

# **Public Health Screening Programme**

Annual Report

1 April 2018 to 31 March 2019

Health Services
Public Health Directorate
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## **Section 1**

# Pregnancy & Newborn Screening

### **Chapter 1 - Pregnancy Screening**

### **Summary**

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.

Pregnancy screening programmes are offered universally to all pregnant women during antenatal visits. During 2018/19, 12,370 NHSGGC residents booked to attend antenatal clinics and 10,897 (88.1%) of first antenatal booking appointments were offered before or equal to 12 weeks and 6 days gestation.

The ethnic origin of pregnant women was White British 8677 (70.1%), Asian Pakistani 664 (5.4%), Asian Indian 282 (2.3%), Black African 212 (1.7%), Chinese 154 (1.2%) and 550 (4.4%) of any other ethnic group.

In November 2017 NHSGGC introduced BadgerNet, a new maternity IT application. A number of data sources were used in producing this report; BadgerNet; TrakCare and both local and national laboratory reports.

### 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 >4 kg at birth), family history of diabetes, previous gestational diabetes and mother's ethnic origin. 4,058 (33.1%) of bookers were recorded as having 'any risk' of GDM and were eligible to be offered an oral glucose tolerance test at 24-28 weeks gestation.

5,153 (42%) of pregnant women had a normal weight at the time of their first antenatal booking appointment. 3,363 (27.4%) pregnant women were overweight, 1706(14.0%) obese and1152 (9.4%) severely obese (35<=BMI >=45).

### Haemoglobinopathies Screening

Of the 12,370 women booked for their first antenatal booking, 12,344 (99.7%) consented and 12,271 (99.1%) had a sample taken for haemoglobinopathies screening (performed) and 26 refused. The blood is checked for risk of thalassaemia for all women who consented.

The Family Origin Questionnaire (FOQ) is completed as part of routine early antenatal risk assessment. Electronic data was available for 9,138 (74.4%) women who had a completed FOQ, the rest of the samples may have been tested with a paper version of FOQ during the development of an IT solution.

The maternal samples tested for haemoglobinopathies identified 46 as sickle cell carriers (HbAS), 6 women as HbD carriers (HbAD) and 7 women as HbE carriers (HbAE). The outcomes for thalassaemia screening identified 48 women as Beta Thalassaemia carriers and 574 as possible iron deficiency and /or Alpha + thalassaemia and 281 possible alpha zero thalassaemia carrier and/or iron deficiency.

Screening outcomes for antenatal haemoglobinopathies screening was available for 12,271 women (99.1%).

Partner testing was recommended to couples where the woman is a carrier for HbS or thalassaemia. In total, 101 partners were required to be offered a test. Six fetus were at risk of major haemoglobinopathy, 41 were not at risk of major haemoglobinopathy and for 54 fetus the risk was not determined.

### Infectious diseases

Uptake was greater than 99.9% for all of the infectious diseases in pregnancy screening tests. Screening identified 10 women who were HIV positive, and 42 women who were chronic carriers of Hepatitis B virus. Five women required treatment for syphilis.

### Down's syndrome and other congenital anomalies screening

Of the 12,370 women booked at antenatal clinics, 7961 (76.9%) were tested either in the 1<sup>st</sup> Trimester and 2393 in the 2<sup>nd</sup> Trimester. 173 high chance results were recorded for the 1<sup>st</sup> Trimester and 72 for the 2<sup>nd</sup> Trimester Down's syndrome screening.

### Congenital anomalies screening

The number of women who gave consent for a fetal anomaly scan was 11,035 (89.2 %) and 10,775 scans were performed and 39 anomalies suspected (0.4%).

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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

<u>Appendix 1.1</u> 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 (<u>Appendix 1.2</u>). 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 <u>Appendix 1.3</u>. Scotland is a low prevalence area for haemoglobinopathy screening and details are included in <u>Appendix 1.4</u>.

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 parents to make an informed decision on whether to continue with the pregnancy.

### 1.4. Infectious diseases in pregnancy screening

Testing for HIV, hepatitis B and syphilis infection is carried out at first antenatal booking when a blood sample is taken. The full screening pathway is shown in **Appendix 1.5**, **Appendix 1.6**, **Appendix 1.7**, **Appendix 1.8** and **Appendix 1.9**.

### 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 1.10**. 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 ethical issues for women. Uptake of Down's syndrome or other congenital anomalies screening depends on whether women would wish further investigation or management.

### 1.5. Delivery of NHSGGC Pregnancy Screening Programmes

Each NHS Board has a statutory requirement to submit data on antenatal activity. In NHSGGC, 12,370 women booked to attend antenatal clinics and 88.1% (10,897) managed to book before or equal to 12 weeks and 6 days gestation (Table 1.1)

Table 1.1 Number of women booked for their first antenatal appointments in NHSGGC 1 April 2018 to 31 March 2019 by gestation age.

Maternity Unit	<=12Wks 6Days	13Wks 0Days - 16Wks 6Days	17Wks 0Days - 20Wks 6Days	21Wks 0Days - 24Wks 6Days	25Wks 0Days - 30Wks 6Days	>=31 Wks 0Days	Total	% <=12W ks 6Days
Princess Royal Maternity Hospital	3362	275	80	42	65	70	3894	86.3
Queen Elizabeth University Hospital	4640	399	100	49	81	116	5385	86.2
Royal Alexandra Hospital	2895	93	26	23	25	29	3091	93.7
Total	10897	767	206	114	171	215	12370	88.1

Source: BADGERNET, August 2019

Within NHSGGC, booking for the 1st antenatal appointment varied according to area of residence. 5,301 (85.1%) of pregnant women living in the most deprived areas booked by 12 weeks and 6 days compared to 2009 (97.1%) of women living in the least deprived areas. Work continues to engage with and support women from more deprived areas to book earlier. (Table 1.2)

Table 1.2 Gestational age at first antenatal booking appointment by deprivation categories for period 1 April 2018 to 31 March 2019

					25Wk			
		13Wk		21Wk	S			
		S		S	0Day			
		0Days	17Wks	0Days	s -			
		-	0Days	-	30Wk			%
	<=12W	16Wk	-	24Wk	S	>=31W		<=12W
	ks	S	20Wks	S	6Day	ks		ks
SIMD 2016 Quintile	6Days	6Days	6Days	6Days	S	0Days	Total	6Dys
1 (Most Deprived)	4517	411	116	68	85	113	5310	85.1
2	1805	120	24	17	36	30	2032	88.8
3	1299	89	29	9	16	23	1465	88.7
4	1433	59	20	6	16	20	1554	92.2
5 (Least Deprived)	1843	88	17	14	18	29	2009	91.7
Total	10897	767	206	114	171	215	12370	88.1

Source: BADGERNET, August

2019

Using Onomap software we identified the ethnic origin of pregnant women as follows White British 8677 (70.1%), Asian Pakistani 664 (5.4%), Asian Indian 282 (2.3%), Black African 212 (1.7%), Chinese 154 (1.2%) and 550 (4.4%) of any other ethnic group **(Table 1.3).** 

Table 1.3 Number of NHSGGC residents booked for their first antenatal appointment by ethnic origin during 1 April 2018 to 31 March 2019

2001 Census Ethnic Group	Number	%
A) WHITE - BRITISH	8667	70.1
B) WHITE - IRISH	773	6.2
C) WHITE - ANY OTHER WHITE BACKGROUND	790	6.4
H) ASIAN OR ASIAN BRITISH - INDIAN	282	2.3
J) ASIAN OR ASIAN BRITISH - PAKISTANI	664	5.4
K) ASIAN OR ASIAN BRITISH - BANGLADESHI	43	0.3
L) ASIAN OR ASIAN BRITISH - ANY OTHER ASIAN BACKGROUND	23	0.2
M) BLACK OR BLACK BRITISH - CARIBBEAN	3	0.0
N) BLACK OR BLACK BRITISH - AFRICAN	212	1.7
R) OTHER ETHNIC GROUPS - CHINESE	154	1.2
S) OTHER ETHNIC GROUPS - ANY OTHER ETHNIC GROUP	550	4.4
Y) UNCLASSIFIED	209	1.7
Total	12370	

Source: BADGERNET, OnoMap, August 2019

### 1.6. Gestational Diabetes Mellitus (GDM)

Women with gestational diabetes are at increased risk of having a large baby, a stillborn baby or a baby who dies shortly after birth. Of the 1170 women with a BMI over 35, 18 had a current diagnosis for type 1 or type 2 diabetes. (Table 1.4)

