)
Mrs Karen Boyle Newborn Hearing Screening Manager

Mr Paul Burton Information Manager

Mrs Lin Calderwood H&IT Service Delivery Manager
Ms Isobel Cook Midwife/Screener, Argyll and Bute

Ms Mary Fingland LMC Representative

Mrs Dorothy Finlay Lead Midwife
Mr Dougie Fraser Service Manager

Mrs Fiona Gilchrist Assistant Programme Manager, Screening Dept

Dr Ruth Hamilton Clinical Scientist
Ms Cathy Harkins Lead Midwife
Mr James Harrigan Head of Audiology

Ms Fiona Jarvis Specialist Speech and Language Therapist

Miss Denise Lyden Project Officer
Ms Karen McAlpine Lead Midwife

Dr Juan Mora Consultant Audiological Physician

Mrs Julie Mullin Assistant Programme Manager, Screening Dept

Dr Andrew Powls Consultant Neonatologist

Mrs Uzma Rehman Public Health Programme Manager
Ms Patricia Renfrew Consultant Practitioner, Argyll and Bute

Ms Vivien Thorpe Clinical Scientist

Ms Heather Young Team Leader, Women and Children's services

# **Chapter 4 - Child Vision Screening**

# **Summary**

### Pre-school Vision Screening Programme

- In 2016/17, 13,112 children aged between four to five years old were identified using the Community Health Index System as being eligible for pre-school vision screening.
- 5,408 (41.2%) children lived in the most deprived areas, with the largest proportion living in Glasgow City 3,812 (70.4%).
- Overall uptake was 87.2%. Lowest uptake was in Glasgow City HSCP sectors and West Dunbartonshire where uptake was below 90% compared to highest uptake in Inverciyde at 93.3%.
- Highest uptake was among children of Chinese ethnicity 90.7%, followed by White British children 89.2%. Lowest uptake was among Black children 79.5%.
- Of the 11,434 children screened, 7,963 (69.6%) had a normal result. Of the 2,650 (23.2%) children referred for further assessment, 1,260 (27.7%) were from the most deprived area.
- The highest proportion of children screened that were referred for further investigation was in Glasgow North East 29.6% (516) and Glasgow South 27.9% (631). The lowest was 15.9% (177) in East Renfrewshire.
- 711 (6.2%) children are currently under follow up by ophthalmology service across NHSGGC.

## **Primary 7 School Vision Screening Programme**

- In 2016/17, 12,166 Primary 7 school children were eligible for a vision test and 10,439 (85.8%) were tested. Highest uptake was in Inverclyde 95.1% and the lowest uptake in East Dunbartonshire 80.7%.
- Highest uptake was among children of white ethnicity 87% and the lowest uptake 68.5% among Black children.
- Of the 12,116 children eligible for vision testing, 1,720 (16.5%) were already wearing prescription spectacles; ranging from 6.9% in Glasgow North West sector to 19.5% in Inverclyde HSCP.
- 1872 (21.5%) were identified with poor visual acuity. The highest proportion of children identified with poor acuity lived in Glasgow North West sector 31.4% (464) and the lowest in Renfrewshire HSCP 9.2% (118).

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#### Pre-school Vision Screening Programme

#### 4.1. Background

Vision Screening is routinely offered to all pre-school age children and Primary 7 school children resident in NHS Greater Glasgow and Clyde area.

Poor vision can be caused by either a squint (strabismus) or differences in the focusing power of each eye (refractive error) which results in the brain receiving different images from each eye. If these problems are not treated early in childhood, this can lead to reduced vision in one or, in some cases, both eyes. The screening programme can also detect reduced vision due to other more uncommon causes.

Vision problems affect 3-6% of children and although obvious squints are easily detected, refractive error and subtle squints often go undetected and long-term vision loss in adulthood can develop. Most problems can be treated using spectacle lenses to correct any refractive error and occlusion therapy to treat strabismus (squint) – mainly using 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.

#### 4.2. Aim of Vision Screening Programmes

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.

#### 4.3. Pre-school Vision 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.

#### 4.4. 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.

#### 4.5. Pre-school Vision Screening Pathway

The list of eligible children (the school intake cohort for the following year), with dates of birth between 1 March 2012 and 28 February 2013 were downloaded from CHI and matched against the lists received from nurseries.

Pre-school vision screening clinics take place in the nursery setting. Children that do not attend nursery or school or whose nursery is unknown or 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.

#### 4.6. Delivery of Pre-school Vision Screening Programme 2016/17

In 2016/17, 13,112 children aged between four to five years old were identified using the Community Health Index System as being eligible for pre-school vision screening.

5,408 (41.2%) of all pre-school children within NHSGGC live in the most deprived quintile. The majority of these are resident within the Glasgow City sectors 3,812 (70.4%) (Table 4.1).

Table 4.1 Number of Eligible NHSGGC Child Residents by HSCP Area and by Deprivation Categories

		SIMD	Quintile	e <b>2016</b>		
	Most deprived				Least deprived	
HSCP	1	2	3	4	5	Total
East Dunbartonshire	64	190	74	198	678	1204
East Renfrewshire	68	98	75	171	805	1217
Glasgow North East	1460	231	209	208	10	2118
Glasgow North West	1027	246	201	203	327	2004
Glasgow South	1325	548	398	262	179	2712
Inverclyde	374	113	99	121	89	796
Renfrewshire	605	415	321	332	334	2007
West Dunbartonshire	485	307	118	105	39	1054
Total	5408	2148	1495	1600	2461	13112
% of Total	41.2	16.4	11.4	12.2	18.8	

Source: Child Health - Pre-School Date Extracted: August 2017

Not all children eligible for vision screening are registered with a nursery. Those that miss screening in nursery are sent an appointment for a hospital clinic. West Dunbartonshire has the highest proportion of children registered with a nursery 95.1% (1002) and North East Glasgow the lowest, 80.9% (1714) (Table 4.2).

Table 4.2 Number of NHSGGC children eligible for screening, number and percentage registered with a nursery by HSCP

HSCP	Children eligible for screening	Registered with a Nursery	% Registered	Not registered with a nursery	% Not Registered
East Dunbartonshire CHP	1204	1143	94.9	61	5.1
<b>East Renfrewshire</b>	1217	1153	94.7	64	5.3
<b>Glasgow North East</b>	2118	1714	80.9	404	19.1
<b>Glasgow North West</b>	2004	1762	87.9	242	12.1
Glasgow South	2712	2371	87.4	341	12.6
Inverclyde	796	756	95.0	40	5.0
Renfrewshire	2007	1800	89.7	207	10.3
West Dunbartonshire	1054	1002	95.1	52	4.9
Total	13112	11701	89.2	1411	10.8

Source: Child Health – Pre-school Date Extracted: August 2017

Using the Onomap software, the number and percentage of children screened by ethnicity was analysed. The highest uptake was among children of Chinese ethnicity

at 90.7% (233), followed by White British ethnicity where uptake was 89.2% (7610). The lowest uptake was among the unclassified group at 69.5% (164) **(Table 4.3).** 

Table 4.3 Pre-school Vision Screening Uptake by Ethnicity

2001 census ethnic group	Not screened	Screened	Total	% screened
White - British	926	7610	8536	89.2
White – Irish	185	1421	1606	88.5
White - any other white background	171	684	855	80.0
Asian or Asian British	174	746	920	81.1
Black or Black British	45	175	220	79.5
Other ethnic groups - Chinese	24	233	257	90.7
Other ethnic groups - any other ethnic group	81	401	482	83.2
Unclassified	72	164	236	69.5
Total	1678	11434	13112	87.2

Source: Child Health - Pre-School, Onomap software, August 2017

11434 (87.2%) children were screened representing an increase of 0.4% from previous year. The highest uptake was in Inverclyde HSCP 93.3% (743) and the lowest in Glasgow North East 82.4% (1745).

69.6% of children screened had a normal result, this ranged from 78.2% in East Renfrewshire to 62.1% in Glasgow North East. Overall 23.2% of children screened were referred for further investigations. The referral rates varied from 15.9% in East Renfrewshire to 29.6% in Glasgow North East **(Table 4.4).** 

Table 4.4 Pre-school Vision Screening Uptake and Outcomes by HSCP Area 1 April 2016 to 31 March 2017

HSCP	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	1204	1102	102	91.5	70.2	23.7	1.2	4.9
East Renfrewshire	1217	1117	100	91.8	78.2	15.9	0.1	5.7
Glasgow North East	2118	1745	373	82.4	62.1	29.6	1.8	6.5
Glasgow North West	2004	1693	311	84.5	66.7	24.7	1.2	7.4
Glasgow South	2712	2264	448	83.5	65.6	27.9	0.6	5.9
Inverclyde	796	743	53	93.3	74.6	18.4	1.2	5.8
Renfrewshire	2007	1826	181	91.0	75.8	16.6	0.9	6.7
West	1054	944	110	89.6	71.9	21.7	0.5	5.8
Dunbartonshire								
Total	13112	11434	1678	<i>87.2</i>	69.6	23.2	1.0	6.2

Source: Child Health - Pre-School

Date Extracted: August 20

A significantly larger proportion of children living in the most deprived areas were referred for further assessment, recalled or required ongoing follow up. Of the 2,650 children referred for further assessment, 1,260 were from the most deprived areas.

110 (1%) children were recalled back to be screened due to difficulties screening their vision during the first screen. The proportion of children with a normal result ranged from 63.3% (2884) among children living in the most deprived area to 76.9% (1730) in the least deprived area. Referrals were also higher for children from the most deprived areas 27.7% compared to 17.3% in the least deprived areas.

Of the 711 (6.2%) children currently under on-going follow up by ophthalmology service, 348 are from the most deprived areas (**Table 4.5**).

The Pre- school vision screening summary of activity for the service in NHS Greater Glasgow and Clyde for the school year 2016-2017 is in **Figure 4.1.** 

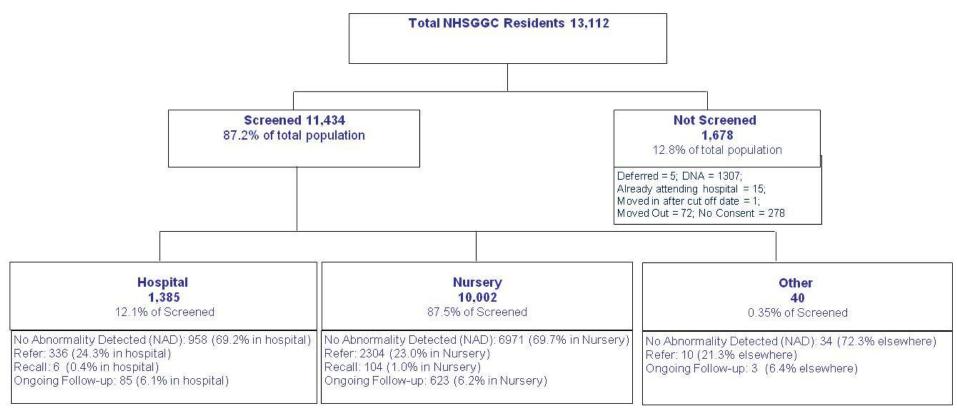
10,002 children were screened in Nurseries and 6,971 (69.7%) had a normal result, 2,304 (23%) were referred and 623 (6.2%) had ongoing follow up by Ophthalmology services. Those not screened in nursery were invited to attend the hospital based service. 1385 children were screened within a hospital setting, 958 (69.2%) had a normal result, 336 referred and 85 had on-going follow up by Ophthalmology services.

Table 4.5 Pre-school Vision Screening Uptake and Outcomes by Deprivation

SIMD	Number of Children Screened	No Abnormality Detected (NAD)	% NAD	Referred	% Referred	Recall	% Recall	Ongoing Follow up	%Ongoing Follow up
1 (Most Deprived)	4555	2884	63.3	1260	27.7	63	1.4	348	7.6
2	1883	1320	70.1	448	23.8	12	0.6	103	5.5
3	1310	948	72.4	283	21.6	9	0.7	70	5.3
4	1437	1081	75.2	270	18.8	12	0.8	74	5.1
5 (Least Deprived)	2249	1730	76.9	389	17.3	14	0.6	116	5.2
Total	11434	7963	69.6	2650	23.2	110	1.0	711	6.2

Source: Child Health - Pre-School Date Extracted: August 2017

Figure 4.1: Summary of NHSGGC Pre-school Vision Screening Activity



Source: Child Health - Pre-School Date Extracted: November 2017

#### **Primary 7 School Vision Screening Programme**

#### 4.7. P7 Vision Test

A visual acuity test is carried out where children are asked to identify a line of letters using a Snellen chart or Logmar if a child is unable to manage a Snellen chart. Testing is carried out on children who already have glasses.

## 4.8. P7 Eligible Population

All school children in Primary 7 resident in NHSGGC are offered a vision test prior to transfer to secondary education.

#### 4.9. P7 Vision Screening Pathway

P7 vision screening takes place in school and is carried out by a School Support Worker. Children that do not attend school or miss their appointment within the school are advised to attend their local community optometrist.

Parents/carers are issued with result letter.

Abnormal results have three referral pathways:

- Parent/carer is given a referral letter to take to their local community optometrist for further examination if a child's visual acuity without glasses is 6/9 or poorer in one or both eyes or with glasses is 6/12 or poorer in the better eye;
- If a child has some specific visual abnormalities e.g. nystagmus (difficulty fixing their gaze on an object) or a visual field problem (problems with central or peripheral vision), they will be referred to a community paediatrician;
- If a child has a sudden onset squint, the School Nurse, GP and parent will be informed on the same day as this can be associated with more serious illness which need urgent assessment and management.

#### 4.10. Delivery of Primary 7 School Vision Screening Programme 2016/17

In 2016/17, 12,166 Primary 7 school children were eligible for a vision test of which 10,439 (85.8%) were tested. The highest uptake was in Inverclyde 95.1% and East Renfrewshire 94.3% and the lowest was in East Dunbartonshire at 80.7% **(Table 4.6).** 

Table 4.6 NHSGGC mainstream schools primary 7 vision screening uptake by HSCP, 1 April 2016 to 31 March 2017

HSCP (School)	Not Screened	Screened	Total	% Uptake
East Dunbartonshire HSCP	239	997	1236	80.7
East Renfrewshire HSCP	74	1225	1299	94.3
Glasgow North East Sector	299	1411	1710	82.5
Glasgow North West Sector	360	1589	1949	81.5
Glasgow South Sector	210	2081	2291	90.8
Inverclyde HSCP	43	826	869	95.1
Renfrewshire HSCP	349	1485	1834	81.0
West Dunbartonshire HSCP	153	825	978	84.4
Total	1727	10439	12166	85.8

Source: CHSP\_PS, October 2017

Analysis of the number and percentage of children screened by ethnicity shows that the highest uptake was among children of White British ethnicity at 87.0% and the lowest uptake was among Black or Black British children at 68.5% (**Table 4.7**).

Table 4.7 NHSGGC Primary 7 Screening Uptake by ethnicity, 1 April 2016 to 31 March 2017

2001 Census Ethnic Group	Not Screened	Screened	Total	% Screened
White – British	1103	7351	8454	87.0
White – Irish	220	1418	1638	86.6
White - any other white background	111	455	566	80.4
Asian or Asian British	103	597	700	85.3
Black or Black British	51	111	162	68.5
Other ethnic groups - Chinese	16	83	99	83.8
Other ethnic groups - any other	80	303	383	79.1
ethnic group				
Unclassified	43	121	164	73.8
Total	1727	10439	12166	85.8

Source: ONO Map

Of the 10,439 children eligible for vision testing, 16.5% were already wearing prescription spectacles (**Table 4.8**).

Table 4.8 NHSGGC mainstream schools primary 7 vision screened pupils 2016-2017: wearing spectacles

HSCP (School)	No Spectacles	Spectacles	Total	% Spectacles
East Dunbartonshire HSCP	816	181	997	18.2
East Renfrewshire HSCP	1004	221	1225	18.0
Glasgow North East Sector	1124	287	1411	20.3
Glasgow North West Sector	1479	110	1589	6.9
Glasgow South Sector	1677	404	2081	19.4
Inverclyde HSCP	665	161	826	19.5
Renfrewshire HSCP	1283	202	1485	13.6
West Dunbartonshire HSCP	671	154	825	18.7
Total	8719	1720	10439	16.5

Source: CHSP\_PS, October 2017

Of the 10,439 children, 83.6% (8,722) were screened using a Snellen test and 6,850 recorded with Acuity of 6/6 which is normal. A follow up with an Optometrist is recommended for children with an Acuity worse than 6/9 (if not wearing spectacles) and Acuity of 6/12 or worse (for those with spectacles). The highest proportion of children identified with poor acuity lived in Glasgow North West sector 31.4% and the lowest in Renfrewshire HSCP 9.2% (Table 4.9).