Table 1.4 Number and percentage of women booked for their first antenatal appointments by body mass index and current diabetes 1 April 2018 to 31 March 2019

		Current Diabetes							
Body Mass Index Categories	Not Recorded	No	Yes Type 1	Yes Type 2	Total				
Not Recorded	36	522	11	3	572				
BMI<18.5	10	327	2	0	339				
18.5<=BMI<25	67	5086	16	7	5176				
25<=BMI<30	63	3300	18	6	3387				
30<=BMI<35	36	1670	10	10	1726				
35<=BMI<40	18	735	1	10	764				
40<=BMI<45	6	287	1	2	296				
BMI>=45	5	101	0	4	110				
Total	241	12028	59	42	12370				

Source: BADGERNET, August 2019

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. 4,058 (33.1%) of bookers were recorded as having 'any risk' of GDM and were eligible to be offered an OGTT at 24-28 weeks gestation. **(Table 1.5)** 

Table 1.5 Number of women booked for their first antenatal appointments in NHSGGC 1 April 2018 to 31 March 2019 and GDM risk factors

Maternity Unit	BMI >=35	Previous Macro somic Baby	Family History Diabetes	Previous Gestational Diabetes	Origin Mother Risk	Any Risk *	Booker s Total	% Any Risk
Princess Royal Maternity Hospital (PRM)	385	41	639	110	589	1384	3866	35.8
Queen Elizabeth University Hospital (QEUH)	424	54	851	92	969	1826	5336	34.2
Royal Alexandra Hospital (RAH)	343	26	485	62	117	848	3067	27.6
Total	1152	121	1975	264	1675	4058	12269	33.1

Source: BADGERNET, August

2019

\* Summed individual risks may exceed any risk total

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

5,153 (42%) of pregnant women had a normal weight at the time of their first antenatal booking appointment. 3,363 (27.4%) pregnant women were overweight, 1706 (14.0%) were obese and a further 1152 (9.4%) were severely obese (35<=BMI >=45) **(Table 1.6).** 

Table 1.6 Number and percentage of women booked for their first antenatal appointments by body mass index and by maternity unit from 1 April 2018 to 31 March 2019

	Gestational Di R		
Body Mass Index Categories	No	Yes	Total
BMI Not Recorded	377	181	558
Underweight BMI<18.5	244	93	337
Normal 18.5<=BMI<25	4018	1135	5153
Overweight 25<=BMI<30	2399	964	3363
Obese 30<=BMI<35	1173	533	1706
Severely Obese 35<=BMI<40	0	753	753
Severely Obese 40<=BMI<45	0	293	293
Severely Obese BMI>=45	0	106	106
Total	8211	4058	12269

Source: BADGERNET, August 2019

### 1.8. 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 Thalassaemia in which there is an abnormality in the amount of haemoglobin produced. Sickle cell disorders, caused by a haemoglobin variant HbS, 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 haemoglobinopathies based on a low prevalence screening model.

Hb D (Hb AD) is one of the haemoglobinopathy 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 haemoglobinopathy carrier trait. 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 screening pathways for haemoglobinopathy screening are in <u>Appendix 1.2</u>, <u>Appendix 1.3</u> and <u>Appendix 1.4</u>.

### Samples taken for haemoglobinopathies screening

Of the 12,370 women booked for their first antenatal booking, 12,344 (99.7%) consented and 12,271 (99.1%) had a sample taken for haemoglobinopathies screening and 26 refused. The blood is checked for risk of thalassaemia for all women who consented. **(Table 1.7)** 

Table 1.7 NHSGGC Number of women who consented for haemoglobinopathies screening from 1 April 2018 to 31 March 2019

Maternity Unit	Total	HBO Refused	HBO Consent Not Known	HBO Test Performed	Consent Presumed	FOQ Completed	FOQ Not Completed	% FOQ Completed
Princess Royal Maternity	3894	11	22	3861	3883	2373	1507	61.1
Queen Elizabeth University Hospital	5385	7	34	5344	5378	4184	1192	77.8
Royal Alexandra Hospital	3091	8	17	3066	3083	2581	499	83.7
Total	12370	26	73	12271	12344	9138	3198	74.0

Source: BADGERNET,

August 2019

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. Electronic data was available for 9,138 (74.4%) women who had a completed FOQ, the rest of the samples may have been tested with a paper version of FOQ due to development of an IT solution. **(Table 1.7)** 

The maternal samples tested for haemoglobinopathies identified 46 as sickle cell carriers (HbAS), 6 women as HbD carriers (HbAD) and 7 women as HbE carriers (HbAE). The outcomes for thalassaemia screening identified 48 women as Beta Thalassaemia carriers and 574 as possible iron deficiency and /or Alpha + thalassaemia and 281 possible alpha zero thalassaemia carrier and/or iron deficiency. (Table 1.8)

Table 1.8 NHSGGC haemoglobinopathies screening carrier status for the period 1 April 2018 to 31 March 2019

	I			
Carrier Status	Glasgow Princess Royal Maternity	Queen Elizabeth University Hospital	Royal Alexandra Maternity Hospital	Total
00: No Record	87	299	66	452
00: Not Carrier (as evidenced by screening)	2274	3039	2508	7821
00: Carrier Status Not Found	8	7	1	16
03 CHPFH: Carrier of Hereditary Persistence of Foetal Haemoglobin	1	2	0	3
04 HCC: Hb C carrier (HbAC)	3	3	1	7
05 HDC: Hb D carrier (HbAD)	0	6	0	6
06 HEC: Hb E carrier (HbAE)	2	3	2	7
07 SCC: Sickle cell carrier (HbAS)	28	13	5	46
08 BTC: Beta thalassaemia carrier	13	34	1	48
10 PIDAT: Possible iron deficiency and/or alpha + thal carrier	197	303	74	574
11 PA0C: Possible alpha zero thal carrier and/or iron deficiency	91	159	31	281
12 NOAHT: No evidence of Abnormal Hb or Thalassaemia	1157	1476	377	3010
Total	3861	5344	3066	12271

Source: BADGERNET, SCISTORE, August 2019

Screening outcomes for antenatal haemoglobinopathies screening was available for 12,271 women (99.1%). Depending on the outcome, or in the absence of FOQ, booking samples are tested for haemoglobinopathies and thalassaemia.

The partners' of 101 women who were carriers required to be offered partner testing

The screening outcome for fetal haemoglobinopathies was 6 at risk for major haemoglobinopathy, and 41 not at risk for major haemoglobinopathy. For 54 cases the fetal risk could not be determined. **(Table 1.9)** 

Table 1.9 NHSGGC haemoglobinopathies screening outcome (carriers & PTSBO only) for the period 1 April 2018 to 31 March 2019

	ı	Maternity Unit		
Screening Outcome	Glasgow Princess Royal Maternity	Queen Elizabeth University Hospital	Royal Alexandra Maternity Hospital	Total
01 FAR: Foetus at risk for major haemoglobinopathy	2	2	1	6
02 FNAR: Foetus not at risk for major Haemoglobinopathy	13	23	5	41
03: Fetal risk not determined	28	24	2	54
Total	43	50	8	101

Source: BADGERNET, SCISTORE, August 2019

Table 1.10 KPIs for Pregnancy and Newborn Screening - Haemoglobinopathy 2018-2019

KPI	Performance threshold	NHSGGC 2018/19
1.1 Coverage	Essential : ≥95% Desirable : ≥ 99%	99.1%
1.3 Completion of FOQ	Essential : ≥ 95% Desirable : ≥99%	74% Some FOQs not recorded electronically during development process within Badger Net

### 1.9. NHSGGC Infectious Diseases in Pregnancy Screening

### Infectious Diseases

These include Hepatitis B, Syphilis and Human Immunodeficiency Virus (HIV): **Hepatitis B** infection can be passed on from mother to baby during birth. HBV 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 Infectious 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 has 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 the screening tests. The screening identified 10 women infected with HIV (9 were previously known) and 42 infected with HBV (26 were previously known) and 5 women infected with syphilis (Table 1.11).