Table 4.9 NHSGGC mainstream schools primary 7 vision screened pupils 2016-17 poor acuity identified

		Snellen	% Snellen	Acuity	% Acuity	Acuity 6/9 or	% Acuity 6/9 or	Acuity 6/12 or	% Acuity 6/12 or	No. referred	% referred
HSCP (School)	Total	Test	Test	6/6	6/6	worse	worse	worse	worse		
East Dunbartonshire	997	817	81.9	618	75.6	163	20.0	36	4.4	199	24.3
East Renfrewshire	1225	1006	82.1	816	81.1	127	12.6	63	6.3	190	18.9
Glasgow North East Sector	1411	1124	79.7	913	81.2	153	13.6	58	5.2	211	18.7
Glasgow North West Sector	1589	1478	93.0	1014	68.6	349	23.6	115	7.8	464	31.4
Glasgow South Sector	2081	1677	80.6	1194	71.2	348	20.8	135	8.1	483	28.8
Inverclyde	826	665	80.5	576	86.6	58	8.7	31	4.7	89	13.3
Renfrewshire	1485	1283	86.4	1165	90.8	83	6.5	35	2.7	118	9.2
West Dunbartonshire	825	672	81.5	554	82.4	79	11.8	39	5.8	118	17.5
Total	10439	8722	83.6	6850	78.5	1360	15.6	512	5.9	1872	21.5

Source: CHSP\_PS, October 2017

Note: data is reported on children who completed Snellen Test Poor Acuity =6/9 or poorer with 6/12 or poorer with spectacles.

#### 4.11. P7 Child Health Screening Information Systems

Child Health Surveillance System—Preschool (CHS-PS) currently supports the delivery of the pre-school vision screening programme across NHS Greater Glasgow and Clyde. School vision testing is supported by the Child Health Surveillance System- School (CHS-S). Both CHS-PS and CHS-S are being reprocured by NHS Scotland.

#### 4.12. P7 Challenges and Future Priorities

- Ensure the co-operation of all nurseries to allow screening to take place.
- Increase the number of children who attend pre-vision screening both in nursery or within a hospital setting.
- Improve the recording of children who attend an Optometrist as a result of prevision or Primary 7 vision screening.
- Ensure that changes in School Nursing provision for NHSGGC does not affect the Primary 7 vision screening programme, which is unique to the Board area.
- Work with NHS Scotland and other boards to ensure the safe and effective continuity of vision screening activities during a change of IT systems.

#### Appendix 4.1

# Members of Child Vision Screening Steering Group (As at March 2017)

Dr Emilia Crighton Head of Health Services Section (Chair)

Mrs Denise Bratten Optometrist

Mr Paul Burton Information Manager

Mrs Lin Calderwood Screening Service Delivery Manager
Mrs Fiona Gilchrist Assistant Screening Programme Manager

Ms Samara Hodi Head of Optometry

Mrs Patricia Mackay Team Lead Children & Families, South Glasgow

Mrs Carolyn MacLellan
Mr Eddie McVey
Ms Morven Campbell
Lead Orthoptist
Optometric Adviser
Vice chair, AOC

Ms Arlene Polet Children's & Families Team Lead, Inverclyde

Mrs Uzma Rehman Programme Manager, Public Health

Mrs Diane Russell Lead Orthoptist

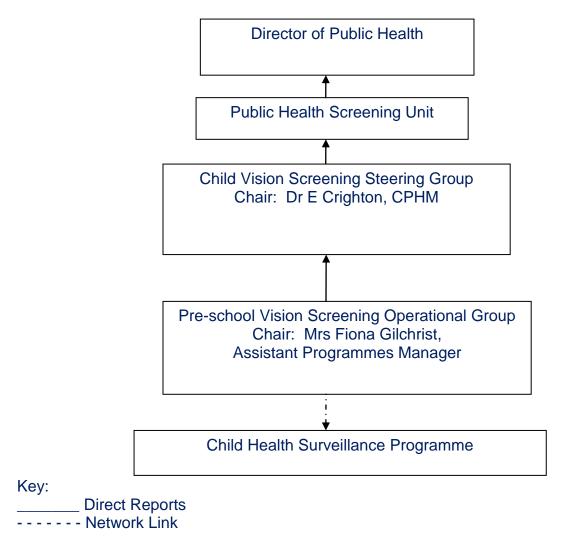
Ms Elaine Salina Principal Optometrist

Ms Anita Simmers Head of Vision, Science Dept, GCU Dr Kathy Spowart Paediatrician, Community Child Health

Mrs Claudine Wallace Lecturer in Orthoptics, GCU

# **Reporting Structure**

# **Child Vision Screening Steering Group**



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# Section 2 Adult Screening

# **Chapter 5 - Abdominal Aortic Aneurysm Screening**

# **Summary**

- An abdominal aortic aneurysm (AAA) is a dilatation of the aorta within the abdomen where the aortic diameter is 3.0 cm or more. Aneurysms are strongly linked to increasing age, hypertension, smoking, other vascular disease and a positive family history of AAA.
- Studies have found that approximately 7% of men aged 65 were found to have an AAA and it is less common in men and women under aged 65 years.
- The aim of AAA screening is the early detection and elective repair of symptomatic AAA in order to prevent spontaneous rupture. AAA screening is associated with a 40% reduction in aneurysm related mortality.
- All men aged 65 years in the Board area are invited to attend AAA screening by a single ultrasound examination. Men aged over 65 years of age are able to self-refer to the programme.
- 5,827 men aged 65 were invited to participate in the AAA Screening programme in 2016-2017.
- 4,680 (80.3%) took up screening, exceeding the minimum standard of 70%.
- Uptake is poorest in the most socio-economically deprived areas and in ethnic minorities. There are also lower uptake rates in some HSCPs that are not wholly explained by socio-economic deprivation.
- 52 men (1.1%) were found to have an aneurysm measuring between 3.00 cm and 5.49 cm and are currently on surveillance.
- 6 men (0.1%) had an aneurysm measuring 5.5 cm or more that required surgical assessment and intervention.
- All essential KPI's for AAA screening were met.

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#### 5.1. Background

An abdominal aortic aneurysm (AAA) is a dilatation of the aorta within the abdomen where the aortic diameter is 3.0 cm or more. Aneurysms are strongly linked to increasing age, hypertension, smoking, other vascular disease and a positive family history of AAA<sup>1</sup>.

Studies<sup>2</sup> have found that approximately 7% of men aged 65 were found to have an AAA and it is less common in men and women under aged 65 years. When an AAA ruptures less than half of patients will reach hospital alive and when an operation is possible mortality is as high as 85%.

#### 5.2. Aim of the Screening Programme and Eligible Population

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

AAA screening was implemented across NHS Greater Glasgow and Clyde in February 2013. The national AAA screening programme performance and quality is monitored via defined National AAA Screening Standards<sup>3</sup> and Key Performance Indicators (KPIs)<sup>4</sup>.

All men aged 65 years who are resident in the NHSGGC area are invited to participate in the AAA screening programme. Men aged over 65 years of age are able to self-refer to the programme.

#### 5.3. Screening Test and Screening Pathway

The screening test involves a single abdominal scan using a portable ultrasound machine. The AAA IT application is used to appoint and manage the patient through their screening pathway. The application obtains the demographic details of the participants by linking with the Community Health Index (CHI). Screening takes

<sup>&</sup>lt;sup>1</sup> Campbell, H (2012) Vardulaki KA, Walker NM, Day NE, Duffy SW, Ashton HA, Scott, RAP (2000) Quantifying the risks of hypertension, age, sex and smoking in patients with abdominal aortic aneurysm. British Journal of Surgery 87: 195-200.

<sup>2</sup> Ashton HA, Buxton MJ, Day NE, Kim LG, Marteau TM, Scott RAP et al (2000). Multicentre Aneurysm Screening Study Group. The Multicentre Aneurysm Screening Study (MASS) into the effect of abdominal aortic aneurysm screening on mortality in men: a randomised controlled trial. Lancet 360 (9345): 1531-9.

<sup>&</sup>lt;sup>3</sup>http://www.healthcareimprovementscotland.org/our\_work/cardiovascular\_disease/screening\_for\_aaa /aaa screening\_standards.aspx (accessed January 2018)

<sup>&</sup>lt;sup>4</sup> <a href="http://www.isdscotland.org/Health-Topics/Public-Health/AAA-Screening/2017-03-07-AAA-KPI-Definitions.pdf">http://www.isdscotland.org/Health-Topics/Public-Health/AAA-Screening/2017-03-07-AAA-KPI-Definitions.pdf</a> (accessed January 2018)

place in the New Victoria Hospital, New Stobhill Hospital, Golden Jubilee Hospital, Renfrew Health Centre, Inverclyde Royal Hospital and Vale of Leven Hospital. Individuals whose aortic diameter is less than 3.0 cm are discharged. Individuals with a positive result from screening (AAA dimensions between 3.0 and 5.4 cm) will be offered interval surveillance scanning and treatment. Men with clinically significant AAA (over 5.5 cm) will be referred to secondary care for assessment (Appendix 5.1).

Individuals with an AAA over 5.5 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 multidisciplinary team decision making 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, for example, an individual has a high BMI, large abdominal girth, bowel gas or previous surgery, which can cause issues with visualisation of the aorta preventing accurate measurements and image capture using ultrasound. If an image cannot be achieved after two appointments the individual will be discharged from the programme and referred to Vascular Services for management locally.

#### 5.4. Programme Performance and Delivery

The AAA programme KPI's cover information on: invitation and attendance at screening, the quality of screening, and vascular referrals. NHS Greater Glasgow & Clyde met the essential threshold for all KPI's for the year ending March 2017 (Appendix 5.2).

An overview of NHGGC AAA screening programme activity during 2016/17 is provided in **Figure 5.1**.

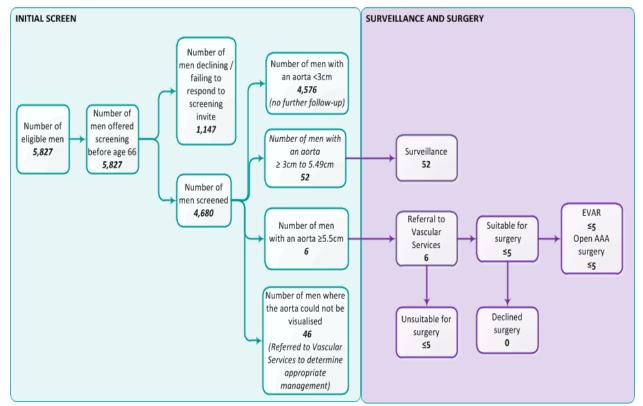


Figure 5.1 Overview NHSGGC AAA screening programme activity, 2016/17

Source: AAA Application, October 2017

Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

For the period 1st April 2016 to 31st March 2017, 5,827 men were eligible for screening. Of these, 4,680 men (80%) were screened before age 66 and 3 months. A further 88 men (over the age of 66 years) self referred to the AAA screening programme during this time period.

In addition to national performance monitoring via annually published KPIs, local monitoring is also undertaken on an annual basis to explore any local variation in programme performance and quality. As a result of differences in data extract dates, numbers in local data analysis may differ from those presented in national reports.

AAA screening was implemented across NHS Greater Glasgow and Clyde in February 2013. The highest uptake rate was in 2013/14 (81.2%) However has remained consistent since then at about 80% (Figure 5.2).

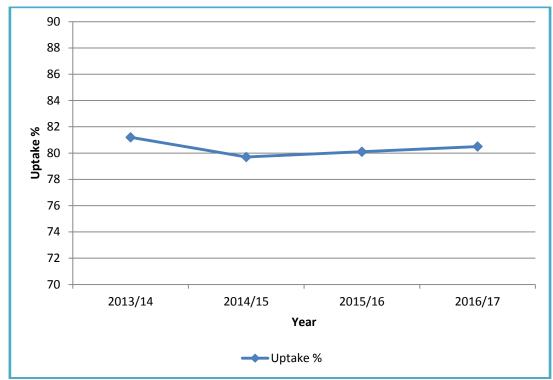


Figure 5.2 Uptake of AAA in NHS GGC from 2013/14 – 2016/17

Source: AAA Application 2017

The essential threshold for screening uptake (70%) was met across all deprivation quintiles. Overall, men who resided in the most deprived areas had uptake rates 11% lower than men residing in the least deprived areas (74.2% vs. 85.2% respectively) (Table 5.2).

Table 5.2 Uptake of AAA screening among eligible population by SIMD quintile for NHSGGC, 2016-2017

SIMD Quintile 2016	Not Screened	Screened*	Total	% Screened
1 (Most Deprived)	513	1,473	1,986	74.2
2	199	752	951	79.1
3	124	620	744	83.3
4	122	749	871	86.0
5 (Least Deprived)	189	1,086	1,275	85.2
Total	1,147	4,680	5,827	80.3

<sup>\*</sup> Attended screening by age 66 years and 3 months Source: AAA Application, October 2017

Chi-Square Tests Linear-by-Linear Association p < 0.0001

The majority (96.4%) of men invited were of white ethnic origin **(Table 5.3).** Uptake of AAA screening differs between ethnic groups, with uptake high across all groups. However, due to low numbers in some ethnic groups it is not possible to directly compare programme uptake across ethnic subgroups.

Table 5.3 Uptake of AAA screening among eligible population by ethnicity for NHSGGC, 2016-2017

2001 Census Ethnic Group	Not Screened	Screened	Total	% Screened
White – British	933	3,888	4,821	80.6
White – Irish	146	557	703	79.2
White - any other white background	28	69	97	71.1
Asian or Asian British	17	114	131	87.0
Black or Black British	0	≤5	≤5	100
Other ethnic groups - Chinese	10	13	23	56.5
Other ethnic groups - any other ethnic group	8	27	35	77.1
Unclassified	≤5	8	13	61.5
Total	1,147	4,680	5,827	80.3

<sup>\*</sup>Attended screening by age 66 years and 3 months Source: AAA Application, OnoMap<sup>5</sup>, October 2017

Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

The essential threshold for screening uptake (70%) was met in all HSCPs, with a highest uptake rate of 86.8% in East Dunbartonshire HSCP and the lowest uptake rate of 75.0% in Glasgow City HSCP North East Sector, a difference in uptake of 11.8%.

However, when the known effects of deprivation and ethnicity are taken into account by standardisation (Standardised Uptake Rate – SUR), the variation in uptake across HSCPs persist, although slightly reduced ( 9.8% difference between highest and lowest), with 85.8% SUR in Inverclyde HSCP compared to 76.0% SUR in Glasgow City HSCP – North West Sector (Table 5.4). This suggests that differences in other local factors are also important in obtaining high AAA screening uptake rates.

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<sup>&</sup>lt;sup>5</sup> OnoMap is a software tool for the classification of names into groups of common cultural, **ethnic** and linguistic origins

Table 5.4 Uptake of AAA screening among eligible population by Health & Social Care Partnership in NHS GGC, 2016-2017

HSCP	Not Screened	Screened*	Total	% Screened	SUR %	LCI	UCI
East Dunbartonshire	79	518	597	86.8	82.9	94.4	112.2
East Renfrewshire	84	430	514	83.7	79.9	90.1	109.0
Glasgow City	627	2125	2752	77.2	78.8	93.9	102.3
North East Sector	212	637	849	75.0	77.8	89.4	104.4
North West Sector	201	622	823	75.6	76.0	87.2	102.1
South Sector	214	866	1,080	80.2	81.6	94.9	108.4
Inverclyde	71	403	474	85.0	85.8	96.4	117.3
Renfrewshire	201	754	955	79.0	77.9	90.1	103.9
West Dunbartonshire	85	450	535	84.1	84.9	96.0	115.5
Total	1,147	4,680	5,827	80.3			

<sup>\*</sup>Attended screening by age 66 years and 3 months

Source: AAA Application, October 2017;

**Table 5.5** shows that 34 of the 5,827 men eligible for screening were registered with a learning disability (0.6%). Men who were registered with a learning disability were more likely to take up screening, compared to men who were not registered with a learning disability, (91.2% vs. 80.3%). This shows an increase in uptake compared to 2015/16 programme statistics however it should be noted that numbers of individuals registered with a learning disability are low.