Table 1.11 NHSGGC Infectious diseases tests and results

	1 April 2018 - 31 March 2019					Results			
	Total number of samples	No. requesting individual test	No. not requesting individual test	uptake	Antibo detecto		antib not det		
	(N)	(N)	(N)	%	(N)	%	(N)	%	
HIV	15,004	14,995	9	99.9	10¹	0.1	14,985	99.9	
HBV	15,004	14,977	7	99.9	42 <sup>2</sup>	0.3	14,935	99.7	
Syphilis	15,004	14,976	7	99.9	5	0.03	14,971	99.9	

Sources: West of Scotland Specialist Virology Centre

### **Notes**

<sup>1. 9</sup> of the 10 HIV infections were previously known about

<sup>2. 26</sup> of the 42 HBV infections were previously known about

### **Key Performance Indicators for Infectious diseases**

In November 2018, NSD published KPIs for the Pregnancy and Newborn Screening Programme which include a number of indicators for infectious diseases screening in pregnancy – namely hepatitis B, syphilis and HIV.

The objectives of the KPIs for syphilis, HIV and hepatitis B screening in pregnancy are to: -

- 1. Maximise the uptake of screening among pregnant women ('coverage');
- 2. Maximise the timely reporting of results ('turnaround') and
- 3. Ensure timely assessment and intervention of women where appropriate.

And for babies born to mothers with chronic hepatitis B;

4. Ensure the first dose of hep B vaccine +/- immunoglobulin is given within 24hrs of birth.

### Results

- 1. Coverage: The infectious diseases in pregnancy screening programme has always demonstrated high uptake across all infections. For the year 2018/19 the uptake was 99.9% for all three infections which exceeds the KPI performance thresholds of 95% (essential) and 99% (desirable).
- 2. Turnaround: Lab figures demonstrated that 100% of results for infectious diseases screening in the year 2018/19 were reported within 5 days. This exceeds the KPI performance thresholds of 95% (essential) and 97% (desirable) for reporting of results within 8 days.
- 3. Timely assessment and intervention:

### HIV

Proportion of women referred to an appropriate specialist within 10 days of the result.

There were 10 women with positive HIV results in the year 2018/19. Of these, only one was a completely new diagnosis and the woman was seen by a specialist within 2 days of the positive result. Two women were aware of their diagnosis but were 'new' to NHS GGC. Both women were reviewed by specialists in less than 7 days from the result being reported. The other 7 women were already known and were attending appropriate ID/sexual health clinics before becoming pregnant and were seen promptly following their screening result.

Result - 100% (10/10). This exceeds the performance thresholds of 97% (essential) and 99% (desirable).

### **Hepatitis B**

Women identified by screening as having HBV had their treatment needs assessed and received timely intervention as appropriate.

There is no simple way to demonstrate meeting this KPI apart from checking the clinical records of the women – when hepatitis B was first diagnosed and their history of attendance at outpatient appointments, both obstetric and ID/gastroenterology. As the board in Scotland with the largest number of women with chronic hepatitis B this means looking at upwards of 40 records. All except three of the women were referred, but were not seen by an ID or gastroenterology specialist during pregnancy. However, it was clear from their clinical records that they had the appropriate management of their infection during pregnancy in accordance with the well-established local clinical guidelines on hepatitis B in pregnancy, i.e. if 'low infectivity' rechecking virus level at 26 weeks to ensure antiviral treatment does not need to be prescribed and that vaccine only, (without immunoglobulin) is administered to the baby at birth.

Result: 93% (39/42). This exceeds the performance thresholds of 70% (essential) and 90% (desirable).

### **Syphilis**

Proportion of women who tested positive who attend for assessment within 10 days.

Five women were followed up and treated.

### 4. Vaccination

43 babies were born in the time period (2018/19) and all 43 received the first dose of hepatitis B vaccine +/- immunoglobulin within the first 24 hrs.

Result: 100% (43/43). This exceeds the performance thresholds of 97% (essential) and 99% (desirable).

Table 1.12 KPIs for Pregnancy and Newborn Screening – Infectious Diseases 2018-2019

KPI	Performance threshold	NHSGGC 2018/19
1.1 Coverage for	Essential : ≥ 95%	99.9% for all
Hepatitis B	Desirable : ≥ 99%	
Syphilis		
HIV		
1.2 Turnaround time (lab)	Essential : ≥95%	100% for all
,	Desirable : ≥97%	
1.3 Syphilis – attending	Essential : ≥ 97%	No cases required treatment
for assessment	Desirable : ≥ 99%	
1.4 HIV – Referred to	Essential : ≥97%	100%
specialist	Desirable : ≥ 99%	
1.5 Hepatitis B	Essential : ≥ 70%	94% (32 out of 34 women)
Timely assessment	Desirable : ≥90%	
1.6 Hepatitis B	Essential : ≥ 97%	100% (43 out of 43)
Vaccination	Desirable : ≥99%	
1.7 Timely assessment of	Essential : ≥ 70%	Clinical pathway followed for
Hepatitis B	Desirable : ≥ 90%	40 women

# 1.10. 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.

### 1.11. 1st and 2nd Trimester Down's syndrome screening

Of the 12,370 women booked at antenatal clinics, 10,354 (83.7%) were tested either for the 1<sup>st</sup> or 2<sup>nd</sup> Trimester.

The 1<sup>st</sup> Trimester samples are taken during 11weeks +2 days to 14 weeks +1 day of pregnancy. The samples are sent to Lothian Laboratory and during 2018/19, 7961 (76.9%) samples were tested. There were 11 late samples (0.14%) and 429 samples (5.3%) had incomplete request details. The number of increased chance results was173 (2.17%). **(Table 1.13)** 

Table 1.13 1st Trimester Down's syndrome screening samples 2018/19

2018/19	Number of sample s	% sample s	Late sampl es	% Late sample s	Incomple te Request details	% Incomple te Request details	Increase d chance results	% Increase d chance results
1 <sup>st</sup> Trimester	7961	76.9	11	0.14	429	5.3	173	2.17

Source: Annual Report – Lothian Lab

The 2<sup>nd</sup> Trimester samples are taken up to 20 weeks+0 days gestation and sent to Bolton Laboratory. During 2018/19, 2393 (23.1%) of samples were taken in the 2<sup>nd</sup> Trimester. There were 12 unsuitable samples (0.5%) and 72 high chance results were reported (3%). **(Table 1.14)** 

Table 1.14 2<sup>nd</sup> Trimester Down's syndrome screening samples 2018/19

2018/19	Number of samples	% Samples	Number of high chance results	% High chance results	Unsuitable samples	% Unsuitable samples
2 <sup>nd</sup> Trimester	2393	23.1	72	3%	12	0.5

Source: Bolton Labs August 2019

### Key Performance Indicators for 1st Trimester Down's syndrome screening

The following data has been reviewed to provide evidence for the NSS Pregnancy and Newborn Screening Key Performance Indicators (KPIs), 2018 from the Lothian Laboratory for Scotland. **Table 1.15** 

Table 1.15 – KPIs for 1st Trimester Down's syndrome screening

KPI 5.2 Turnaround time	Number of results reported to maternity services within 72 working hours of sample receipt in the laboratory. Overall 99.36 % of results were reported within 72 working hours of sample receipt, fulfilling the desirable target of ≥ 99 %.
KPI 5.3 Completion of	The proportion of laboratory request forms with complete data, as defined by the KPI list of required fields, is 97 %,
laboratory request forms	which fulfils the essential performance criteria.
KPI 5.5 Screen Positive Rate (SPR)	The overall screen positive rate is 2.2 %.
KPI 5.6 Detection Rate (DR)	Provisional data which is still awaiting final confirmation for the whole of Scotland gives a detection rate of 81 %.

### **Amniocentesis**

139 amniocentesis samples were analysed by the Cytogenetics Laboratory and 27 abnormalities were detected (19.4%) and of these 15 (10.8%) had a diagnosis of trisomy 21 (Down's syndrome) **(Table 1.16)** 

Table 1.16 Amniocentesis Referrals 1st April 2018 - 31st March 2019

	Biochemical Screening	Maternal Age	Abnormalities on Scan	NIPT	Other	Total
Number of women (= number of tests)	59	1	53	3	23	139
% total referral reasons	42.4	0.7	38.1	2.2	16.5	100
Number with normal results	57	1	33	0	21	112
Number with diagnostic trisomy	2	0	10	3	0	15
% number with diagnostic trisomy	3.39	0.00	18.87	100.00	0.00	10.79
Number of other non trisomy abnormalities	0	0	10	0	2	12
Total number of abnormalities	2	0	20	3	2	27
% total number of abnormalities	3.39%	0.00%	37.74%	100.00%	8.70%	19.42%

Source: Cytogenetics Laboratory 2019

### **Chorionic Villus Biopsies (CVS)**

98 chorionic villus biopsies were analysed by the Cytogenetics Laboratory in 2018/19. 43 abnormalities were detected (43.9%) and 30 of those (30.6%) had a diagnosis of trisomy 21 (Down's syndrome) **(Table 1.17)** 

Table 1.17 Chorionic Villus Biopsy referrals and outcomes 1st April 2018 - 31st March 2019

		Referral Typ	oe .			
	Biochemical Screening	Maternal Age	Abnormalities on Scan	NIPT	Other	Total
Number of women (= number of tests)	12	0	60	6	20	98
% total referral reasons	12.2%	0.0%	61.2%	6.1%	20.4%	100.0%
Number with normal results	7	0	27	2	19	55
Number with diagnostic trisomy	3	0	23	4	0	30
% total with diagnostic trisomy	25.0%	0.0%	38.3%	66.7%	0.0%	30.6%
Number of other non trisomy abnormalities	2	0	10	0	1	13
Total number of abnormalities	5	0	33	4	1	43
% total number of abnormalities	41.67%	0.00%	55.00%	66.67%	5.00%	43.88%

Source: Cytogenetics Laboratory 2019

### 1.12. 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 11,035 (89.2 %) and 10,775 scans were performed (Table 1.18).