Table 5.5 Uptake of AAA by Learning Disability in NHSGGC, 2016-2017

Learning Disability	Not Screened	Screened*	Total	% Screened
Rest of population	1,144	4,649	5,793	80.3
Registered with a learning disability	≤5	31	34	91.2
Total	1,147	4,680	5,827	80.3

\*Attended screening by age 66 years Source: AAA Application, October 2017

Fisher's Exact Test p = 0.131

#### 5.5. Abdominal Aneurysm Screening Results and Mortality

**Table 5.6** shows that 58 men (1.2%) had an enlarged aorta (≥3cm). Fifty two (1.1%) men had an aorta measuring between 3cm to 5.49cm, requiring surveillance scans. Six men (0.1%) had a large aneurysm measuring 5.5 cm or more, requiring surgical assessment and intervention. Of the 88 men who self referred to the programme, less than 5 had an enlarged aorta (≥3cm).

Table 5.6 Abdominal Aneurysm screening results for NHSGGC, 2016-2017

	Largest Measure (cm)						
Result Type	<3	≥3 - 5.49	≥5.5	Not Known	Total		
Negative	4,576	0	0	0	4,576		
Non Visualisation	0	0	0	45	45		
Positive	0	52	6	0	58		
Technical Fail	0	0	0	≤5	≤5		
Total	4,576	52	6	46	4,680		

Source: AAA Application, NRS, October 2017

Numbers ≤5 redacted Redact numbers ≤5 as per ISD Statistical Disclosure

**Control Protocol** 

**Table 5.7** shows that there were no deaths reported in those patients with an aneurysm measuring 5.5 cm or more.

Table 5.7 Abdominal Aneurysm screening mortality for NHSGGC, 2016-2017

Largest Measure (cm)							
Mortality	<3	≥3 - 5.49	≥5.5 (No Surgery)*	≥5.5 (Surgery)	Not Known	Total	
Total Deceased	33	≤5	0	≤5	≤5	35	
<b>Total Not Deceased</b>	4,543	51	≤5	≤5	45	4,645	
Total	4,576	52	≤5	≤5	46	4,680	
% Mortality	0.7	1.9	0.0	0.0	2.2	4.8	

Source: AAA Application, NRS, October 2017

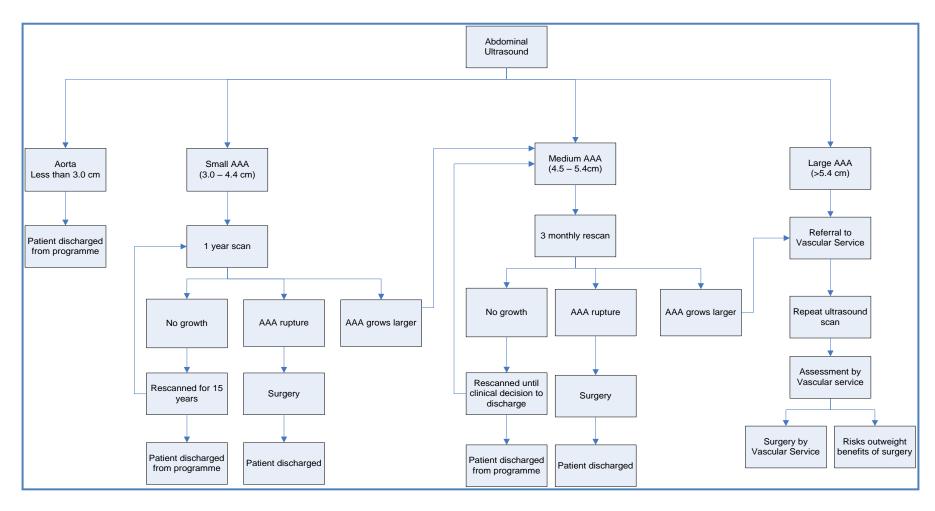
Numbers ≤5 redacted Redact numbers ≤5 as per ISD Statistical Disclosure Control Protocol

## **5.6.** Challenges and Future Priorities

- To maintain the screening staffing level and screening locations to ensure stability in the delivery of AAA Screening Programme.
- To continue to monitor vascular waiting times.
- Implementation of national External Quality Assurance.
- To continue to review uptake for men registered with a learning disability and for men registered with a severe and enduring mental illness, and work with specialist learning disability and mental health staff to develop approaches to support participation in AAA screening.

# **Appendix 5.1**

# **Positive Abdominal Aortic Aneurysm Screening Pathway**



**Appendix 5.2** 

# Abdominal Aortic Aneurysm Key Performance Indicators, NHS Greater Glasgow & Clyde (2015 – 2017)

KPI	Description	Essential Threshold	Desirable Threshold	Year ending 31 <sup>st</sup> March 2015	Year ending 31 <sup>st</sup> March 2016	Year ending 31 <sup>st</sup> March 2017
		tation and at	tendance			
1.1	Percentage of eligible population who are sent an initial offer to screening before age 66	≥ 90%	100%	69.0%	99.9%	100.0%
1.2	Percentage of men offered screening who are tested before age 66 and 3 months	≥ 70%	≥ 85%	79.7%	80.1%	80.5%
1.3	Percentage of men residing in SIMD 1 areas (most deprived) offered screening who are tested before age 66 and 3 months;	≥ 70%	≥ 85%	72.8%	72.7%	73.1%
1.4a	Percentage of annual surveillance appointments due where men are tested within 6 weeks of due date	≥ 90%	100%	93.3%	93.0%	94.0%
1.4b	Percentage of quarterly surveillance appointments due where men are tested within 4 weeks of due date	≥ 90%	100%	96.7%	98.6%	92.1%
	Q	Quality of scre	eening			
2.1a	Percentage of screening encounters where aorta could not be visualised	< 3%	< 1%	1.6%	2.4%	2.8%
2.1b	Percentage of men screened where aorta could not be visualised	< 3%	< 1%	1.4%	2.1%	2.3%
2.2	Percentage of screened images that failed the quality assurance audit and required immediate recall	< 4%	< 1%	0.4%	1.4%	1.0%
	Referral, clini	ical intervent	ion and outc	omes		
3.1	Percentage of men with AAA≥5.5cm seen by vascular specialist within two weeks of screening	≥ 75%	≥ 95%	81.8%	100.0%	100.0% <sup>6</sup>
3.2	Percentage of men with AAA≥5.5cm deemed appropriate for intervention/operated on by vascular specialist within eight weeks of screening	≥ 60%	≥ 80%	77.8%	53.8%	62.5% <sup>7</sup>

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<sup>&</sup>lt;sup>6</sup> KPI 3.1 Cumulative total to 31 March 2017 95.1% (39/41 seen by vascular specialist within 2 weeks)

<sup>2</sup> weeks) <sup>7</sup> KPI 3.2 Cumulative total to 31 March 2017 65.7% (23/35 operated on within 8 weeks appropriate for surgery)

# Appendix 5.3

# Members of Abdominal Aortic Aneurysm Screening Steering Group (as at March 2017)

Dr David Morrison Consultant in Public Health Medicine (Chair)

Mr Paul Burton Information Manager

Mrs Lin Calderwood HI&T Service Delivery Manager

Mrs Mairi Devine Radiographer

Ms Mary Fingland LMC Representative

Mrs Irene Fyfe Health Records Services Manager

Mrs Antonella Grimon AAA Data Administrator

Dr Oliver Harding Consultant in Public Health Medicine, NHS Forth

Valley

Ms Heather Jarvie Public Health Programme Manager
Dr Ram Kasthuri Consultant Interventional Radiologist
Ms Karen Loudon Clinical Service Manager (Vascular)

Miss Denise Lyden Project Officer, Public Health

Mrs Elizabeth Rennie Programme Manager, Screening Department Ms Sandra Robertson Radiology Department Manager, Forth Valley

Mrs Lynn Ross General Manager, Diagnostics

Mr Wesley Stuart Lead Clinician

# Chapter 6 - Bowel Screening Programme

# **Summary**

- Colorectal (Bowel) Cancer is the third most common cancer in Scotland for both men and women in 2015. Ninety five percent of bowel cancers detected are among people aged over 50 years of age.
- In the time period between 2005 and 2015, the age-standardised incidence rate of bowel cancer in Scotland decreased in both men and women (by 14.4% and 3.1% respectively). Age-standardised mortality rates also decreased in men by 9.4% and in women by 2.1%.
- In 2015, 691 people (354 men and 337 women) residing in the NHS
   Greater Glasgow & Clyde area were diagnosed with bowel cancer. In the
   same year, 322 people (168 men and 154 women) with a diagnosis of
   bowel cancer died.
- The aim of bowel screening is to detect bowel cancer at an early stage where treatment is more effective. In some cases, pre-cancerous polyps can be removed and cancer prevented. The programme invites all men and women between the ages of 50 – 74.
- In 2015-17, 355,285 NHSGGC residents were invited to participate in the bowel screening programme.
- The overall uptake of screening was 172,643, 48.6%, against a target of 60%.
- Uptake is poorest in men, younger people (aged 50-54 years), the most socio-economically deprived residents, people with learning disabilities and in ethnic minorities. There are also lower uptake rates in some HSCPs that are not wholly explained by socio-economic deprivation.
- Results are most likely to be positive among men, older people and the most socio-economically deprived.
- In residents of NHS Greater Glasgow and Clyde area, 426 people were diagnosed with bowel cancer in 2016, of which 120 (28.2%) were detected through screening.
- A new screening test, qFIT (quantitative faecal immunochemical test) was introduced in November 2017, accompanied by public information campaigns. We anticipate that this will increase uptake by about 5% and NHSGGC have added an information letter prior to screening, to further help encourage participation.

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# 6.1. Background

Colorectal (Bowel) Cancer is the third most common cancer in Scotland for both men and women<sup>8</sup>. Every year in Scotland approximately 4,000 people are diagnosed with the disease. Ninety five percent of bowel cancers detected are among people aged over 50 years of age<sup>9</sup>.

In 2015, the most recent year for which completed data is available, 691 people (354 men and 337 women) residing in the NHSGGC area were diagnosed with bowel cancer<sup>10</sup>. This gives an age-standardised incidence rate of 82.9per 100,000 population for men, lower than the Scotland rate. For women this gives an age-standardised incidence rate of 58.4per 100,000 population for men, comparable with the Scotland rate. In the same year, 322 people (168 men and 154 women) with a diagnosis of bowel cancer died, giving a standardised mortality rate of 42.7 per 100,000 population for men 26.2 per 100,000 population for women.

In the time period between 2005 and 2015, the age-standardised incidence rate of bowel cancer in Scotland decreased in both men and women (by 14.4% and 3.1% respectively). Age-standardised mortality rates also decreased in men by 9.4% and in women by 2.1%. Standardised incidence and mortality rates over rolling 3 year periods for bowel cancer for NHSGGC and Scotland are illustrated in **Figure 6.1**.

The main preventable risk factors for bowel cancer are lack of physical activity; consumption of red and processed meats and other typical elements of the "Western diet"; alcohol; and long term smoking<sup>11</sup>.

<sup>&</sup>lt;sup>8</sup> http://www.isdscotland.org/Health-Topics/Cancer/Publications/2017-10-

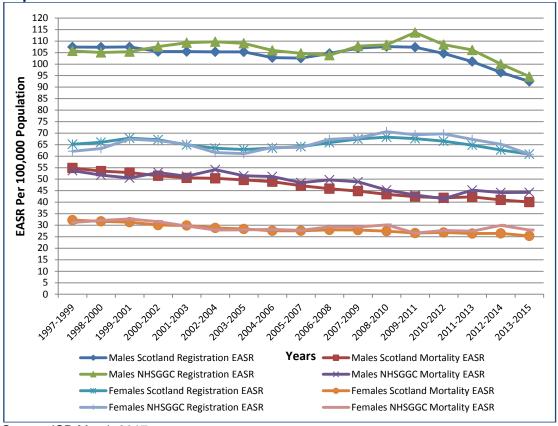
<sup>31/</sup>Cancer\_in\_Scotland\_summary\_m.pdf (accessed January 2018)

http://www.isdscotland.org/Health-topics/Cancer/Bowel-Screening/ (accessed January 2018) http://www.isdscotland.scot.nhs.uk/Health-Topics/Cancer/Publications/2017-04-

<sup>25/</sup>i cancer colorectal.xls (accessed January 2018)

https://www.isdscotland.org/Health-Topics/Cancer/Publications/2017-04-25/2017-04-25-Cancer-Incidence-Report.pdf(accessed January 2018)

Figure 6.1: Colorectal Cancer Registration & Mortality 1997-2015 (Rolling 3 Years) European Age Standardised Rate (EASR) Per 100,000 Population.



Source: ISD March 2017

#### 6.2. Aim of the Screening Programme

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

The purpose of bowel screening 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.

The national bowel screening programme performance and quality is monitored via defined Key Performance Indicators (KPI's)<sup>12</sup> and National Bowel Screening Standards<sup>13</sup>.

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http://isdscotland.org/Health-Topics/Cancer/Bowel-Screening/ (accessed January 2018)
http://www.healthcareimprovementscotland.org/our\_work/cancer\_care\_improvement/programme\_resources/bowel\_screening\_standards.aspx(accessed January 2018)

## 6.3. Eligible Population

The programme invites all men and women between the ages of 50-74 years of age 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. Individuals may request screening above the age of 74.

#### 6.4. The Screening Test and Pathway

Guaiac Faecal Occult Blood test (gFOBt) testing kit is completed at home and returned to the National Bowel Screening Centre in Dundee for analysis. A new test, the quantitative Faecal Immunochemical Test (FIT), will be introduced in November 2017 throughout Scotland. This test is recommended as the first choice for population-wide colorectal cancer screening by the European Guidelines for Quality Assurance in Colorectal Cancer Screening<sup>14</sup>.

FIT is easier to do, requiring only one sample (rather than the three for gFOBt) and is more accurate. Greater accuracy means that it is better at detecting cancers and also better at determining patients who are unlikely to have cancer.

The National Bowel Screening Centre in Dundee issues invitation letters and screening kits to all eligible residents of NHSGGC 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 a telephone assessment and be offered a colonoscopy. Patients who are unable to undergo colonoscopy will be offered a CT colonography. If required, patients are then referred for further diagnostic investigations and treatment. **Figure 6.2** provides an overview of the bowel screening pathway.

<sup>&</sup>lt;sup>14</sup> https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4482205/ (accessed January 2018)

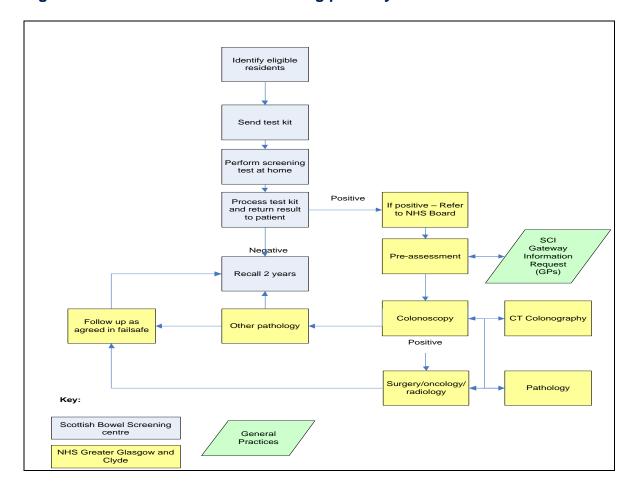


Figure 6.2 Overview of bowel screening pathway

If a patient refuses or does not turn up for colonoscopy, a letter is sent to the patient and their GP, asking them to get in touch within 6 months if they change their minds. Otherwise they will be removed from the waiting list. The Bowel Screening Centre is also informed so that the patient is invited to take part in bowel screening in two years' time.

#### 6.5. Programme Performance and Delivery

The bowel screening programme KPI's cover information on uptake of screening (completed kits), results of screening, quality of colonoscopy and cancer diagnosis and staging. The KPIs are reported for a two year (screening) period. Appendix 6.1 summarises NHSGGC activity performance against KPIs for the time period 1st November 2014 and 31st October 2016.

**Figure 6.3** summarises bowel screening activity between April 2015 and March 2017. During this time period, 355,285 NHSGGC residents were invited for bowel screening. Just under half (48.6%) of those invited returned the screening test, of which 4,027 tested positive (2.3%). Of those individuals who had a positive result, 3,369 (84%) accepted pre-assessment and three quarters (75%) had a colonoscopy. Subsequently, 170 cancers and 1,225 adenomas were detected.