Table 1.18 Uptake rate for other congenital anomalies (fetal anomaly scan) for the period 31 March 2018 to 1 April 2019

Maternity Unit	Number of bookers	Number of Consents	% Consented	Number of fetal anomaly scans performed	% fetal anomaly scans performed
Princess Royal Maternity Hospital (PRM)	3,894	3476	89.3	3,384	97.4
Queen Elizabeth University Hospital (QEUH)	5,385	4,778	88.7	4,669	97.7
Royal Alexandra Hospital (RAH)	3,091	2,781	90.0	2,722	97.9
Total	12,370	11,035	89.2	10,775	97.6

Source: BADGERNET, August 2019

\* Any 'anomlay' scan performed

Of the 10,775 fetal scans performed, 39 anomalies were suspected. (Table 1.19).

Table 1.19 Outcome of fetal anomaly scans performed for the period 1 April 2018 to 31 March 2019

Maternity Unit	Number of bookers	Number of Fetal scans performed	Anomaly not suspected	Anomaly Suspected	% Anomaly Suspected
Princess Royal Maternity Hospital (PRM)	3,894	3,384	3,358	26	0.8
Queen Elizabeth University Hospital (QEUH)	5,385	4,669	4,657	12	0.3
Royal Alexandra Hospital (RAH)	3,091	2,722	2,721	1	0.0
Total	12,370	10,775	10,736	39	0.4

Source: BADGERNET, August 2019 \* Any 'anomlay' scan

performed

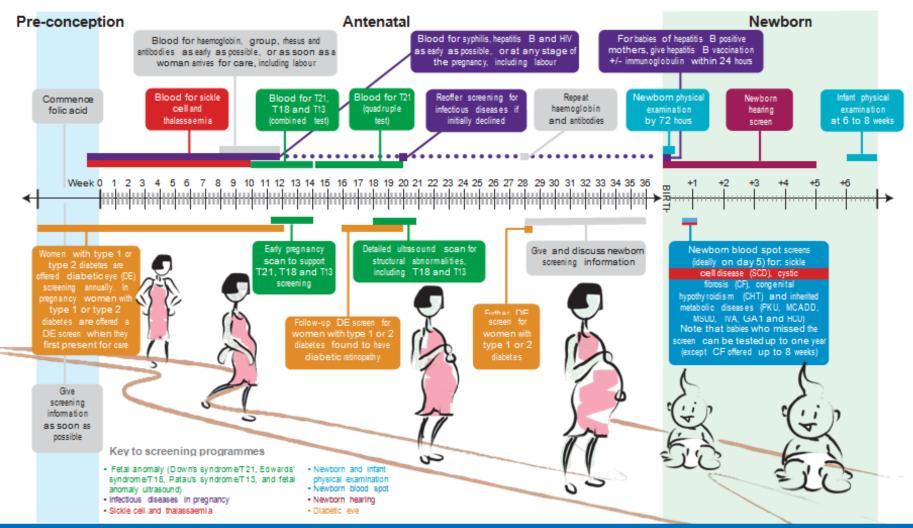
### 1.13. **Information Systems**

The report contains data extracted from Badger Net, Trakcare and Laboratories.

### 1.14. **Challenges and Priorities**

- Implement changes to meet programme KPIs.
- Meeting the testing and reporting timelines for pregnancy screening programmes
- Reviewing all pregnancy data from BadgerNet and addressing any quality issues.
- Developing national reports for Pregnancy Screening from Badger Net.
- Setting up reports to capture all Pregnancy Screening Programmes against the **NSD Key Performance Indicators**



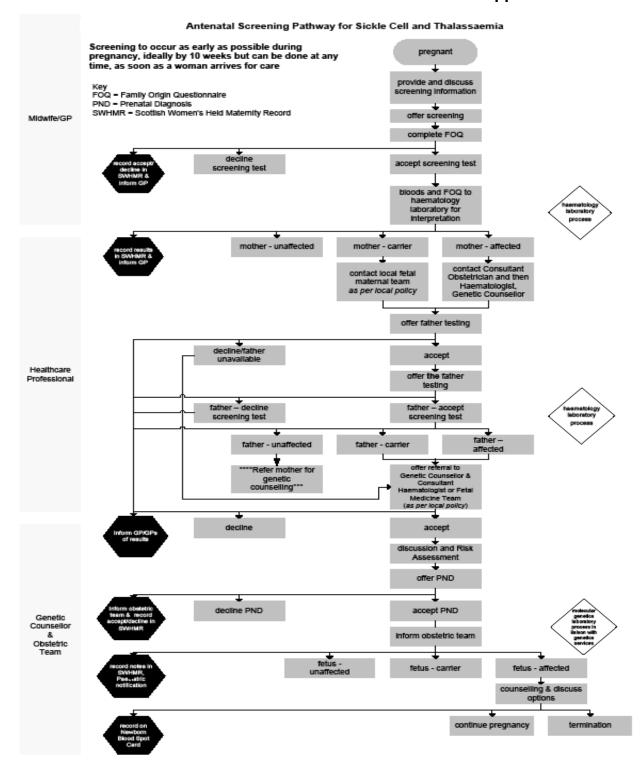


Antenatal and newborn screening timeline – optimum times for testing

Screening should be a personal informed choice. Women and their families should be supported to understand the tests and choose what's right for them.

Version 8.4, January 2019, Gateway ref: 2014696, www.gov.uk/phe/screening

### Appendix 1.2



# This form must be attached securely to the haematology laboratory request form with the antenatal blood samples. A second copy of the form should be added to the patient's maternity record. (A third copy can be added to the hospital records if applicable). The completion of this form is an ESSENTIAL part of the screening process.

# Screening for Haemoglobinopathies Family Origin Questionnaire (FOQ)

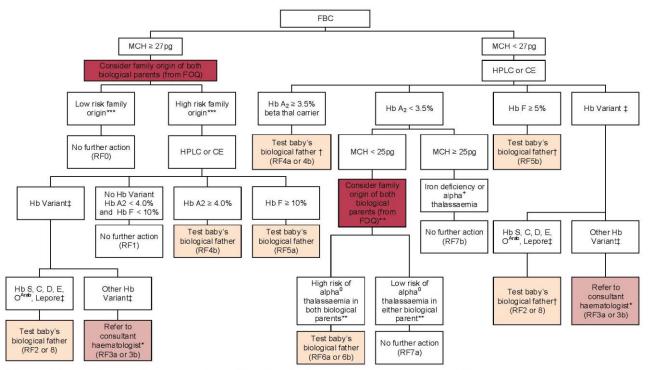


1	Hospital Name
	CHI No.
	Estimated Delivery Date
	Surname
	Forename
	Date of Birth
	Address 1
	Address 2
/	Postcode

A.	AFRICAN OR AFRICAN CARIBBEAN (BLACK)	Woman	Baby's fathe
1/	Caribbean Islands		
2/			
3/	Any other African or African-Caribbean family origins (please write in)		
В.			S1
1/	India or African-Indian		
2/	Pakistan		
3/	Bangladesh		
C.	SOUTH EAST ASIAN (ASIAN)	- u	<b>-</b> #
1/	China including Hong Kong, Taiwan, Singapore	# #	# #
2/		# #	# #
3/	Malaysia, Vietnam, Philippines, Cambodia, Laos	#	#
4/	Any other Asian family origins (eg Caribbean-Asian) (please write in)		
D.	OTHER NON-EUROPEAN (OTHER)		25 <u></u>
1/	North Africa, South America etc		
2/	Middle East (Saudi Arabia, Iran etc)		
3/	Any other Non-European family origins (please write in)		
E.			Political
1/	Sardinia	#	#
2/	Greece, Turkey, Cyprus	#	#
3/	Italy, Portugal, Spain		
4/	Any other Mediterranean country		
5/	Albania, Czech Republic, Poland, Romania, Russia etc		
F*	UNITED KINGDOM (WHITE) refer to guidance at the back		
1/	England, Scotland, N Ireland, Wales		
	NORTHERN EUROPEAN (WHITE) refer to guidance at the back		
	Austria, Belgium, Ireland, France, Germany, Netherlands		
2/			
3/	Any other European family origins, refer to chart (eg Australia, N America, S Africa) (please write in)		
*Hb	Variant Screening Requested by F and/or G (ie request from low risk group)		
	ligher risk for alpha zero thalassaemia		
H.	DON'T KNOW (incl. pregnancies with donor egg/sperm)		
I.	DECLINED TO ANSWER		
	ESTIMATED DELIVERY DATE (please write in if not above)		
K.	GESTATION AT TIME OF TEST		
)FF	ER haemoglobin variant screening to all women if they or their baby's fat	her have answer	s in a shaded box
gned	d Print Name		