SCREENING & PRE-ASSESSMENT Number Invited 355,285 182,642 Completed FOBt 172,643 (Uptake 48.6%) Negative 168,616 Positive 4.027 (Positivity rate 2.3%) Pre-assessment not Pre-assessment offered **INVESTIGATION & DIAGNOSIS** Pre-assessment completed Colonoscopy Colonoscopy not 3,369 refused 177 offered Colonoscopy offered

Colonoscopy performed 3,020

Further

Figure 6.3 Movement of eligible NHSGGC residents through bowel screening pathway (1 April 2015 to 31 March 2017)

Source: Bowel Screening IT system (May 2017)

Other investigation

offered 76

Incomplete colonoscopy

Further analysis was undertaken explore variations in uptake by sex, age, deprivation, ethnicity, learning disability and HSCP area.

Men were significantly less likely to return a bowel screening test than women (45.5% vs. 51.6% respectively) **(Table 6.1).** 

Colonoscopy

Complete

colonoscopy 2.905

Confirmed Cancer 170 Confirmed Adenoma 1,225

Table 6.1 Uptake of bowel screening by sex in NHSGGC, 2015-17

Sex	Not Screened	Screened	Total	% Screened
Male	95,585	79,956	175,541	45.5
Female	87,057	92,687	179,744	51.6
Total	182,642	172,643	355,285	48.6

Chi-Square Tests p < 0.0001

Source: Bowel Screening IT system (May 2017)

There was progressively greater uptake of bowel screening with increasing age **(Table 6.2).** Uptake was lowest among those who were first invited for screening (aged 50-52 years), at 38.9% and increased to 58.2% between 65 and 74 years. However, no age group achieved the minimum uptake target of 60%.

Table 6.2 Uptake of bowel screening by age in NHGGC, 2015-17

Age Group	Not Screened	Screened	Total	% Screened
50-54	67,651	4,4846	112,497	39.9
(50-52)	(46,355)	(29,512)	(7,586)	(38.9)
55-59	43,802	3,8815	82,617	47.0
60-64	26,251	27,015	53,266	50.7
65-69	29,392	40,855	70,247	58.2
70-74	15,546	21,112	36,658	57.6
Total	182,642	172,643	355,285	48.6

Chi-Square Tests Linear-by-Linear Association p < 0.0001

Source: Bowel Screening IT system (May 2017)

The difference in uptake between men and women was greatest at younger ages and much smaller at older ages (Table 6.7).

There was a consistent pattern that uptake of bowel screening programme increased with decreasing levels of deprivation (**Table 6.3**). It was lowest in people living in the most deprived Board areas (39.5%) and highest in the least deprived areas (59.5%).

Table 6.3 Uptake of bowel screening by deprivation in NHSGGC, 2015-17

SIMD Quintile 2016	Not Screened	Screened	Total	% Screened
1 (Most Deprived)	74,563	48,745	123,308	39.5
2	31,725	27,441	59,166	46.4
3	23,540	23,712	47,252	50.2
4	22,524	28,265	50,789	55.7
5 (Least Deprived)	30,290	44,480	74,770	59.5
Total	182,642	172,643	355,285	48.6

Chi-Square Tests Linear-by-Linear Association p < 0.0001

Source: Bowel Screening IT system (May 2017)

Uptake of screening is lower than the target 60% in all ethnic groups in NHSGGC, but it is poorest in the non-white population **(Table 6.4).** The lowest uptake of bowel screening is among Asian and Black British people.

Table 6.4 Uptake of bowel screening by ethnicity in NHSGGC, 2015-17

	Not			%
2001 Census ethnic group	Screened	Screened	Total	Screened
White - British	149,860	148,719	298,579	49.8
White – Irish	18,191	16,155	34,346	47.0
White - any other white background	4,488	2,860	7,348	38.9
Asian or Asian British	5,640	2,433	8,073	30.1
Black or Black British	490	237	727	32.6
Other ethnic groups - Chinese	1,163	934	2,097	44.5
Other ethnic groups - any other ethnic group	2,104	996	3,100	32.1
Unclassified	706	309	1,015	30.4
Total	182,642	172,643	355,285	48.6

Source: Bowel Screening IT system (May 2017); OnoMap

Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

There are large variations in bowel screening uptake across HSCPs (**Table 6.5**). They range from 44% in Glasgow City HSCP to 59% in East Dunbartonshire HSCP. No HSCP, therefore, meets the minimum target of 60%. However, when the known effects of age, sex, deprivation and ethnicity are taken into account by standardisation, the differences in update across HSPCs are much smaller (SUR% ranging from 46% to 51%). This tells us that most of the differences in uptake across HSCP's is explained by their differences in population demographics rather than local practice.

Table 6.5 indirectly standardised uptake of bowel screening by HSCP in NHGGC, 2015-17

HSCP	Not	Screened	Total	%	SUR	SUR	SUR
	Screened			Screened	%	%	%
						LCI	UCI
East	15,591	22,103	37,694	58.6	50.9	50.3	51.6
Dunbartonshire							
East	13,214	17,271	30,485	56.7	49.2	48.4	49.9
Renfrewshire							
Glasgow City	96,456	74,396	170,852	43.5	46.9	46.5	47.2
Glasgow North	30,313	22,154	52,467	42.2	47.3	46.6	47.9
<b>East Sector</b>							
<b>Glasgow North</b>	29,714	23,608	53,322	44.3	46.0	45.4	46.6
West Sector							
<b>Glasgow South</b>	36,429	28,634	65,063	44.0	47.3	46.7	47.8
Sector							
Inverclyde	13,852	13,932	27,784	50.1	50.1	49.3	50.9
Renfrewshire	27,928	29,984	57,912	51.8	49.6	49.0	50.1
West	15,601	14,957	30,558	48.9	50.3	49.5	51.1
Dunbartonshire							
Total	182,642	172,643	355,285	48.6			

Source: Bowel Screening IT system (May 2017)

People who were registered with a learning disability had poorer uptake of bowel screening **(Table 6.6).** It was 29.6% compared to 48.7% in the rest of the population.

Table 6.6 Uptake of bowel screening by learning disability in NHGGC, 2015-17

Learning Disability	Not Screen		Total	% Screened
	Screened			
Rest of population	181,159	172,020	353,179	48.7
Registered with a LD	1,483	623	2,106	29.6
Total	182,642	172,643	355,285	48.6

Chi-Square Tests p < 0.0001

Source: Bowel Screening IT system (May 2017) Learning Disability Register (September 2017)

#### 6.6. Screening Test Positivity

Overall, about 2.3% (4,027 of 172,643) of completed screening test came back positive, meriting further investigation. Groups with higher prevalence of bowel cancer are more likely to have positive screening results. Thus, men have a higher positivity than women (2.8% vs. 2.0%, respectively); older people have higher positivity than younger people (3.1% aged 70-74 vs. 1.8%).

aged 50-54); and those living in our most deprived communities have higher positivity than the least deprived (3.3% vs. 1.4%, respectively) **(Tables 6.7 and 6.8).** 

Table 6.7 Uptake for Bowel screening and positivity rate by age and sex for NHGGC, 2015-17

Candan		Age Group							
Gender	50-54	55-59	60-64	65-69	70-74	All			
Male Uptake (%)	36.0	43.9	48.0	56.2	56.7	45.5			
Female Uptake (%)	43.8	50.1	53.4	60.0	58.4	51.6			
Total Uptake (%)	39.9	47.0	50.7	58.2	57.6	48.6			
Male Positivity (%)	2.1	2.5	2.9	3.2	3.6	2.8			
Female Positivity (%)	1.5	1.8	1.9	2.2	2.7	2.0			
Total Positivity (%)	1.8	2.1	2.4	2.7	3.1	2.3			

Chi-Square Tests Linear-by-Linear Association p < 0.0001;

Source: Bowel Screening IT system (May 2017)

Table 6.8 Bowel screening positivity rate by deprivation for NHS Greater Glasgow and Clyde, 2015-17

SIMD Quintile 2016	Negative	Positive	Total	% Screened
1 (Most Deprived)	47,145	1,600	48,745	3.3
2	26,704	737	27,441	2.7
3	23,183	529	23,712	2.2
4	27,743	522	28,265	1.8
5 (Least Deprived)	43,841	639	44,480	1.4
Total	168,616	4,027	172,643	2.3

Chi-Square Tests Linear-by-Linear Association p < 0.0001

Source: Bowel Screening IT system (May 2017)

There was no significant difference in positivity between people registered with a learning disability and the rest of the population **(Table 6.9).** 

Table 6.9 Bowel screening positivity rates by learning disability for NHSGGC, 2015-17

Learning Disability	Negative	Positive	Total	% Positive
Registered	603	20	623	2.3
Rest of population	168,013	4,007	172,020	3.2
Total	168,616	4,027	172,643	2.3

Chi-Square Tests p = 0.143

Source: Bowel Screening IT system (May 2017); Learning Disability Register (September 2017)

# 6.7. Adenoma and Polyp Detection

Of the 4,027 people who had a positive screening test, 3,096 people underwent a colonoscopy (3,020 people) or other investigation (76 people). Of these 3,096 investigations, 1,225 people had a confirmed adenoma detected and a further 170 people had a confirmed colorectal cancer diagnosis.

**Table 6.10** shows the proportion of polyps identified at colonoscopy and the adenoma pathology diagnosis. 59.6% of men and 39.6% of women who underwent colonoscopies had polyps. Adenomas were diagnosed in 48.9% of men and 30.5% of women.

Table 6.10 Adenoma and polyp detection rate by gender and HSCP in NHS GGC, 2015-17

Age Group	Patients having investigations* performed			% Polyps Detected			% Adenomas Detected		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
50-54	318	300	618	53.8	30.7	42.6	44.0	22.3	33.5
55-59	352	283	635	56.3	32.5	45.7	42.0	25.4	34.6
60-64	265	196	461	59.2	39.8	51.0	50.9	34.2	43.8
65-69	459	375	834	63.2	45.3	55.2	52.7	33.9	44.2
70-74	251	221	472	65.3	50.7	58.5	55.8	39.4	48.1
Total	1645	1375	3020	59.6	39.6	50.5	48.9	30.5	40.6

Source: Bowel Screening IT system (Data extracted: May 2017)

**Table 6.11** shows the numbers of all detected colorectal cancers diagnosed by Dukes staging during 2015 to 2016. Patients whose bowel cancers are detected through screening are three times more likely to be diagnosed with earliest stage cancers and half as likely to have widespread, metastatic cancer when diagnosed compared to those who have symptoms. In 2016, 426

<sup>\*</sup> Colonoscopy or other investigation

people were diagnosed with bowel cancer, of which 120 (28.2%) were screen detected.

6.11 Dukes' stage and mode of detection of colorectal cancel for NHSGGC, 2015 - 2016

Detection				DUKES	STAGE			
Mode	99	Α	В	C1	C2	D	Total	%
			Year 2	2015				
Interval	9	16	24	18	≤5	23	94	24.1
Post Colonoscopy	0	0	0	0	0	0	0	0.0
Screen	≤5	31	22	20	≤5	10	90	23.1
Symptomatic	37	22	53	45	≤5	44	206	52.8
Total	47	69	99	83	15	77	390	
			Year 2	2016				
Interval	7	14	24	21	≤5	21	88	20.7
Post Colonoscopy	0	≤5	≤5	≤5	0	0	≤5	0.7
Screen	12	43	27	33	≤5	≤5	120	28.2
Symptomatic	55	23	49	29	7	52	215	50.5
Total	74	81	101	84	11	75	426	

Source: NHSGGC Bowel Screening Application & Cancer Audit, September 2017 Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

## 6.8. Quality Improvement in Colonoscopy

The Public Health Screening Unit leads a programme of audit of bowel screening. It has been focused on the quality of colonoscopy services but may in the future extend to other parts of the screening pathway. A multi-disciplinary group reviews the performance of all individuals who carry out colonoscopy as part of screening. Three main measures are recorded: adenoma detection rate; completion rate; and complication rate. At the time of writing, a set of minimum standards and expected responses is being drafted. This will be distributed for consultation and Board-wide agreement. It will stipulate, for example, that where an individual's performance falls below a set standard, all cases will be reviewed with the sector clinical lead.

New NHSGGC guidelines on the management of polyps are being drafted. A pre-guideline survey of polyp management will be conducted and repeated after the guidelines have been implemented to measure their impact.

## 6.9. Challenges and Future Priorities

- To implement new "teaser" letter in NHSGGC (although not nationally).
   We expect that both of these changes will increase uptake by about 5% and that a similar benefit will be found in groups who have historically had lower uptake, such as men and those from more deprived areas.
- To continue to review uptake for men registered with a learning disability and for men registered with a severe and enduring mental illness, and work with specialist learning disability and mental health staff to develop approaches to support participation in bowel screening.
- To continue to work in partnership with CRUK to support GP practices to sustain good practice to support eligible patients to participate in bowel screening programme.

# Appendix 6.1

# **Key Performance Indicators: May 2017 data submission**

KPI	Key Performance Indicator Description	Target	Scotland %	NHSGCC %			
	Screening Uptake						
1.	Overall uptake of screening - percentage of people with a final outright screening test result, out of those invited.	60%	56.4%	51.9%			
2.			43.4% Quintile 1	40.1% Quintile 1			
	Overall uptake of screening by deprivation category *- percentage of people with a final outright screening test result		51.5% Quintile 2	46.4% Quintile 2			
	for which a valid postcode is available,  *by Scottish Index of Multiple Deprivation (SIMD) quintile 1 (most	60%	57.9% Quintile 3	51.0% Quintile 3			
	deprived) to quintile 5 (least deprived)		62.3% Quintile 4	55.9% Quintile 4			
			65.7% Quintile 5	59.9% Quintile 5			
3.	Percentage of people with a positive test result, out of those with a final outright screening test result.	N/A	2.05%	2.36%			
	Referral, clinical intervention and outcomes	5					
4.	Percentage of people where the time between the screening						
	test referral date  0 to 4 weeks >4 to 8 weeks > 8 weeks	N/A	52.0% 36.8% 11.2%	37.1% 50.9% 12.0%			
5.	Percentage of people with a positive screening test result going on to have a colonoscopy performed.	N/A	77.7%	74.6%			
6.	Percentage of people having a completed colonoscopy, out of those who had a colonoscopy performed.	90%	95.2%	96.6%			
7.	Percentage of people requiring admission for complications arising directly from the colonoscopy, out of those who had a colonoscopy performed.	N/A	0.51%	0.35%			
8.	Percentage of people with colorectal cancer, out of those with a final outright screening test result.	N/A	0.104%	0.107%			
9-14.	Percentage of people with colorectal cancer staged as  9. Dukes' A.  10. Dukes' B.  11. Dukes' C1.  12. Dukes' C2.  13. Dukes' D.  14. Dukes' Not known.	N/A	35.7% 25.7% 23.2% 2.4% 5.7% 3.7%	34.8% 21.7% 24.4% 3.9% 5.8% 9.2%			

			1	
15 –	Percentage of people with colorectal cancer	_		
16.	15. Where the stage has not yet been supplied.	N/A	2.4%	1.4%
	16. That has a recorded stage		97.6%	98.6%
17.	Percentage of people with polyp cancer out of those with a final	N/A	0.021%	0.015%
	outright screening test result.	•		
18.	Percentage of people with polyp cancer, out of those with colorectal cancer.	N/A	20.3%	13.5%
19.	Percentage of people with adenoma as the most serious			
	diagnosis, out of those with a final outright screening test result.	N/A	0.593%	0.670%
20.	Percentage of people with high risk adenoma as the most			
	serious diagnosis, out of those with a final outright screening test result.	N/A	0.080%	0.091%
21.	Percentage of people with a colorectal cancer, out of those with	N/A	6.5%	6.1%
	a positive screening test result and a colonoscopy performed.	,		
22.	Percentage of people with adenoma, out of those with a	N/A	37.1%	38.1%
	positive screening test result and a colonoscopy performed.			
23.	Percentage of people with high risk adenoma, out of those		5.0%	5.2%
	with a positive screening test result and a colonoscopy performed.	N/A	3.070	3.270
24.	Percentage of people with high risk adenoma or a colorectal		11 50/	11 20/
	cancer, out of those with a positive screening test result and a colonoscopy performed.	N/A	11.5%	11.3%
25.	Percentage of people with a malignant outcome or adenoma,			
	out of those with a positive screening test result and a	N/A	43.6%	44.2%
	colonoscopy performed.			
26.	Percentage of people with a colorectal cancer that is a			
	malignant neoplasm of the:		66.5%	63.8%
	colon (ICD-10 C18)	N/A	2.9%	0.5%
	rectosigmoid junction (ICD-10 C19)		30.4%	0.5% 35.7%
	rectum (ICD-10 C20)		30.470	33.1/0

# **Appendix 6.2**

#### **Members of Bowel Screening Steering Group (as at March 2017)**

Dr David Morrison Consultant in Public Health Medicine, Chair

Ms Fiona Aitken Endoscopy W/L Coordinator
Mrs Margaret Anderson Lead Nurse - Endoscopy
Dr Stuart Ballantyne Lead Clinician for Radiology