### Appendix 1.4

### Haemoglobinopathy Screening in Low Prevalence Areas



- Refer analytical results to consultant for an opinion on the need for a clinical referral or consult the laboratory support service helpline.
- Consider at high risk if any ethnic origins in China (including Hong Kong), Taiwan, Thailand, Cambodia, Laos, Vietnam, Indonesia, Burma, Malaysia, Singapore, Philippines, Cyprus, Greece, Sardinia, Turkey, or if ethnic/family origin is uncertain or unknown. Reconsider low risk couples if fetal anaemia/hydrops seen on ultrasound scanning or if family history of hydrops fetalis.

  \*\*\*\* Low risk or high risk as determined by the family origin questionnaire. Note: If baby's father is in high risk group, test the mother's sample regardless of her family origins.

  † In all cases consider coexisting  $\alpha^0$  thalassaemia if both parents are from a high risk area and MCH <25pg.

  † Consider co-existing beta thalassaemia

### "The primary aim of screening women for these conditions is to ensure a plan for treatment and management for affected individuals and their babies". NHS QIS Clinical Standards, Pregnancy and Newborn Screening On confirmation of pregnancy woman is referred for antenatal care Woman 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 Overarching Principles - Pregnancy Screening leaflet. offers blood tests, obtains Relevant information, which outlines the benefits and consent and informs woman when risks of screening should be provided in a user-friendly and how she will receive her results manner so that women and their partners can make an (within 21 days, Standard informed choice. This information should be provided 3c.1,2,4,5) by her midwife with additional support from appropriate 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. unselling and/or further tests provided within 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 Positive syphilis serology (Standard3d.1) - Positive for HIV infection Test is negative. Woman informed by letter of negative screening REFER TO SIGNIFICANT TEST tests within 21 days (Standard 3c5). Confirmation that woman has received screening tests results should be recorded at subsequent RESULT CARE PATHWAY FOR EACH INFECTION antenatal visits.

Offering Routine Antenatal Communicable Disease Screening Tests

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

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

Version No V5.3 24 May 2016 Communicabl April 2011 Revised: Approved by: Date Approved:

ble Diseases in Pregnancy Steering Group

Next revision date: May 2019

# 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 risk of delivery is high:
- Seek informed consent for screening (HIV, Syphilis, hepatitis B, rubella)
- Fill one 9ml purple topped EDTA bottle and complete a virology request form, clearly indicating which tests (HIV, 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/amended%20taxi%20protocol%20-%20phase%201 acute%20services.pdf

- As with ALL emergency blood tests ensure results are followed up immediately they are available. In normal hours the lab is able to process and produce results within 1-2 hours of receipt.
- Communication with paediatricians is essential as their management may be significantly altered by these results however the responsibility for taking and sending these investigations and obtaining these results remains with the midwifery / obstetric team.
- Ensure tests are recorded on PNBS at next opportunity.

### Appendix 1.7

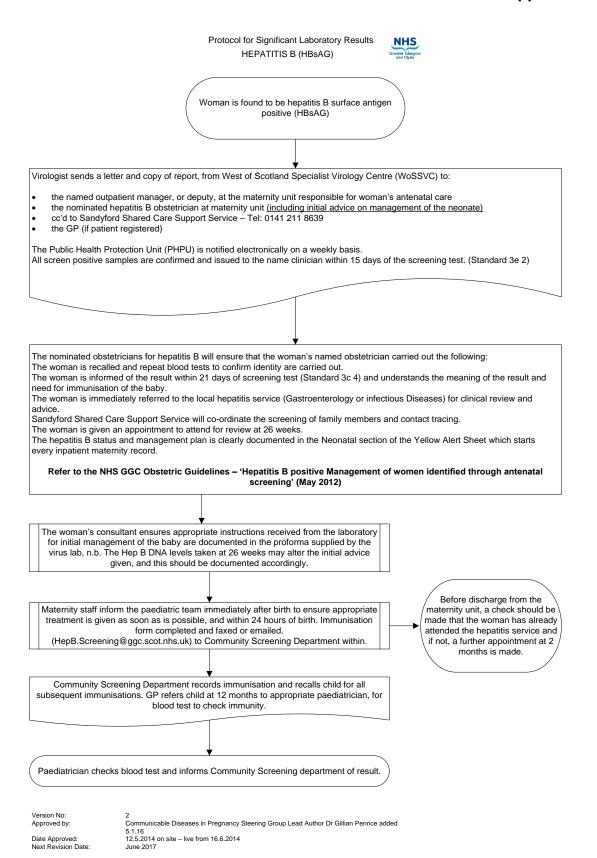
### Protocol for Significant Laboratory Results **SYPHILIS** Microbiologist detects positive syphilis serology from booking blood. All screen positive samples undergo confirmatory tests and results issued to named clinician within 15 days. (Standard 3e2) Microbiologist telephones Sexual Health Advisors Microbiologist telephones outpatient manager (or 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 (Standard 3c.2) Sandyford Initative FAO Sexual Health Advisors 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 December 2014 Next Review 31/01/2017

Version No:

Approved by: Date Approved: Next Revision Date:

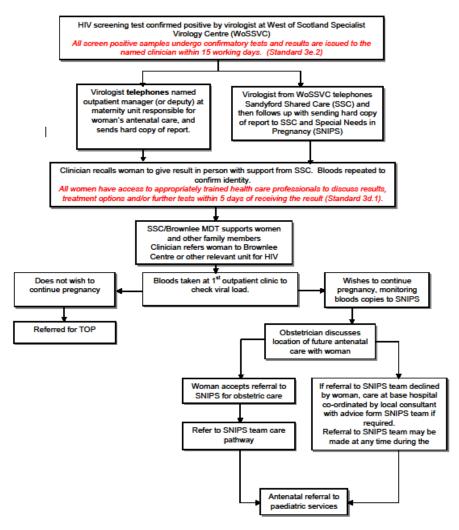
### Appendix 1.8





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

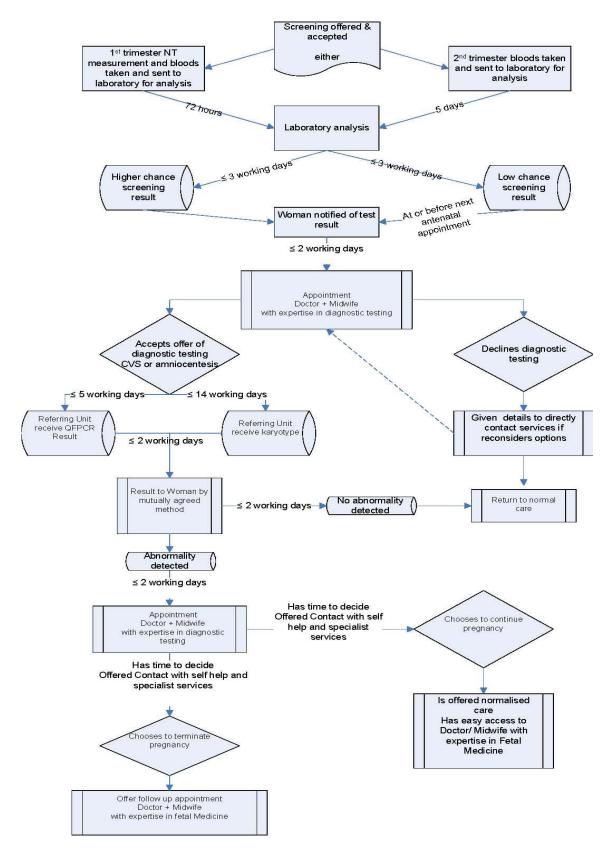
### HIV



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

### Appendix 1.10

### Down's syndrome screening pathway for women accepting screening



# Members of Pregnancy Screening Steering Group (as at March 2018)

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Ms Louise Jack Midwife

Mrs Jaki Lambert Lead Midwife

Mr Sam King Sexual Health Advisor
Ms Victoria Mazzoni Senior Community Midwife

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Ms Valerie McAlpine Senior Charge Midwife

Ms Marie-Elaine McClair Interim Clinical Service Manager

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

Ms Jane McOwan Technical Manager, Specialist Virology Centre

Ms Elizabeth Rennie Programme Manager

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Ms Samantha Shepherd Clinical Scientist

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Dr Andrew Thomson Consultant Obstetrician & Gynaecologist

## **Chapter 2 – Newborn Bloodspot Screening**

## **Summary**

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 numbers 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 babies are screened for 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), homocystinuria (HCU).

12,009 babies resident in NHSGGC were screened, that is a total of 98.8% of the total eligible population of 12,155. The uptake of screening ranged from 98.0% to 99.4% across HSCP geographical areas. 8,150 (68.1%) of babies screened were White, 893 (7.5%) South Asian and 569 (5.2%) were of Southern or Other European ethnicity.

Following screening, seven babies were diagnosed with congenital hypothyroidism (CHT) and less than five babies with PKU (phenylketonuria).

The cystic fibrosis results showed that nine babies tested positive. For haemoglobinopathy, six babies were diagnosed with haemoglobinopathy variants and 77 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 numbers 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), homocystinuria (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 (2018-19), 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. Live and Stillbirths – Comparing SMR02 with National Records of Scotland

There were 11,588 live births recorded on SMR02 compared to 11,707 on National Records for Scotland during 2018/19. Details by HSCP areas in **Table 2.1** 

Table 2.1 Number of live and still births NHSGGC residents, 1 April 2018 to 31 March 2019

	Live births SMR02	Live births NRS	Stillbirths SMR02	Stillbirths NRS
East Renfrewshire	851	863	1	2
East Dunbartonshire	929	947	3	5
Glasgow City	6,598	6,643	28	27
Renfrewshire	1,673	1,700	4	5
Inverclyde	668	678	2	2
West Dunbartonshire	869	876	3	3
NHSGGC	11,588	11,707	41	44

Sources: SMR02 and NRS Birth Registration

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

**Figure 2.1** illustrates newborn bloodspot uptake rates and the results of the screening programme from 1 April 2018 to 31 March 2019.

The total number of babies eligible for screening was 12,155 and of these 12,009 (98.8%) of babies were screened. Results were not available for the 146 (1.2%) babies that moved into the NHSGGC Board area or who transferred out of UK on or after day seven.

Following screening seven babies were diagnosed with congenital hypothyroidism (CHT), less than five babies were diagnosed with PKU (phenylketonuria) and nine tested positive for cystic fibrosis.

The results for Haemoglobinopathy showed that although six were diagnosed with haemoglobinopathy variants, 77 babies were identified as haemoglobinopathy carriers.

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

Figure 2.1

Positive

<5

Negative

11930

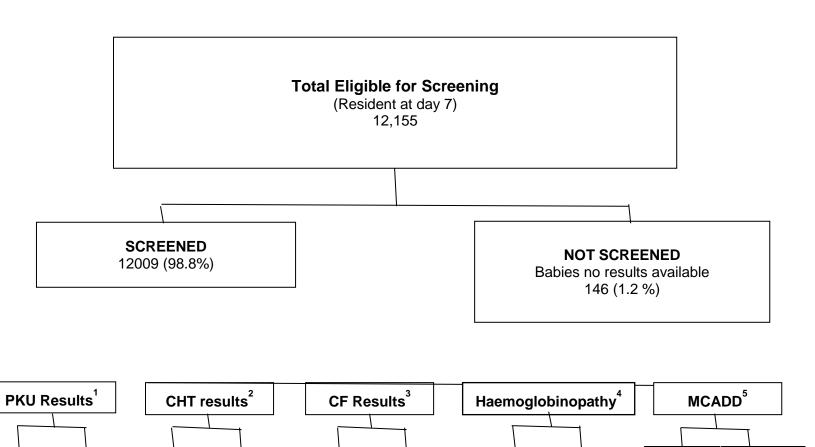
**Positive** 

7

**Negative** 

11920

# NHS Greater Glasgow & Clyde Residents Summary of Bloodspot Screening Uptake & Results for babies born 1 April 2018 to 31 March 2019



**Negative** 

11826

**Positive** 

9

**Positive** 

0

**Negative** 

11848

**Positive** 

6

Negative

11

Source: Child Health (CH2008); Date extracted: June 2019

Notes:

- 1 Total includes 1 verification
- 2 Total includes 4 verifications
- 3 Total includes 98 late and 1 verification
- 4 Total includes 77 carriers and 1 verification
- 5 Total includes 1verification

The percentage uptake rate of Newborn Bloodspot screening was greater than 97% across all HSCP areas and deprivation categories. (**Table 2.2**)

Table 2.2 Uptake rate of Newborn Bloodspot screening by HSCP and deprivation

	Most Depri	ved			SIMD 2 Quint					Least Deprived		
HSCP	1		2		3		4		5	;	Tota	al
	No. Screened	% uptake	No. Screened	% uptake	No. Screened	% uptake	No. Screened	% uptake	No. Screened	% uptake	No. Screened	% uptake
East Dunbartonshire	58	100.0	160	99.4	60	100.0	190	99.5	525	99.1	993	99.3
East Renfrewshire	71	98.6	84	96.6	66	98.5	152	99.3	507	97.5	880	97.9
Glasgow North East	1376	99.3	249	98.4	237	96.7	251	100.0	11	100.0	2124	99.0
Glasgow North West	994	99.3	239	98.4	230	99.1	196	98.5	404	99.0	2063	99.0
Glasgow South	1265	99.0	545	98.7	411	97.6	286	98.3	184	99.5	2691	98.7
Inverclyde	357	99.2	88	100.0	97	100.0	83	100.0	60	98.4	685	99.4
Renfrewshire	524	98.9	356	97.5	260	98.1	263	98.1	286	96.9	1689	98.0
West Dunbartonshire	392	99.5	245	98.8	114	96.6	91	100.0	42	97.7	884	98.9
<b>Grand Total</b>	5037	99.2	1966	98.4	1475	98.0	1512	99.0	2019	98.3	12009	98.8
Source: Child Health (CH2	008); Date extract	ted: June 20	19									

#### 2.6. Ethnicity of babies born in 2018/19

The breakdown of the ethnicity groups for babies tested within NHSGGC shows that 8.150 (68.1%) of babies screened were UK White, 893 (7.5%) South Asian and 569 (5.2%) were of Southern and Other European ethnic groups **(Table 2.3).** 

Table 2.3 NHSGGC Newborn Bloodspot screening – ethnicity of the babies tested 1 April 2018– 31 March 2019

	Cly	de	Glas	sgow	To	otal
Ethnicity Group	N	%	N	%	N	%
African or African	23	0.7	350	4.0	373	3.1
Caribbean (Black)						
South Asian (Asian)	57	1.8	836	9.5	893	7.5
South East Asian (Asian)	11	0.4	163	1.8	174	1.5
Other non-European (Other)	21	0.7	268	3.0	289	2.4
Southern & Other European (White)	113	3.6	456	5.2	569	4.8
United Kingdom (White)	2,575	82.4	5,575	63.1	8150	68.1
North Europe (White)	25	0.7	116	1.3	137	1.0
Don't Know / Decline to Answer	0	0	2	0	2	0
Any Mixed Background	129	4.1	561	6.3	690	5.8
Not Stated	174	5.6	514	5.8	688	5.8
Total	3,124		8,841		11,965	

Source: Scottish Newborn Screening Laboratory - Newborn Bloodspot Screening 2018/19

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

#### 2.7. Ethnicity of Babies 2012/13 to 2018/19

Across NHSGGC the changes in population and migration from other countries is illustrated when data is compared for ethnicity recorded on the Newborn Bloodspot card. Comparing the percentages for the ethnic groups in 2013/14 to those recorded in 2018/19 showed:

For African and African Caribbean residents the percentage has decreased from 1.1% in Clyde to 0.7% but increased from 3.2% to 4.0% for Glasgow. For the South Asian community there is a slight increase from 1.7% to 1.8% in Clyde and an increase from 8.6% to 9.5% for Glasgow.