Mr Paul Burton Information Manager

Mrs Lin Calderwood H&IT Service Delivery Manager

Mrs Lisa Cohen
Ms Ailsa Connelly
Dr Fraser Duthie
Dr Patrick Finn

CRUK Project Facilitator
Lead Nurse, New VIC
Lead Clinician for Pathology
Consultant Surgeon, RAH

Ms Ailsa Forsyth Lead Nurse, GGH

Ms Irene Fyfe Health Records Manager

Mrs Elaine Garman Public Health Specialist, NHS Highland

Ms Alyson Goodwin
Ms Alana Laing
Lead Nurse, QEUH
CRUK Project Facilitator

Miss Denise Lyden Project Officer

Ms Natalie Marshall Clinical Services Manager, North Sector Dr David Mansouri Clinical Lecturer, Glasgow University

Mrs Susan McFadyen Interim General Manager
Mrs Tricia McKenna Colorectal Nurse Endoscopist

Ms Gill Mitan Administration Manager, North Sector

Dr Jude Morris Consultant Physician and Gastroenterologist

Ms Eileen Murray Staff Nurse, New VIC

Dr Kenneth O'Neill Clinical Director, South Sector CHP

Ms Lorna Reid Lead Nurse, RAH

Mrs Rebecca Reid Clinical Services Manager, RAH
Mrs Elizabeth Rennie Programme Manager, Screening Dept

Dr Andrew Renwick Consultant, RAH

Ms Ann Traquair-Smith Clinical Services Manager, QEUH Dr Jack Winter Lead Clinician for Endoscopy (North)

# **Chapter 7 - Breast Screening Programme**

# **Summary**

- During 2015/16, the Scottish Breast Screening Programme implemented a new Scottish Breast Screening System (SBSS) IT system. At the time of this report, data reporting was not possible from the SBSS system; therefore it was not possible to access any nationally validated annual statistics relating to breast screening uptake and outcomes. It is envisaged that reporting functionality will be in place in early 2018.
- Breast cancer is the most common cancer in women in Scotland, accounting for 29.1% of all new cancers diagnosed in women.
- In 2015, 1,059 new breast cancers were registered among women residing in NHSGGC. In the same year, 200 women with a diagnosis of breast cancer died.
- In the time period between 2005 and 2015, the age-standardised incidence rate of breast cancer in Scotland increased by 9.5%, however age-standardised mortality rate decreased by 10.2%.
- 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.
- Women aged 50-70 years are invited for a routine screen once every three years. Women aged over 70 years are screened on request.

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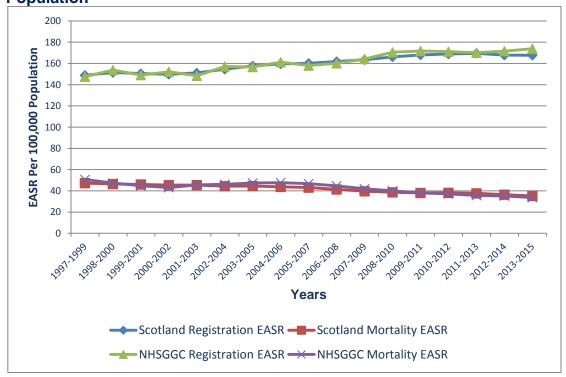
### 7.1. Background

Breast cancer is the most common cancer in women in Scotland, accounting for 29.1% of all new cancers diagnosed in women 15.

In 2015, the most recent year for which completed data are available, 1,059 new breast cancers were registered among women residing in NHSGGC. This gives a standardised incidence rate of 184.5 per 100,000 per population, greater than the Scotland rate of 168.8 per 100,000. In the same year, 200 women with a diagnosis of breast cancer died, giving a standardised mortality rate of 34.5 per 100,000 population, comparable with the Scotland rate of 34.7 per 100,000.

In the time period between 2005 and 2015, the age-standardised incidence rate of breast cancer in Scotland increased by 9.5%, however age-standardised mortality rate decreased by 10.2%. The increase in incidence of breast cancer is partly due to increased detection by the Scottish Breast Screening Programme and to changes in the prevalence of known risk factors, such as mother's age at birth of first child, increases in obesity and alcohol consumption. Standardised incidence and mortality rates over rolling 3 year periods for breast cancer for NHSGGC and Scotland are illustrated in **Figure 7.1**.

Figure 7.1 Breast Cancer Registration (Incidence) & Mortality 1997-2015 (Rolling 3 Years) European Age Standardised Rate (EASR) Per 100,000 Population



Source: ISD March 2017

http://www.isdscotland.org/Health-Topics/Cancer/Publications/2017-10-31/Cancer\_in\_Scotland\_summary\_m.pdf (accessed January 2018)

### 7.2. Aim of Screening Programme

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.

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.

### 7.3. 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.

### 7.4. The Screening Test and Pathway

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).

The West of Scotland Breast Screening Centre screens NHSGGC residents either in the static centre in Glasgow or in mobile units that visit preestablished sites across the NHSGGC area.

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 (care homes, prisons, and mental health hospitals) 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.

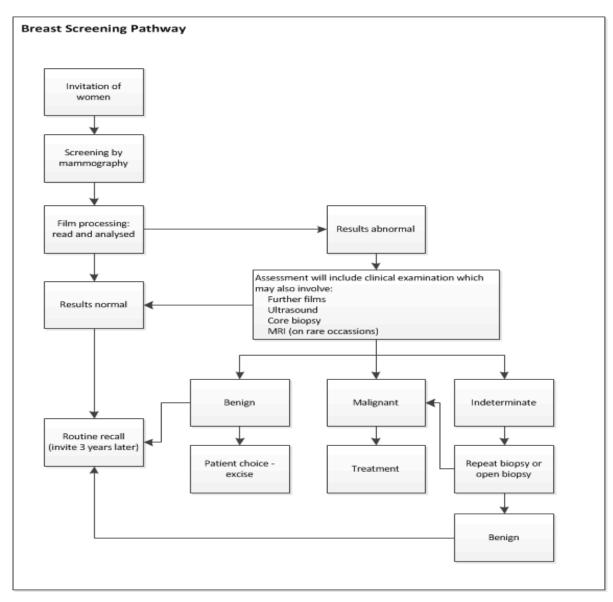
If a woman is found to have cancer, she is referred to a consultant surgeon to discuss the options available to her. This usually involves surgery: a lumpectomy where just the lump and a small amount of surrounding tissue is removed or a mastectomy where the whole breast is removed. Surgery is

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.

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 QEUH, New Victoria Hospital, New Stobhill Hospital and Royal Alexandra Hospital and a small proportion of women with palpable tumours are referred for treatment to local breast teams. **Figure 7.1** illustrates the breast screening pathway.

Figure 7.1 Breast screening Pathway



### 7.5. Delivery of Breast Screening Programme

During 2015/16, the Scottish Breast Screening Programme implemented a new Scottish Breast Screening System (SBSS) IT system. At the time of this report, data reporting was not possible from the SBSS system; therefore it was possible to access any nationally validated annual statistics relating to breast screening uptake and outcomes. It is envisaged that reporting functionality will be in place in early 2018.

### 7.6. Challenges and Future Priorities

- To implement recommendations made from Health Improvement Scotland review of breast screening.
- More effective ways of organising screening will be explored in 2018. In particular, we will explore screening clusters of congruent GP practices at a time rather than each practice on its own.
- Location of mobile units will be explored to optimise accessibility and uptake.

### **Appendix 7.1**

# Members of Breast Screening Steering Group (As at March 2017)

Dr David Morrison Consultant in Public Health Medicine (Chair)

Mr Paul Burton Information Manager

Mrs Lin Calderwood H&IT Service Delivery Manager – Screening

Dr Emilia Crighton Health of Health Services Section

Dr Marie-Louise Davies Consultant Radiologist

Mrs Elaine Garman Public Health Specialist, NHS Highland

Dr Aileen Holliday Health Effectiveness Coordinator, Forth Valley

Ms Marion Inglis Administration Manager
Ms Alana Laing CRUK Project Facilitator

Miss Denise Lyden Project Officer, Public Health - Health Services

Ms Aileen McLennan Director, Diagnostics

Dr Rosemary Millar Acting Consultant in Public Health, NHS

Lanarkshire

Ms Ann Mumby

Superintendent Radiographer

Ms Elaine Murray

Community Liaison Officer

Dr Tasmin Sommerfield Consultant in Public Health, NHS Lanarkshire

# **Chapter 8 - Cervical Screening**

# Summary

- Cervical cancer was the tenth most common cancer in females in 2015 in Scotland and most common cancer in women under the age of 35 years. In 2015, 79 new cervical cancers were registered among NHSGGC residents. In the same year, 22 women with a diagnosis of cervical cancer died.
- In the time period between 2005 and 2015, the age-standardised incidence rate of cervical cancer in Scotland increased by 2.7%, however age-standardised mortality rate decreased by 0.8%.
- 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.
- Women aged 25-49 are offered screening every three years and women aged 50-64 are offered screening every five years. Women who were already enrolled in the screening programme aged less than 25 will continue to be screened every three years until they are 50.
- The percentage of eligible women (aged 25 to 64) who were recorded as screened adequately within the specified period was 72.6% against a target of 80%.
- Uptake was higher in areas of lower deprivation. Uptake for women aged 25 to 64 in the least deprived areas was 77.7% compared with 69.9% in the most deprived areas, however there is not a clear trend across socioeconomic groups.
- Cervical screening uptake is highest in HPV vaccinated women across ages 21-25 when compared to non-vaccinated women.
- Uptake is poorest women aged between 25-29, residents with learning disabilities and in ethnic minorities. There are also lower uptake rates in some HSCPs that are not wholly explained by socio-economic deprivation.
- Due to changes in GMS contract from 2016, there may potential impact on uptake of cervical screening
- The Queen Elizabeth University Hospital processes all smear test specimens for NHSGGC and in 2016-17 processed 103,788 cervical screening tests. Of all tests processed, 97.0% were of satisfactory quality i.e. there were enough cells in the sample.
- Of the satisfactory quality tests 89.9% had a negative (normal) result, 7.5% had a low grade cell change and the remaining 1.0% had high grade cell

changes.

- The business case for an alternative approach to cervical screening high risk HPV has been approved by the Scottish Government and the new approach introduced later in 2017. High risk HPV screening involves the same clinical examination (a cervical smear) but only women whose virology results are positive for specific types of Human Papilloma Virus will have cervical cytology results tested.
- NHSGGC has carried out a multi-disciplinary review of all invasive cervical cancer cases since 2006 to audit the screening and management of every case.
- In 2016, 48% of all invasive cervical cancers in NHSGGC were detected through screening.

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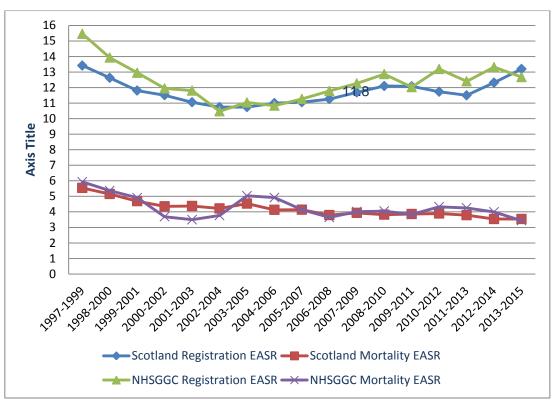
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### 8.1. Background

Cervical cancer was the tenth most common cancer in females in 2015 in Scotland and most common cancer in women under the age of 35 years <sup>16</sup>. In 2015, the most recent year for which completed data is available <sup>17</sup>, 79 new cervical cancers were registered among NHSGGC residents. This gives an age-standardised incidence rate of 13.4 per 100,000 population, comparable to the Scotland rate of 13.8 per 100,000. In the same year, 22 women with a diagnosis of cervical cancer died, giving a standardised mortality rate of 3.8 per 100,000 population lower than the Scotland rate of 4.1 per 100,000.

In the time period between 2005 and 2015, the age-standardised incidence rate of cervical cancer in Scotland increased by 2.7%, however age-standardised mortality rate decreased by 0.8%. Standardised incidence and mortality rates over rolling 3 year periods for cervical cancer for NHSGGC and Scotland are illustrated in **Figure 8.1**.

Figure 8.1 Cervical Cancer Registration & Mortality 1997-2015 (Rolling 3 Years) European Age Standardised Rate (EASR) Per 100,000 Population



Source: ISD March 2017

<sup>&</sup>lt;sup>16</sup> http://www.isdscotland.org/Health-Topics/Cancer/Publications/2017-10-31/Cancer\_in\_Scotland\_summary\_m.pdf (access January 2018)

<sup>&</sup>lt;sup>17</sup><u>http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Female-Genital-Organ/#cervix</u> (accessed January 2018)

#### 8.2. Risk Factors

Most cervical cancers are caused by oncogenic types of human papilloma virus (HPV), mainly types 16 and 18. While the majority of women clear the HPV virus, a minority have persistent HPV infection which can transform normal cervical cells into abnormal ones. These changes can occur over a period of 10 to 20 years through precancerous lesions to invasive cancer and death.

Other risk factors for cervical cancer include factors which increase exposure to the virus (such as having a high number of sexual partners), factors that factors that make your body more vulnerable to infection or affect immune response (including HIV) and smoking.

### 8.3. Aim of Screening Programme and Eligible Population

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.

Women who live in the Greater Glasgow and Clyde area and who have a cervix are invited for screening. Until June 2016, women aged 20 to 60 were invited every three years. From June 6<sup>th</sup> 2016, a Change in Age Range and Frequency (CARAF) was made to reflect new evidence about the effectiveness of screening. The CARAF means that women aged 25-49 are offered screening every three years and women aged 50-64 are offered screening every five years. Women aged less than 25 who were already enrolled in the screening programme will continue to be screened every three years until they are 50.

#### 8.4. Programme Monitoring

The national cervical screening programme delivery and quality is monitored against key programme statistics<sup>18</sup> and National Cervical Screening Standards<sup>19</sup>. Information Services Division plan to carry out a consultation during 2017 on the Scottish Cervical Screening Programme statistics.

<sup>19</sup>http://www.healthcareimprovementscotland.org/previous resources/standards/cervical screening.aspx (accessed January 2018)

https://www.isdscotland.org/Health-Topics/Cancer/Publications/2017-09-05/2017-09-05-Cervical-Screening-Report.pdf (accessed January 2018)

The uptake of cervical screening is monitored using two different methods to define the eligible population:

- i) National and Health Board level uptake: this method identifies all women in the Health Board area in the eligible age groups minus those who have no cervix (for example, following a total or radical hysterectomy).
- ii) General Medical Services (GMS) uptake: this method is used to calculate payments to GP Practices, and includes several other exclusions such as repeated non-attendance ("patients who have been recorded as refusing to attend review who have been invited on at least three occasions during the preceding 12 months").

### 8.5. The Screening Test and Pathway

A "smear test" involves collecting cells from the surface of the cervix or 'neck of the womb'.

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 screened automatically and if there is evidence of any abnormality, examined under a microscope by a cytologist.

**Figure 8.2** illustrates the pathway for the cervical screening programme. Following the invitation being issued, a woman will make an appointment to 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 three years (normal result, aged 25-49) or five years (normal results, aged 50-64), six 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 8.1**). Treatment of invasive cervical cancers follows agreed cancer treatment pathways.

**Cervical Screening Pathway** Screened by Results Liquid Based Repeat smear Unsatisfactory Cytology (LBC Results 6 month re-call Borderline Results Abnormal Treatment if cancer Results normal Colposcopy for Surgical/ assessment. Chemotherapy/ treatment and Radiotherapy/ follow-up Palliative 25-49 years old : invite in 3 years 50-64years old: invite in 5 years

Figure 8.2 Cervical screening pathway

The Scottish Cervical Call Recall System (SCCRS) provides women with a complete e-health record detailing their whole smear history which professionals involved with the screening programme access. 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.

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

#### 8.6. HPV Vaccination

Since 2008, all girls aged 11 to 13 years in their second year of secondary school are routinely offered vaccinations to protect them against the Human Papilloma Virus (HPV).

The purpose of the HPV immunisation programme is to protect girls from the two types of HPV that cause around 75% of cases of cervical cancer. The HPV vaccine does not protect against all cervical cancers, so regular cervical screening is still important.

In 2016/17, vaccination uptake amongst S1 girls in NHSGGC was 91.7% (1<sup>st</sup> dose) and 93.7% in S2 girls (1<sup>st</sup> dose). The uptake for girls in S3 is shown below in **Table 8.1**.

Table 8.1 HPV immunisation uptake rates by the end of the school year 2016/17 by NHS Board of school girls in S3

		Dose	1	Dose 2	2
NHS Board of school	Number eligible	Number immunised	% Uptake	Number immunised	% Uptake
Ayrshire & Arran	1,802	1,658	92.0	1,594	88.5
Borders	538	512	95.2	490	91.1
Dumfries & Galloway	698	659	94.4	646	92.6
Fife	1,729	1,560	90.2	1,435	83.0
Forth Valley	1,475	1,418	96.1	1,297	87.9
Grampian	2,736	2,550	93.2	2,446	89.4
<b>Greater Glasgow &amp; Clyde</b>	5,542	5,300	95.6	5,124	92.5
Highland	1,539	1,372	89.1	1,298	84.3
Lanarkshire	3,515	3,329	94.7	3,151	89.6
Lothian	3,969	3,671	92.5	3,475	87.6
Orkney	108	87	80.6	84	77.8
Shetland	114	105	92.1	105	92.1
Tayside	2,015	1,869	92.8	1,764	87.5
Western Isles	152	138	90.8	131	86.2
Scotland	25,932	24,228	93.4	23,040	88.8

Source: CHSP School/SIRS

The business case for an alternative approach to cervical screening – high risk HPV has been approved by the Scottish Government and the new approach introduced later in 2017. High risk HPV screening involves the same clinical examination (a cervical smear) but only women whose virology results are positive for specific types of HPV will have cervical cytology results tested.

#### 8.7. General Medical Services (GMS) Delivery of Cervical Screening

The GMS contract introduced in 2004 included cervical screening in the additional services domain and awarded practices for providing the service under the Quality and Outcomes Framework (QOF). Payment based on the QOF ceased at the end of March 2016

Previously, the GMS cervical screening indicator was based on the percentage of women who had a cervical smear performed in the last 5 years. Points were awarded on a sliding scale to encourage GP practices continue to maintain high levels of uptake in cervical screening. The contract allowed GP practices to exception-report (exclude) specific patients from data collected to calculate achievement scores, therefore not penalising GP practices where exception reporting occurs.

**Table 8.2** outlines the reasons and number of eligible women with a GMS exclusion from cervical screening in the 2016/17 contract year.

Table 8.2 Number and proportion of women excluded from GMS cervical screening programme by exclusion category, 2016/17

GP list size: Number of eligib	le women	340,224
Exclusion reason	Number	%
Defaulter	69,532	76.8
No Cervix	16,218	17.9
Opted Out	3,355	3.7
Pregnant	568	0.6
Not clinically appropriate	558	0.6
No Further Recall	285	0.3
Anatomically impossible	31	0.0
Co-morbidity	23	0.0
Terminally ill	6	0.0
Total	90,576	100.0
% of eligible women with exclu	sion applied	26.6

Source: SCCRS (August 2017)

During 2016/17 contract year, there were 340,224 women aged 25 to 64 years residing in NHSGGC area and registered with an NHSGGC GP practice. Of these, 26.6 % (90,576) had a GMS exclusion applied. The highest proportions of women excluded under the GMS exception reporting were classified as defaulters (76.8%), having not responded after three invitations sent.

GMS cervical screening activity is monitored quarterly, in relation to uptake, unsatisfactory smear rates and percentage of defaulters (**Table 8.3**).

Table 8.3 GMS uptake rates, unsatisfactory smear rates and percentage of defaulters 2016/17

СНР	No Cervix Uptake				GMS Contract Uptake				% Unsatisfactory				% Defaulters (of List Size)							
	Jun- 16	Sep- 16	Dec- 16	Mar- 17	Jun- 17	Jun- 16	Sep- 16	Dec- 16	Mar- 17	Jun- 17	Jun- 16	Sep- 16	Dec- 16	Mar- 17	Jun- 17	Jun- 16	Sep- 16	Dec- 16	Mar- 17	Jun- 17
East Dunbarton- shire	82.1	80.7	82.2	82.1	82.1	94.0	93.8	93.1	91.0	91.5	3.6	2.0	1.7	2.7	2.5	17.1	16.9	16.2	14.2	14.7
East Renfrew- shire	81.8	80.0	81.6	81.3	81.1	93.7	93.6	91.9	90.5	90.9	3.7	2.7	1.8	3.7	2.8	17.3	17.4	15.8	14.5	15.2
Glasgow North East	74.0	71.8	73.4	73.2	73.1	90.4	90.1	88.2	86.5	86.8	2.6	2.5	2.9	2.9	2.8	24.0	24.2	23.0	21.6	22.2
Glasgow North West	67.8	65.2	66.5	66.2	66.4	86.5	86.2	85.2	82.4	82.6	2.8	2.6	2.3	2.9	3.1	27.3	27.9	27.4	25.2	25.3
Glasgow South	74.3	72.1	74.0	73.7	73.6	90.5	90.4	88.6	86.7	86.7	3.1	2.0	2.6	2.4	2.3	23.1	23.2	21.6	20.2	20.5
Inverclyde	75.4	73.9	75.3	75.2	75.3	91.0	90.2	88.3	86.8	88.0	3.5	2.3	2.3	3.5	2.9	22.5	21.9	20.7	19.7	20.7
Other <sup>1</sup>	61.5	55.8	59.0	64.7	55.6	87.5	77.8	72.0	69.2	68.4	0.0	0.0	0.0	0.0	0	38.5	37.2	35.9	23.5	29.6
Renfrew- shire	78.5	76.7	78.2	78.3	78.4	92.2	91.7	90.4	89.2	90.1	3.1	2.5	2.6	2.5	2.8	19.4	19.0	18.0	16.9	17.8
West Dunbarton- shire	76.8	75.0	76.9	77.0	77.0	92.2	91.4	60.2	91.0	89.3	3.3	2.0	1.6	3.0	2.7	21.6	21.4	20.2	19.2	19.5
GGC	74.9	72.9	74.4	74.2	74.3	90.7	90.3	88.9	87.2	87.4	3.1	2.4	2.3	2.8	2.7	22.5	22.6	21.5	20.0	20.5

<sup>&</sup>lt;sup>1</sup> Other = Challenging Behaviour, Nursing Homes Practice, Homelessness Unit; High percentages are due to small numbers Source: SCCRS (August 2017)

### 8.8. Programme Performance and Delivery

The cervical screening programme statistics cover information on uptake of screening, results of screening, quality of laboratory and colposcopy, and cancer diagnosis. The statistics are reported for a one year period. **Appendix 8.2** provides a summary of NHSGGC activity against these statistics for the time period 1st April 2016 and 31st March 2017.

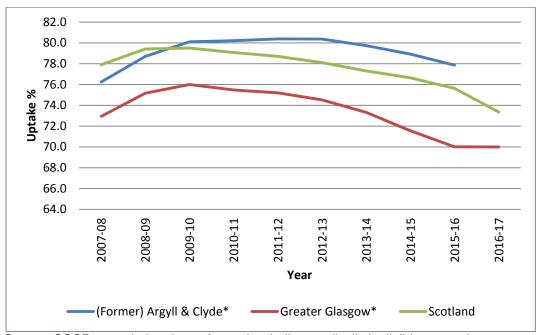
National and Health Board level uptake is based on all women in the Health Board area in the eligible age groups minus those who have no cervix (for example, following a total or radical hysterectomy).

Uptake is age-appropriate, based on being screened within the specified period (within last 3.5 or 5.5 years).

Please note that these figures have been produced from local data extract from the SCCRS system in August 2017, therefore figures may differ from those quoted in national statistics (Appendix 8.2).

There has been a decline over time in uptake of cervical screening in Scotland and NHS Greater Glasgow and Clyde, and since 2012 the overall uptake target of 80% has not been reached nationally (**Figure 8.4**).

Figure 8.4 Uptake rate of cervical screening in NHSGGC and Scotland by year (2007-2017)



Source: SCCRs population denominator (excluding medically ineligible women)

\* 2007-16 data are based on the pre-2006 Health Board configuration (former Argyll & Clyde);
Greater Glasgow figures do not include the Clyde area. 2016-17 figures NHS Greater
Glasgow now include the Clyde area.

Younger women have more than a 10% poorer uptake of cervical screening than older women (**Table 8.4**). Among women aged 25 to 29, the uptake rate was 63.8% compared to women aged over 40, whose uptake rate was 74.5%. The CARAF might lead to an improvement in overall uptake rates but no age group achieves the 80% target uptake.

Table 8.4 Uptake of cervical screening among eligible population by age for NHGGC, 2016-17 in previous 5.5 years (combined uptake)

Age Group	Not Screened	Screened	Total	% Uptake
25-29	15,728	27,717	43,445	63.8
30-34	14,145	34,850	48,995	71.1
35-39	10,859	32,016	42,875	74.7
40-44	8,616	28,143	36,759	76.6
45-49	9,210	32,467	41,677	77.9
50-54	10,056	32,410	42,466	76.3
55-59	10,377	27,777	38,154	72.8
60-64	9,696	19,939	29,635	67.3
Total	88,687	235,319	324,006	72.6

Source: SCCRS (August 2017)

Chi-Square Tests Linear-by-Linear Association p < 0.0001

Overall, uptake of cervical screening is increases with decreasing deprivation; however the target of 80% is not met in any deprivation quintile **(Table 8.5).** The lowest uptake was among women living in the most deprived areas at 69.9% compared to 77.7% among women living in the least deprived areas.

Table 8.5 Uptake of cervical screening among eligible population by SIMD for NHS Greater Glasgow and Clyde, 2016-17 in previous 5.5 years (combined uptake)

SIMD Quintile 2016	Not Screened	Screened	Total	% Uptake	
1 (Most Deprived)	35,162	81,709	11,6871	69.9	
2	14,555	39,764	54,319	73.2	
3	12,956	32,578	45,534	71.5	
4	12,285	33,455	45,740	73.1	
5 (Least Deprived)	13,729	47,813	61,542	77.7	
Total	88,687	235,319	324,006	72.6	

Source: SCCRS (August 2017)

Chi-Square Tests Linear-by-Linear Association p < 0.0001

There was a large variation in uptake across the different ethnic groups **(Table 8.6).** The highest uptake was among White – British ethnic category at 76.5%, and the lowest uptake of 38.7% was among Chinese women.

Table 8.6 Uptake of cervical screening among eligible population by ethnicity for NHS Greater Glasgow and Clyde, 2016-17 in previous 5.5 years (combined uptake)

2001 Census Ethnic	Not Screened	Screened	Total	%
Group				Screened
White – British	59,080	192,757	251,837	76.5
White – Irish	5,519	15,368	20,887	73.6
White - any other white				
background	8,190	9,596	17,786	54.0
Asian or Asian British	5,671	8,429	14,100	59.8
Black or Black British	1,010	1,359	2369	57.4
Other ethnic groups -				
Chinese	4,373	2,760	7,133	38.7
Other ethnic groups -				
any other ethnic group	2,884	3,515	6,399	54.9
Unclassified	1,960	1,535	3,495	43.9
Total	88,687	235,319	324,006	72.6

Source: SCCRS (August 2017); OnoMap<sup>20</sup>

The target for cervical screening uptake (80%) was met only in East Dunbartonshire and East Renfrewshire HSCPs. The lowest uptake rate of 63.8% was in Glasgow City HSCP North West Sector, a difference in uptake of 17.2% (Table 8.7).

However, when the known effects of deprivation and ethnicity are taken into account by standardisation (Standardised Uptake Rate – SUR), the variation in uptake across HSCPs is reduced, however a significant difference remains (9.9% difference between highest and lowest), with 76.5.% SUR in East Dunbartonshire HSCP compared to 66.8% SUR in Glasgow City HSCP – North West Sector. This tells us that there are local practices that explain the variation in addition to the population demographics.

<sup>20</sup> OnoMap is a software tool for the classification of names into groups of common cultural, **ethnic** and linguistic origins

Table 8.7 Indirectly Standardised Uptake of Cervical Screening by HSCP in NHS Greater Glasgow and Clyde, 2016-17

HSCP	Not Screened	Screened	Total	% Screened	SUR %	SUR % LCI	SUR % UCI
East Dunbartonshire	5,356	22,823	28,179	81.0	76.0	75.0	77.0
East Renfrewshire	4,721	19,440	24,161	80.5	75.9	74.8	76.9
<b>Glasgow City</b>	57,135	123,568	180,703	68.4	70.6	70.2	71.0
Glasgow North East Sector	15,202	36,343	51,545	70.5	72.6	71.8	73.3
Glasgow North West Sector	23,220	40,844	64,064	064 63.8		66.2	67.5
Glasgow South Sector	18,713	46,381	65,094	71.3	72.7	72.0	73.4
Inverclyde	5,251	1,5406	20,657	74.6	74.9	71.7	74.0
Renfrewshire	10,407	35,579	45,986	77.4	72.9	74.1	75.7
West Dunbartonshire	5,817	18,503	24,320	76.1	75.0	73.9	76.0
Total	88,687	235,319	324,006	72.6			

Source: SCCRS (August 2017); OnoMap<sup>21</sup>

Women who were registered with a learning disability had poorer uptake of cervical screening **(Table 8.8)**. It was 24.9% compared to 72.9% in the rest of the population.

Table 8.8 Uptake of cervical screening among eligible population by learning disability for NHS Greater Glasgow and Clyde 2016-17, in previous 5.5 years

Learning Disability	Not Screened	Screened	Total	% Uptake
Rest of population	87,486	234,920	322,406	72.9
Registered	1,201	399	1,600	24.9
Total	88,687	235,319	324,006	72.6

Source: SCCRS (August 2017) Chi-Square Test p < 0.0001

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### 8.9. NHSGGC Cytopathology Laboratories

**Table 8.9** provides an overview of the number of cervical screening tests processed and the results of cervical screening tests carried out at NHSGGC laboratory and across Scotland for the period 1st April 2016 to 31st March 2017. This data is sourced from nationally produced annual reports from SCCRS Laboratory Report.

The total number of smear tests processed in NHSGGC laboratory in 2016/17 was 103,788. 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.

Of the 103,788 cervical samples processed, 3,142 (3%) were reported as unsatisfactory smears. Quarterly comparative performance is fed-back to individual smear takers based on the proportion of unsatisfactory smears reported. The unsatisfactory smear rate in 2016/17 (3.0%) was similar to other years in the past decade.

Table 8.9 Cervical screening tests processed and results of cervical screening tests carried out at NHSGGC Laboratory and Scotland in Scotland: 1<sup>st</sup> April 2016 – 31<sup>st</sup> March 2017

		Result of satisfactory screens											
Laboratory	All Unsatis- screens factory		Takal	Negative	Borderline Dyskaryosis			High grade dyskaryosis	Glandular	Endocervical Adeno-	Endometrial or other		
		smears	Total N	ivegative	Change in endocervical cells	Change in squamous cells	Low grade	High grade (moderate)	High grade (severe)	invasive	abnormality	carcinoma	malignancy
Scotland	417,267	11,562		371,153	449	16,475	13,380	2,161	1,781	97	170	5	34
	·	(2.7%)	405,705	(91.5%)	(0.1%)	(4.1%)	(3.3%)	(0.5%)	(0.4%)	(0.02%)	(0.04%)	(0.00%)	(0.01%)
NHS Greater Glasgow & Clyde	103,788	3,142	100,646	90,521 (89.9%)	178 (0.2%)	4,576 (4.5%)	4,201 (4.2%)	692 (0.7%)	414 (0.4%)	18 (0.02%)	38 (0.04%)	-	8 (0.01%)

A nil result is indicated by ' - ' Source: SCCRS Laboratory Report 09A

Of the 103,788 smears tests received by the laboratories, 100,646 (97%) were satisfactory and processed. Of these 100,646 smears tests, 90,521 (89.9%) were reported to be negative.

Abnormal smears results include: borderline, mild, moderate and severe dyskaryosis, severe dyskaryosis/invasive, glandular abnormality and adenocarcinoma. In 2016/17, 10,125 (10.1%) of satisfactory smears) were reported as abnormal the same proportion as in the previous year. **Appendix 8.1** shows the management and follow up advice for cytology results.