For the South East Asian community there was a slight decrease from 0.6% to 0.4% in Clyde and from 2.5% to 1.8% in Glasgow. Other non-Europeans had an increase from 0.2% to 0.7% for Clyde and 1.4% to 3.0% in Glasgow for 2018/19 (Table 2.4).

Table 2.4 NHSGGC Newborn Bloodspot screening – ethnicity of the babies tested 1 April 2012 – 31 March 2019

	2013/14		2014/15		2015/16		2016/17 2017/18			2018/19		
	Glasgow	Clyde	Glasgow	Clyde	Glasgow	Clyde	Glasgow	Clyde	Glasgow	Clyde	Glasgow	Clyde
African or African Caribbean (Black)	3.2%	1.1%	2.7%	1.2%	3.2%	0.7%	3.5%	0.8%	3.7%	0.5%	4.0%	0.7%
South Asian (Asian)	8.6%	1.7%	8.6%	1.6%	8.9%	1.9%	9.1%	2.4%	9.5%	2.2%	9.5%	1.8%
South East Asian (Asian)	2.5%	0.6%	2.6%	0.5%	2.3%	0.5%	2.3%	0.5%	1.8%	0.5%	1.8%	0.4%
Other non- European	1.4%	0.2%	1.5%	0.2%	1.4%	0.2%	2.3%	0.2%	2.6%	0.5%	3.0%	0.7%

Source: Scottish Newborn Screening Laboratory data from 2013/14 to 2018/19

## 2.8. Specimen Tests and Outcomes for 2018/19

During 2018/19, the Scottish Newborn Screening Laboratory received 12,547 newborn bloodspot cards and 12,009 (98.8%) babies from NHSGGC were screened. The number and reason for repeat tests due to avoidable problems is detailed in **Table 2.5.** 

Table 2.5: Number and reason for repeat samples

Reason	Number	Percentage
Insufficient sample	97	0.8
Sample taken <96 hours	45	0.4
Incorrect blood application	5	0
Compressed /damaged sample	18	0.1
Blood quality of sample	35	0.3
Missing CHI	133	1.1
Expired card used	14	0.1
>14 days in transit	5	0
Total	352	

Source: SNSL Report 2018-19

#### 2.9. Key Performance Indicators for Newborn Bloodspot Screening

The table below shows the Newborn Bloodspot Screening against Key Performance Indicators for NHSGGC during 2018-19. (**Table 2.6**)

Table 2.6 NBBS KPIs and performance during 2018-19 for NHSGGC

NBBS KPI	Performance	2018/19
	threshold	
8.1 Coverage	95-99%	12,009 screened (98.8%)
8.2 Movers in	95-99%	137 children offered and 1 refused (100%)
8.3 Avoidable repeats	<1.0 to <2.0 %	Reasons for repeats 0.1 to 1.1 %
8.4 Null or incomplete result on CHIS	Essential – regular checks to identify babies	Checks carried out on daily basis on CMOD for overdue NBBS result.
8.5 CHI number recorded on bloodspot card	98-100%	98.9 % had valid CHI
8.6 Timely sample collection	95-99%	9836 samples (96- 120 hrs of life) (82.3%)
8.7 Timely receipt of sample in the lab	95-99%	11,135 samples received on time (93%)
8.8 Timely second sample for CF screening	95% taken on day 21-24	5 out of 8 samples (62.5%)
8.9 Timely second sample for borderline CHT screening	95 – 99%	22 out of 36 samples (61%)
8.10 Timely second sample for CHT for preterm infant	95 – 99%	73 out of 117 samples (62.3%)
8.11 Timely processing CHD & IMD	Clinical referral within 3 days – 100%	All referred by 2 days
8.12 Timely entry into clinical care	IMDs appt by 14 days – 100%	No babies identified with IMD
	CHT appt by 21 days – 100%	Appointed by 18-19 days
	CF and HCU by appt by 28 days – 95-100%	Appointed by 10-12 days
	CF appt by 35 days – 80- 100%	Appointed by 24-31 days

The main areas which did not reach the expected performance levels were:

Timely sample collection within maternity– 82.3%

Timely receipt of sample in the lab – 93%

Timely second sample for CF screening – 62.5%

Timely second sample for borderline CHT screening – 61%

Timely second sample for borderline CHT pre term – 62.3%

#### 2.10. 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.

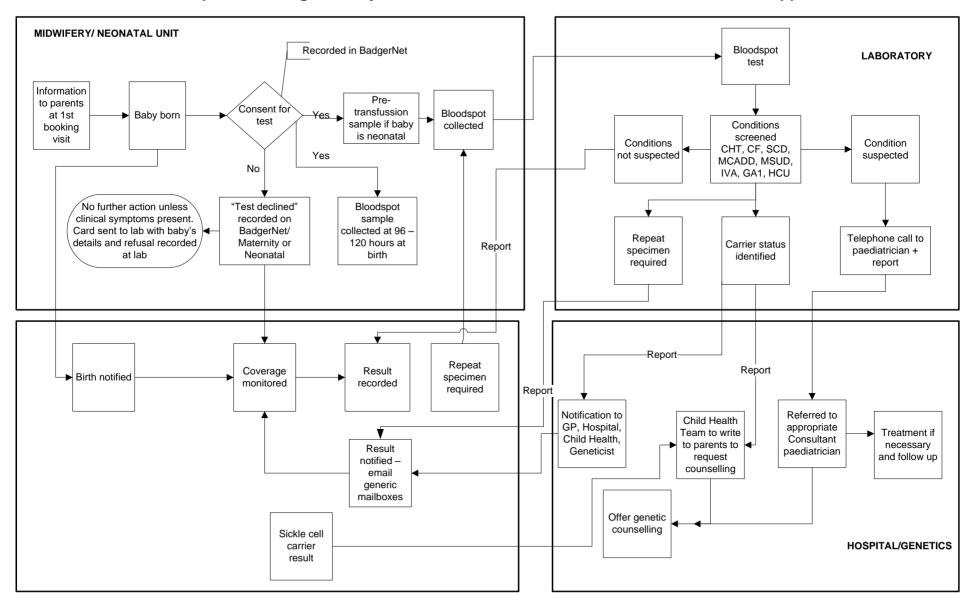
The results of the Bloodspot test are recorded against the individual child's record held within the Scottish Immunisation and Recall System (SIRS) application that supports the failsafe processes for newborn bloodspot screening.

#### 2.11. Challenges and Service Improvements

- Review Standing Operating Procedures to meet KPI requirements
- Support parents whose children are identified as carriers of Sickle Cell Disease to access genetic counselling.
- Ensure that the website with information about haemoglobinopathies for staff and parents in available on staff net and the Badger Net App.

### **NHSGGC Newborn Bloodspot Screening Pathway**

#### Appendix 2.1



# Members of Newborn Bloodspot Screening Steering Group As at March 2018

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

Mr Paul Burton Information Manager

Dr Elizabeth Chalmers Consultant Paediatric Haematologist

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Ms Barbara Cochrane Metabolic Dietician

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Dr Peter Galloway Consultant Clinical Biochemist

Mrs Jaki Lambert Lead Midwife

Dr Helen Mactier Consultant Neonatologist

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Ms Elizabeth Rennie Programme Manager

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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 in babies as well mild and unilateral losses.

Of the 11,760 eligible babies, 11,619 were screened for hearing loss giving an uptake of 98.8%.

1,148 (9.9%) babies required a second stage follow up and, of these, 170 (1.5%) babies were referred to audiology. Forty-five babies were confirmed with a hearing loss (0.3% of the screened population). Twenty babies had confirmed bilateral hearing loss and 25 babies had confirmed unilateral hearing loss.

141 (1.2%) babies did not complete the screening programme, of these 10 parents declined or withdrew consent. The rest included babies who did not attend for screening (94), are deceased (20) or have moved away (3) 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 programme is offered to all newborns by 4 weeks of corrected age. The corrected age is the actual age in weeks plus the number of weeks the baby was preterm. 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

A second screening test may be required if the baby does not pass the initial test. This can be because the baby was unsettled during the test, there was fluid or a temporary blockage in the ear or the baby has a hearing loss.

Detailed screening pathway is shown in Appendix 3.1.