### 8.10. Colposcopy

**Table 8.10** shows the activity data across NHSGGC Colposcopy service. In 2016/17, there were 7,123 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 8.10 NHSGGC Colposcopy service workload 1 April 2016 to 31 March 2017

	Т	ype of Episode		Total	
Attendance Status	New Outpatients	Return/ Follow Up Outpatients	Inpatients	Episodes (Types 1-3)	
Patient was Seen (Attended)	4,292	2,764	67	7,123	
Cancelled by Patient	315	436	0	751	
Cancelled by Clinic or Hospital	15	129	≤5	145	
Patient attended but was not seen (CNW)	≤5	≤5	0	9	
Patient Did Not Attend	502	772	0	1,274	

Source: National Colposcopy Clinical Audit System (Extracted December 2017)
Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

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.

#### 8.11. 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 quality of the service.

In 2016, we reviewed the notes of 56 women who developed invasive cervical cancer and had a pathology diagnosis made in NHS Greater Glasgow and Clyde laboratories.

**Table 8.11** shows numbers and the distribution of women's age at diagnosis for years 2010 to 2016. The largest number of cervical cancers occurred in women aged between 30 and 39 years.

Table 8.11 Number of NHSGGC residents with invasive cervical cancers by age at diagnosis and year of diagnosis

		Year (Diagnosis)									
A = = C = = = =	2010	2011	2012	2012	2014	2015	2016	Total			
Age Group	2010	2011	2012	2013	2014	2015	2016	Total			
20-29	10	7	12	6	9	8	16	68			
30-39	23	16	27	23	21	18	7	135			
40-49	22	10	17	17	14	16	10	106			
50-59	7	10	9	10	11	9	10	66			
60-69	≤5	7	11	≤5	6	10	8	50			
70-79	10	8	7	7	≤5	≤5	≤5	44			
80+	≤5	≤5	≤5	≤5	≤5	≤5	≤5	19			
Total	80	61	86	70	69	66	56	488			

Source: NHSGGC Invasive Cancer Audit (January 2018)

Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

**Figure 8.5** shows the distribution of cervical cancers by deprivation for the period 2010 to 2016. The highest proportion of cervical cancers occurred in women living in the most deprived (SIMD1) areas.

**Numbers Diagnosed** Year (Diagnosis) ■1 (Most Deprived) ■2 ■3 ■4 ■5 (Least Deprived)

Figure 8.5 Numbers of NHSGGC residents diagnosed with invasive cervical cancer 2010-2016.

Source: NHSGGC Invasive Cancer Audit (January 2018)

**Table 8.10** shows the distribution of clinical stage at diagnosis over a six year period from 2010 to 2016.

Table 8.11 Number of women with invasive cervical cancers by clinical stage by year of diagnosis

		Year (Diagnosis)						
Clinical Staging	2010	2011	2012	2013	2014	2015	2016	Total
Not Known	6	≤5	≤5	0	0	0	0	10
1a1 (less than 3mm deep and >=7mm wide)	21	12	20	19	14	11	19	116
1a2 (3-5mm deep and <7mm wide)	≤5	≤5	≤5	≤5	≤5	≤5	≤5	8
1b (confined to cervix)	14	14	24	19	26	21	10	128
2 or Greater (spread outwith cervix)	39	33	38	30	29	33	24	226
Total	80	61	86	70	69	66	56	488

Source: NHSGGC Invasive Cancer Audit (January 2018)

Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

**Table 8.12** shows that, in 2016, 27 of the 56 (48%) cases were screen detected. The rest of the cases presented to the service with symptoms or were incidental findings.

Table 8.12 Number of women with invasive cancers split by modality of presentation by year of diagnosis

	Year (Diagnosis)							
Presentation	2010	2011	2012	2013	2014	2015	2016	Total
Not Known	24	20	0	0	≤5	0	3	48
Incidental Finding	≤5	≤5	≤5	≤5	≤5	≤5	≤5	7
Smear detected	29	20	39	31	33	28	27	207
Symptomatic	27	21	46	38	34	36	24	226
Total	80	61	86	70	69	66	56	488

Source: NHSGGC Invasive Cancer Audit (January 2018)

Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

In 2016, 22 women of 56 (39%) women had a complete smear history compared to 29 (51%) women who had incomplete smear histories **(Table 8.13)**. Over the seven years audited, 61 (13%) women out of the 488 that developed cancer had never had a smear; 179 (37%) had complete smear histories and 244 (50%) of women had incomplete smear histories.

Table 8.13 Smear histories of women with invasive cervical cancer

		Year (Diagnosis)						
Smear History	2010	2011	2012	2013	2014	2015	2016	Total
Not Known	1	0	0	0	0	0	0	1
Adequate	25	25	34	24	28	21	22	179
Incomplete	42	22	40	36	36	39	29	244
Not Applicable	12	14	11	10	≤5	≤5	≤5	61
Not Known	0	0	≤5	0	0	≤5	≤5	≤5
Total	80	61	86	70	69	66	56	488

Source: NHSGGC Invasive Cancer Audit (January 2018)

Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

**Table 8.14** 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 8.14 Smear histories of women with invasive cervical cancer

	Year (Diagnosis)							
Smear History	2010	2011	2012	2013	2014	2015	2016	Total
Not Known	≤5	≤5	≤5	≤5	≤5	0	≤5	16
Death	7	9	11	≤5	0	≤5	0	35
Early Recall	0	0	≤5	0	0	0	≤5	≤5
Lost to colposcopy service	≤5	0	≤5	≤5	≤5	≤5	0	6
No further recall  - total hysterectomy	0	≤5	0	0	0	≤5	8	11
On follow up at colposcopy	21	8	24	18	13	11	15	110
On follow up at oncology/Beatson	47	38	46	46	52	48	29	306
Total	80	61	86	70	69	66	56	488

Source: NHSGGC Invasive Cancer Audit (January 2018)

### 8.12. Challenges and Future Priorities

- To support national public health information campaigns to increase cervical screening uptake among women in younger age groups.
- To plan for the introduction of high risk HPV testing.
- To continue monitoring of impact of changes to GMS contract on uptake of cervical screening. To continue to work in partnership with CRUK and Jo's Trust to support GP practices to sustain good practice to support eligible women to participate in cervical screening programme.
- To continue to review uptake for women registered with a learning disability and women registered with a severe and enduring mental illness, and work with specialist learning disability and mental health staff to develop approaches to support participation in cervical screening.

### **Appendix 8.1**

- i. Management and follow-up advice for cytology results
- ii. Management and follow up for cytology results: Post Total Hysterectomy <u>prior</u> local test of cure implementation
- iii. Management and follow up for cytology results: Post Total Hysterectomy <u>after</u> local test of cure implementation
- iv. Management and follow up for cytology post treatment cervical smear and HPV test (Test of Cure)

### i. Management and follow-up advice for cytology results

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

# **Appendix 8.1 (continued)**

# ii. Management and follow up for cytology results: Post Total Hysterectomy <u>prior</u> local test of cure implementation

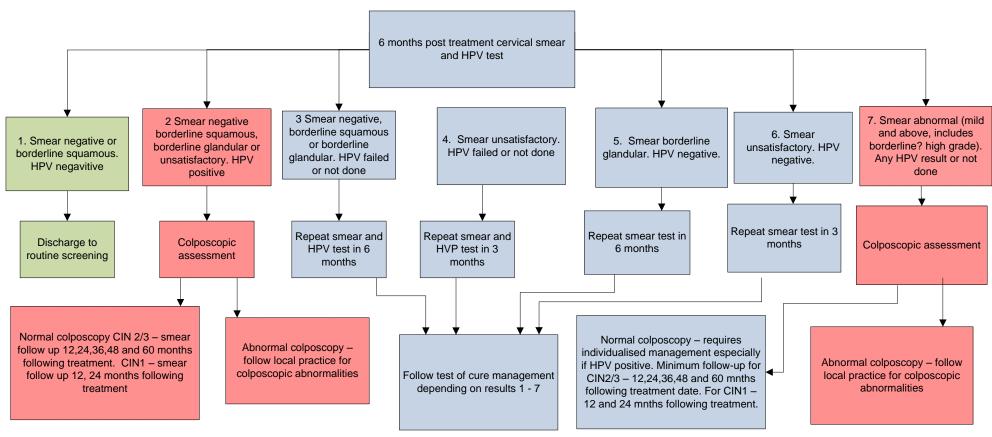
On routine recall No CIN/CGIN in hysterectomy	No further recall
On non-routine recall No CIN/CGIN in hysterectomy	No further recall
CIN/CGIN in hysterectomy	Vault smears at 6 and 18 months.
completely excised	If negative, no further recall
Low grade CIN/CGIN in	Vault smears at 6, 12 and 24 months.
hysterectomy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

# iii. Management and follow up for cytology results: Post Total Hysterectomy <u>after</u> 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.	Vault smears at 6 and 18 months.
Completely excised	If negative, no further recall
Low grade CGIN in hysterectomy	Vault smears at 6, 12 and 24
incompletely excised	months. If negative, no further recall
High grade CCIN in bystorectomy	Vault smears at 6 and 12 months,
High grade CGIN in hysterectomy incompletely excised	and then annual vault smears to 5
incompletely excised	years. If negative, no further recall

CIN = cervical intraepithelial neoplasia CGIN = cervical glandular intraepithelial neoplasia

# Appendix 8.1 (continued) iv. Management and follow up for cytology post treatment cervical smear and HPV test (Test of Cure)



# **Appendix 8.2 National Performance Standards 2016-2017**

Source: ISD Scotland <a href="http://isdscotland.org/Health-Topics/Cancer/Cervical-Screening/">http://isdscotland.org/Health-Topics/Cancer/Cervical-Screening/</a>

# Uptake for Cervical Screening; Scotland & NHSGGC 1st April 2016 to 31st March 2017

Percentage uptake of females aged 25-64. Uptake based on being screened within the specified period (within last 3.5 or 5.5 years).

Screening uptake	Standard %	Scotland %	Greater Glasgow & Clyde %			
The percentage of eligible women (aged 25 to 64) who were recorded as screened adequately	80	73.4	70.0			
Percentage uptake by deprivation quintile						
SIMD 1 (most deprived)		67.4	67.0			
SIMD 2		71.2	69.8			
SIMD 3	80	73.8	69.9			
SIMD 4		76.5	71.0			
SIMD 5 (least deprived)		78.3	75.4			

# Uptake for Cervical Screening by HPV vaccinated: Scotland & NHSGGC Percentage uptake of females who had a record of a previous screening test taken within last 3.5 years by 5-year age groups

	AGE				
HPV vaccination status	21	22	23	24	25
Immunised (full) <sup>1</sup>					
NHSGGC	48.5	57.7	68.7	69.3	72.2
Scotland	50.9	61.5	70.9	70.7	72.7
Immunised (incomplete) <sup>2</sup>					
NHSGGC	29.1	52.3	60.3	69.1	68.0
Scotland	35.4	54.0	68.2	66.4	70.0
Non-Immunised					
NHSGGC	17.9	24.9	33.9	31.7	34.8
Scotland	22.8	29.6	40.8	37.9	40.3

<sup>&</sup>lt;sup>1</sup>The Immunisation Status of FULL is where the individual has been Fully Immunised i.e. had all HPV doses.

<sup>&</sup>lt;sup>2</sup>Incomplete is where the individual has had at least one of the Immunisations but not all of them.

# **Appendix 8.2 (continued)**

# Cervical screening tests processed<sup>1</sup>: Scotland & NHSGGC laboratories, 1st April 2016 to 31st March 2017

Year/ quarter	Scotland	Greater Glasgow & Clyde
Q4	107,520	27,752
Q3	95,256	23,400
Q2	116,414	28,719
Q1	98,077	23,917
TOTAL	417,267	103,788

<sup>&</sup>lt;sup>1.</sup> Data includes unsatisfactory screening tests.

Laboratory Turnaround times<sup>1</sup> for 95% of all cervical screening tests processed at NHS laboratories: Scotland & NHSGGC laboratories, 1st April 2016 to 31st March 2017

Year/ quarter	Scotland	Greater Glasgow & Clyde
Q4	22	16
Q3	29	25
Q2	27	21
Q1	25	28

<sup>&</sup>lt;sup>1.</sup> The turnaround time is defined as the number of days from the date the sample was received by the laboratory to the date the report was issued by the laboratory.

Average reporting times<sup>1</sup> for cervical screening tests: Scotland & NHSGGC laboratories, 1st April 2016 to 31st March 2017 (Mean number of days by quarter)

Year/ quarter	Scotland	Greater Glasgow & Clyde
Q4	22	19
Q3	30	25
Q2	28	21
Q1	25	22

### Appendix 8.3

### Members of Cervical Screening Steering Group (As at March 2017)

Dr David Morrison Consultant in Public Health Medicine (Chair)
Ms Christine Black Consultant in Sexual and Reproductive Health

Dr Kevin Burton Consultant Gynaecologist Mr Paul Burton Information Manager

Mrs Lin Calderwood HI&T Service Delivery Manager

Mrs Pam Campbell Records Manager
Ms Mary Fingland LMC Representative

Mrs Elaine Garman Public Health Specialist, NHS Highland Mrs Fiona Gilchrist Assistant Programme Manager, Screening

Dept

Dr Robert Henderson Consultant in Public Health Medicine, Highland

Mrs Kathy Kenmuir Practice Nurse Support and Development Team Manager

Ms Alana Laing CRUK Facilitator, West of Scotland Dr Margaret Laing Staff Grade in Cytology/Colposcopy

Ms Linda McAllister Head of Health Records

Miss Denise Lyden Project Officer

Mrs Michelle McLachlan General Manager, Obstetrics Dr Abigail Oakley Consultant Pathologist

Dr Ken O'Neill Clinical Director, Glasgow City HSCP

Mrs Christine Paterson General Practice Support and Development Nurse

Mr Graham Reid Specialty Manager, Cytology

Mrs Elizabeth Rennie Programme Manager, Screening Dept

Mrs Alison Street General Practice Support and Development Nurse

Ms Stella Williamson Referral Management and Clinic Build Lead

# **Chapter 9 - Diabetic Retinopathy Screening**

### Summary

- Due to the implementation of a new national IT system, VECTOR, routine data reporting was not available at the time of this report. Therefore it has not been possible to undertake additional local analysis for DRS screening uptake and outcomes.
- National performance statistics for screening participation for the quarter 3
  period (1st April 2016 and 31st December 2016) and national supplementary
  uptake data (1st April 2016 to 31st March 2017) are provided in this report to
  provide insight to 2016/17 programme performance and delivery.
- Diabetes mellitus is a long-term condition in which the level of glucose in the blood is raised leading to abnormal fat metabolism and other complications.
   There are two main types of diabetes: type 1 and type 2.
- In Scotland, there were 291,981 people with known diabetes recorded on local diabetes registers in 2016, representing 5.4% of the population.
- In Greater Glasgow and Clyde, there were 62,874 people with known diabetes in 2016 compared to 48,602 people in 2007, an increase of 29.3%.
- Prevalence of diabetes among NHS Greater Glasgow and Clyde adult residents has gradually increased from 4.1% in 2007 to 5.5% in 2016.

Based on nationally reported supplementary programme statistics for the full year period (1<sup>st</sup> April 2016 to 31<sup>st</sup> March 2017):

- There were 66,755 people with known diabetes in NHS Greater Glasgow and Clyde. Of these, 58,097 (87.0%) were eligible for DRS screening.
- 10,171 (15.2%) people were not eligible for screening because they were either permanently or temporarily suspended from the programme.
- Of the 58,097 people with diabetes eligible for DRS screening, 39,497 (67.9%) attended screening.

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### 9.1. Background

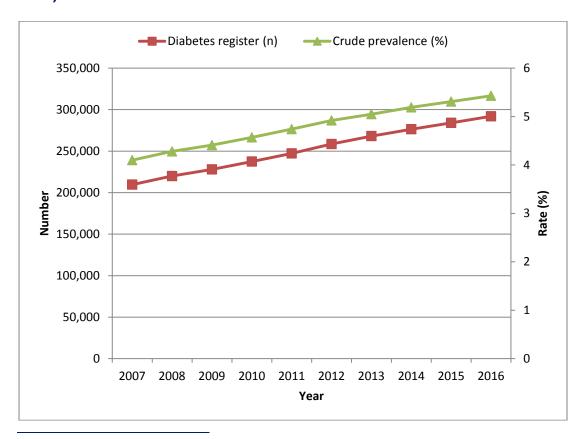
Diabetes mellitus is a long-term condition in which the level of glucose in the blood is raised leading to abnormal fat metabolism and other complications. There are two main types of diabetes: type 1 and type 2. Type 1 often develops before the age of 40 and usually during the teenage years. Type 2 is far more common than type 1, and typically affects people over the age of 40 (although increasingly younger people are affected as well). It is often associated with being overweight or obese and people of South Asian, African-Caribbean or Middle Eastern origin are more frequently affected.

In Scotland, there were 291,981 people with known diabetes recorded on local diabetes registers in 2016, representing 5.4% of the population<sup>22</sup>.

In Greater Glasgow and Clyde, there were there were 62,874 people with known diabetes in 2016, (5.5% of the population) compared to 48,602 people in 2007(4.1% of the population) <sup>23</sup> an increase of 29.3%.

Over the last decade, the crude prevalence of diabetes (all types) has increased by 1.3% (Figure 9.1).

Figure 9.1 Number of people with diabetes, crude prevalence of diabetes and changes in numbers/proportions by year. (Source: Scottish Diabetes Survey 2016)



http://www.diabetesinscotland.org.uk/Publications/Scottish%20Diabetes%20Survey%202016.pdf http://www.diabetesinscotland.org.uk/Publications/Scottish%20Diabetes%20Survey%202007.pdf

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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, treatment can prevent the progression of the disease and save sight for many years in most patients.

### 9.2. Aim of the Screening Programme and Eligible Population

The national Diabetic Retinopathy Screening Programme (DRSP) is an integral part of patients' diabetes care. 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.

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

DRS screening was implemented across NHSGGC between 2004/05. The national DRS screening programme performance and quality is monitored via defined National DRS Screening Standards<sup>24</sup> and Key Performance Indicators (KPIs)<sup>25</sup>.

### 9.3. 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.

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

- i) SOARIAN provided the call/recall, image capture, grading, quality assurance and result delivery. The SORIAN system was replaced by the VECTOR system, requiring 3 weeks service down-time during February 2017, with a go live date on 1st March 2017.
- ii) SCI-Diabetes is an essential component for effective Diabetic Retinopathy Screening. It provides the diabetes population register for diabetic retinopathy screening call/recall and the screening results where they can be viewed by clinical staff involved in the care of patients with diabetes.

-

<sup>&</sup>lt;sup>24</sup>http://www.healthcareimprovementscotland.org/our\_work/long\_term\_conditions/programme\_resour\_ces/diabetic\_retinopathy\_screening.aspx

http://www.ndrs-wp.scot.nhs.uk/?page\_id=147

### 9.4. Clinic Setting

The screening programme takes place in a variety of settings. This can either be at a hospital, health centre or clinic. Across Greater Glasgow and Clyde screening takes place at five hospital locations and 14 health centres or clinics.

The service also provides a slit lamp service from the five hospitals and two of the health centres/clinics for patients who are not suitable for retinal photography.

### 9.5. Screening Pathway

**Figure 9.2** illustrates the pathway to reduce diabetes related blindness in general population by identifying and treating sight threatening diabetic retinopathy.

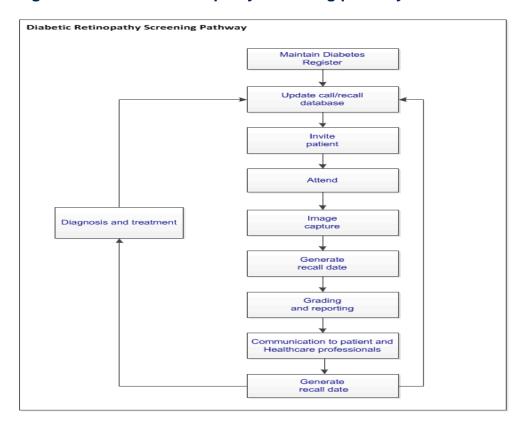


Figure 9.2 Diabetic Retinopathy screening pathway

### 9.6. Delivery of NHSGGC Diabetic Retinopathy Screening Programme

Due to the implementation of VECTOR, routine data reporting was not available for 2016/17 at the time of writing this report, therefore, it was not possible to undertake any additional local analysis.

This report uses available data produced by NSD Scotland for the year 2016/17.

The DRS screening programme KPI's cover information on uptake of screening, screening performance, outcomes of screening and Ophthalmology performance. **Appendix 9.1** summarises the most recent (Quarter 3) nationally reported KPIs for

DRS screening programme for the time period 1<sup>st</sup> April to 2016 to 31<sup>st</sup> December 2016.

The national annual screening uptake target for quarter 3 is 60%. NHSGGC achieved this target (61%) by the end of Quarter 3 2016/17.

Supplementary nationally reported data detailing DRS screening programme eligibility and uptake for full year (1<sup>st</sup> April to 2016 to 31<sup>st</sup> March 2017) provides demographic breakdown of eligible population and those successfully screened during 2016/17.

During 2016/17 contract year, there were 66,755 people with known diabetes in NHS Greater Glasgow and Clyde. Of these, 58,097 (87.0%) were eligible to for DRS screening (Table 9.1).

A total of 10,171 (15.2%) people were not eligible for screening because they were either permanently or temporarily suspended from the programme. The main reason for suspension from screening was ongoing ophthalmology care following attendance in diabetic retinopathy screening.

Table 9.1 DRS eligible population and screening uptake in NHSGGC, 2016-17 (full year)

Board of treatment	Total Population (with diabetes)	Temporarily suspended	Permanently suspended	Temporarily unavailable	Eligible* Population	Attended Screening (full year)
Greater Glasgow and Clyde	66,755	6,666	3,505	1,513	<b>58,097</b> (87.0%)	<b>39,467</b> ( <i>67.9%</i> )

Source: DRS national programme statistics 2016/17

Of the 58,097 people with diabetes eligible for screening, 39,467 (67.9%) attended screening during 2016/17. This means that 59.1% of the total population with diabetes in NHSGGC were successfully screened between 1st April 2016 and 31stMarch2017.

**Table 9.2** shows that more than half (55.3%) of the eligible population were male. Males were also slightly more likely to be successfully screened than females (68.7% vs. 67.0%).

<sup>\*</sup>Eligible Population = Total Population- Temporarily Suspended –Permanently Suspended + Temporarily Unavailable)

Table 9.2 Uptake of DRS screening by sex in NHSGGC, 2016-17

Sex	Eligible Population	% of eligible population	Attended Screening (full year)	% Attended Screening (full year)
Female	25,981	44.7	17,395	67.0
Male	32,110	55.3	22,072	68.7
Unknown	6	0.0	0	0.0
TOTAL	58,097	100.0	39,467	67.9

Source: DRS national programme statistics 2016/17

**Table 9.3** shows that half of the eligible population are aged between 55 to 74 years of age. Eligible individuals aged 65 to 74 years were most likely to attend DRS screening (73.8%) compared to other age groups.

Table 9.3 Uptake of DRS screening by age in NHSGGC, 2016-17

Age	Eligible Population	% of eligible population	Attended Screening (full year)	% Attended Screening (full year)
12 to 14	147	0.3	95	64.6
15 to 24	983	1.7	527	53.6
25 to 34	1,694	2.9	829	48.9
35 to 44	3,466	6.0	1,938	55.9
45 to 54	8,801	15.1	5,539	62.9
55 to 64	14,449	24.9	10,007	69.3
65 to 74	14,727	25.3	10,875	73.8
75 to 84	10,509	18.1	7,536	71.7
85+	3,320	5.7	2,121	63.9
TOTAL	58,096	100.0	39,467	67.9

Source: DRS national programme statistics 2016/17

Forty percent of the eligible population resided in the most deprived Board areas. There was a consistent pattern that DRS screening uptake increased with decreasing levels of deprivation **(Table 9.4).** Uptake was lowest among people residing in the most deprived areas (65.3%) and highest among those residing in the least deprived areas (72.4%).

**Table 9.4** shows that the majority of the eligible population are White British (79.9%). DRS screening uptake was also highest among this group (69.2%).

Table 9.4 Uptake of DRS screening by deprivation in NHSGGC, 2016-17

SIMD	Eligible Population	% of eligible population	Attended Screening (full year)	% Attended Screening (full year)
1 (most deprived)	23,456	40.4	15,324	65.3
2	10,410	17.9	6,974	67.0
3	6,960	12.0	4,871	70.0
4	6,439	11.1	4,582	71.2
5 (least deprived)	8,173	14.1	5,919	72.4
Unknown	2,659	4.6	1,797	67.6
TOTAL	58,097	100.0	39,467	67.9

Source: DRS national programme statistics 2016/17

**Table 9.5** shows that the majority of the eligible population are White British (79.9%). DRS screening uptake was also highest among this group (69.2%).

Table 9.5 Uptake of DRS screening by ethnicity in NHSGGC, 2016-17

Ethnicity	Eligible Population	% of eligible population	Attended Screening (full year)	% Attended Screening (full year)
White - British	46,426	79.9	32,146	69.2
White - Irish	307	0.5	204	66.4
White - any other white background	1,584	2.7	923	58.3
Asian or Asian British	4185	7.2	2,786	66.6
Black or Black British	529	0.9	328	62.0
Chinese	382	0.7	231	60.5
Other ethnic groups	663	1.1	413	62.3
Unclassified	4,021	6.9	2,436	60.6
TOTAL	58,097	100.0	39,467	67.9

Source: DRS national programme statistics 2016/17

### 9.7. 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.

### **Appendix 9.1**

### Diabetic Retinopathy Screening Service reports for Quarter 3 2016/2017

Report start date 01/04/2016 report end date 31/012/2016 Report Interval = 274 days. All data taken from Vector.

Source: DRS National statistics 2017

	HIS Target June		Board of treatment		
КРІ	2016 (where applicable)	Description	Greater Glasgow & Clyde	Scotland	
		Total Population (TP)	66,685	314,887	
		Temporarily suspended (TS)	6,765	24,587	
KPI 0: Summary		Permanently suspended (PS)	3,444	23,850	
Statistics		Temporarily unavailable (TU)	1,642	4,337	
		Eligible Population (EP = TP-TS-PS+TU)	58,088	270,787	
		Screening Uptake			
Call/Recall (HIS	Within 30 calendar days for newly diagnosed appointment offer. (HIS Standard 2.3)	2.3 The invitation to attend diabetic retinopathy screening is offered to all newly diagnosed patients within 30 calendar days of the DRS Collaborative4 receiving notification.	96.6%	95.1%	
Standards 2)	Within 90 calendar days for newly diagnosed appointment date. (HIS Standard 2.4)	2.4 The date of the appointment offered to all newly diagnosed patients is within 90 calendar days of the DRS Collaborative4 receiving notification.	100%	99.2%	
KPI 1: Screening invitation rate (HIS Standard 3)	75% for Q3 of eligible people, regardless of	People attending screening without invitation (API)	4,459	33,189	
	personal circumstances or	People invited at least once (INV)	41,743	182,910	

	characteristics are offered an opportunity to attend. (HIS Standard 3.3)	% (100 * INV / (EP - API))	77.8%	77.0%
KPI 2: Screening uptake rate	NHS boards achieve an attendance of 60% for Q3.	People attending at least once (ATT)	35,435	166,578
(HIS Standard 3)	(HIS Standard 3.1)	% (100 * ATT / EP)	61.0%	61.5%
DNA rate	Indicative DNA rate by %	% (100 * INV - ATT)	16.8%	15.5%
KPI 3: Annual successful screening rate	NHS boards achieve an uptake of 80% pa. (HIS	People successfully screened in the previous year (ANN)	45,156	209,216
(HIS Standard 3)	Standard 3.2)	% (100 * SUC1 /EP)	77.7%	77.3%
KPI 4: Successful screening rate (HIS Standard 3)	NHS boards achieve an uptake of 60% for Q3	People successfully screened in reporting period (SUC)	34,902	162,689
	(HIS Standard 3.2)	% (100 * SUC2 /EP)	60.1%	60.1%
KPI 5: Biennial successful screening rate	NHS boards achieve an uptake of 80% pa. (HIS Standard 3.2)	People successfully screened (biennial) (BIE)	51,006	235,871
(HIS Standard 3)		% (100 * BIE / EP)	87.8%	87.1%
KPI 6: Annual patient technical recall rate	As low as possible	People unsuccessfully screened (UNSUC)	879	5,191
recalitate		% (100 * UNSUC / EP)	1.5%	1.9%
KPI 7A: Annual	NHS boards achieve a	Photographic screenings (PS)	43,952	212,815
photographic technical failure rate (HIS Standard 4)	maximum rate of ungradeable images of 2.5% for digital imaging. (HIS	Unsuccessful photographic screening episodes (UPS)	928	5,648
	Standard 4.3)	% (100 * UPS/ PS)	2.1%	2.7%
	NHS boards			

technical failure rate	maximum rate of ungradeable images of 2.0% for slit lamp	Unsuccessful slit lamp screening episodes (USL)	0	255
	examinations. (HIS Standard 4.3)	% (100 * USL / SL)	0.0%	1.5%
		Slit lamp screenings + photographic screenings (SLPS)	47,650	229,837
KPI 7: Annual overall technical failure rate	As low as possible	Unsuccessful slit lamp screenings & photographic screenings (USLUPS)	928	5,903
		% (100 * USLUPS / SLPS)	1.9%	2.6%
		Screening performance		
		Longest recorded number of days to written report (LRD)	92	180
KPI 8: Duration to written report	A minimum of 95% of people screened are	Average of the number of days to written report (AD)	5	5
	sent the result within 20 working days of being screened.	Median of the number of days to written report (MD)	3	4
KPI 9: Written report success		Episodes with <= 20 working days to written report (E20D)	34,980	170,772
rate		% (100 * E20D / NE)	94.2%	97.1%
		Screening outcomes		
		Successful screening episodes (excl. ophthalmology examinations) (SSE)	35,977	170,475
KPI 10: Twelve		% (100* SSE/EP)	61.9%	63.0%
Month Recall result rate		Screening episodes (excl. ophthalmology examinations) with negative result (SEN)	34,068	162,579
		% (100 * SEN / SSE)	94.7%	95.4%

KPI 11: Six Month Recall result rate	Screening episodes (excl. ophthalmology examinations) with observable result (SEO)	579	2,644
result face	% (100 * SEO / SSE)	1.6%	1.6%
	People with last result 'observable' in the first 6 month of the interval (POR)	192	894
KPI 12: Six Month recall rescreen rate	People within POR who commenced an examination within 6 month (PC6M)	40	351
	% (100 * PC6M / POR)	20.8%	39.3%
KPI 13: Referable Result rate	Screening episodes (excl. ophthalmology examinations) with referable result (SER)	1,507	6,505
	% (100 * SER / SSE)	4.2%	3.8%
	Ophthalmology performance	e	
	Patients with an outcome of 'Refer to Ophthalmology ' in the first 6 month of the interval (RO)	491	2109
	% (100 * RO/EP)	0.8%	0.8%
	Patients within RO with a subsequent Ophthalmology examination (SOE)	312	968
KPI 14: Ophthalmology	% (100 * SOE/RO)	63.5%	45.8%
Report Interval	Longest recorded days to ophthalmology examination for the first qualifying episode (LRDOE)	173	180
	Longest recorded to Ophthalmology examination for the first qualifying episode (based on 30 days/month – months & days)	24 weeks 5 days	25 weeks 5 days

	Average of the number of days to Ophthalmology examination (ADOE)	53	56
	Patients with an outcome of 'Refer to Ophthalmology ' in the first 6 months of the interval (RO)	491	2,109
KPI 15: Ophthalmology review target	Number of these patients for whom the days to Ophthalmology examination is less than or equal to referral target (90 days) (REFT)	321	923
	% (100 * REFT / RO)	65.4%	43.8
KPI 16: Ophthalmology attendance rate	People who attended at least 1 Ophthalmology examination with a screening outcome of 'Re-screen in 12 months', 'Re-screen in 6 months' or 'Retain under Ophthalmology review' (OPHTH)	5,347	10,537
	Screening population (SP)	63,011	289,461
	% (100 * OPHTH / SP)	8.5%	3.6%
KPI 17: Ophthalmology	People temporarily suspended from screening for reason of "under the care of Ophthalmologist" (UCO)	4,923	18,674
suspensions rate	Screening population (SP)	63,011	289,461
	% (100 * UCO / SP)	7.8%	6.5%

### **Appendix 9.2**

# Members of Diabetic Retinopathy Screening Steering Group (As at 31<sup>st</sup> March 2017)

Dr David Morrison Consultant in Public Health Medicine (chair)

Mr Jim Bretherton Clinical Service Manager Mr Paul Burton Information Manager

Mrs Lin Calderwood
Mrs Fiona Gilchrist
Mrs Fiona Heggie

HI&T Screening Service Delivery Manager
Assistant Programme Manager, Screening Dept
Clinical Nurse Co-ordinator, Retinal Screening

Ms Heather Jarvie Public Health Programme Manager

Miss Denise Lyden Project Officer

Ms Gillian Kinstrie Co-ordinator for MCN for Diabetes

Mrs Chris McNeill Head of Community Health & Care, Partnerships

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