#### 3.5. Delivery of NHSGGC Universal Newborn Hearing Screening Programme

The uptake of Newborn Hearing Screening is high across all areas and ranged from 97.8% in Glasgow North East to 99.4% in Renfrewshire (**Table 3.1**).

Table 3.1 Percentage Uptake for newborn hearing screening by HSCP

HSCP	Not Screened	Screened	Total	% Uptake
East Dunbartonshire	7	926	933	99.2
East Renfrewshire	7	849	856	99.2
Glasgow North East	45	2012	2057	97.8
Glasgow North West	28	2016	2044	98.6
Glasgow South	33	2599	2632	98.7
Inverclyde	5	669	674	99.3
Renfrewshire	10	1687	1697	99.4
West Dunbartonshire	6	861	867	99.3
Total	141	11619	11760	98.8

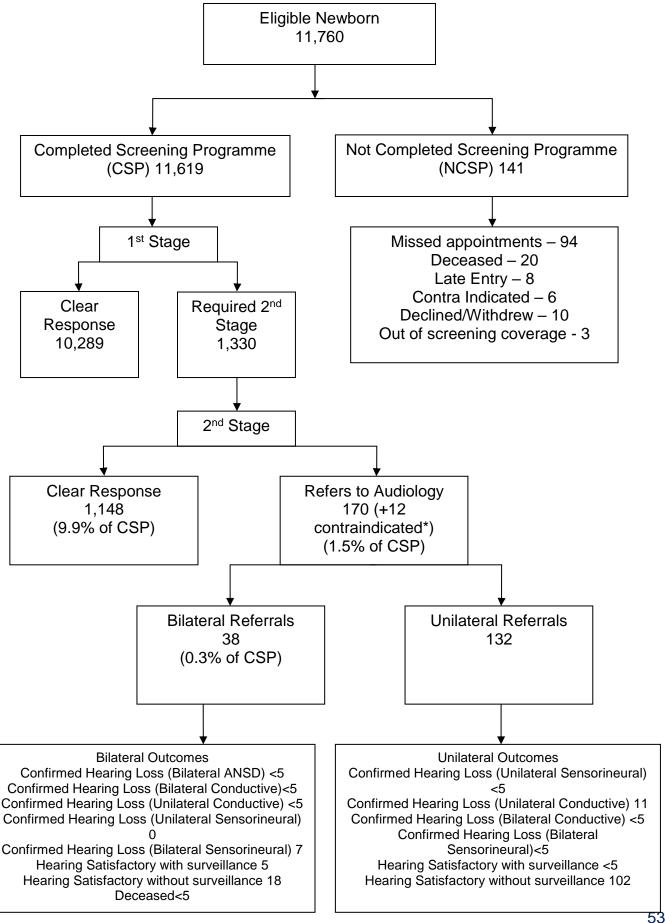
Source: Scottish Birth Record (SBR) Extracted: August 2019

Of the 11,760 eligible babies, 11,619 were screened for hearing loss giving an uptake of 98.8%.

1,148 (9.9%) babies required a second stage follow up and, of these, 170 (1.5%) babies were referred to audiology. Forty-five babies were confirmed with a hearing loss (0.3% of the screened population). Twenty babies had confirmed bilateral hearing loss and 25 babies had confirmed unilateral hearing loss.

141 (1.2%) babies did not complete the screening programme, of these 10 parents declined or withdrew consent. The rest included babies who did not attend for screening (94), are deceased (20) or have moved away (3) from their current home address or transferred to another Board area. (Figure 3.1).

Figure 3.1 Summary of NHSGGC Residents Universal Newborn Hearing Screening activity for period 1 April 2018 to 31 March 2019



#### **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 complete the 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

#### **Definitions - Outcomes**

Hearing Under assessement: all babies who have referred from the screen but have not attended for diagnostic tested at time report was compiled.

Incomplete: 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 or more.

Source: Scottish Birth Record (SBR); Extracted August 2019

### 3.6. Universal Newborn Hearing Screening KPIs 2018-19

7.1The proportion of babies eligible for UNHS for whom the screening process is complete by 4 weeks corrected age	11619 completed screening i.e. 98.8%	UNHS: Coverage Essential ≥ 98% Desirable ≥99.5%
7.4 The proportion of well babies tested using the AABR protocol who do not show a clear response in both ears at AABR1	1330 required 2 <sup>nd</sup> stage 11.4%+	UNHS: Test Performance - (3) Referral rate for AABR1 for well babies Essential ≤15% Desirable ≤12%
7.5 The proportion of babies with a screening outcome who require an immediate onward referral to audiology for a diagnostic assessment	170 referred to Audiology 1.5%	UNHS: Test Performance - (4) Referral rate to diagnostic audiology assessment Essential ≤15% Desirable ≤12%
7.6 The proportion of babies with a no clear response result in one or both ears or other result that require an immediate onward referral for audiological assessment who receive an appointment within the required timescale. The required timescale is either 4 weeks of scan completion or by 44 weeks gestational age.	86.7% (151/174)	UNHS: Time from screening outcome to initial appointment offered for = audiology assessment Essential ≥97% Desirable ≥99%
7.7 The proportion of babies with a no clear response result in one or both ears or other result that requires an immediate onward referral for audiological assessment who receive	75.9% (132/174)	UNHS: Time from screening outcome to attendance at an audiology assessment appointment

an appointment within the required	Essential ≥90%
timescale. The required timescale is	Desirable ≥95%
either 4 weeks of scan completion or	
by 44 weeks gestational age.	

## 3.7. Information Systems

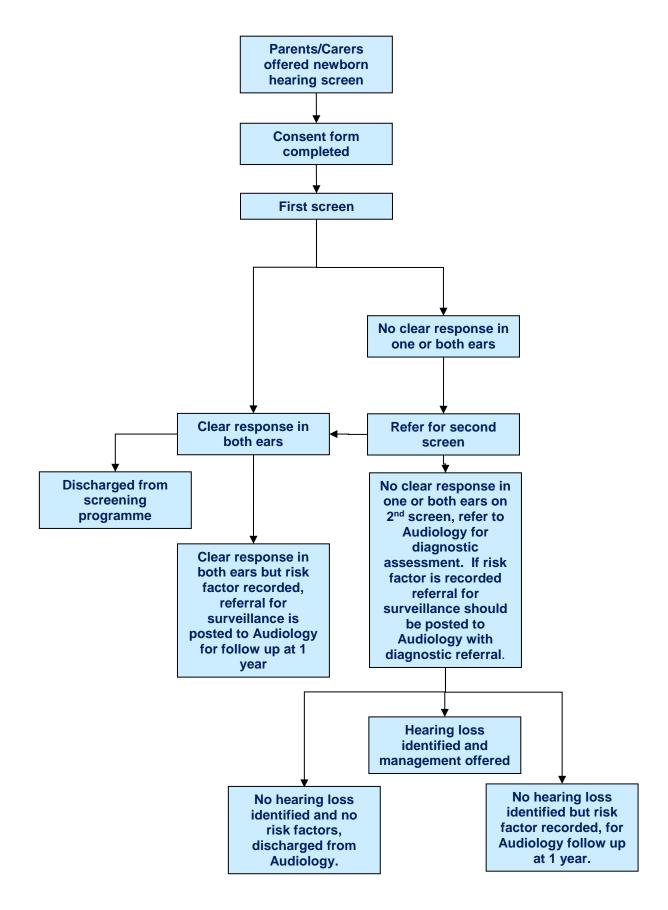
The Universal Newborn Hearing Screening programme is supported by the Scottish Birth Record (SBR) to deliver hearing screening.

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.

#### 3.8. Challenges and Future Priorities

- Meet service KPIs.
- 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.

#### **NHSGGC Universal Newborn Hearing Screening Pathway**



#### Appendix 3.2

# **Universal Newborn Hearing Screening Programme Steering Group As at March 2018**

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

Paul Burton Information Manager

Ms Isobel Cook Midwife/Screener, Argyll and Bute

Mrs Dorothy Finlay
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Lead Midwife
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Ms Fiona Jarvis Specialist Speech and Language Therapist

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Dr Andrew Powls Consultant Neonatologist

Mrs Uzma Rehman Public Health Programme Manager
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Ms Vivien Thorpe Clinical Scientist

## **Chapter 4 - Child Vision Screening**

### Summary

#### **Pre-school Vision Screening Programme**

Vision Screening is routinely offered to all pre-school age children resident in NHS Greater Glasgow and Clyde areas. 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 can develop in adulthood. Most problems can be treated using spectacle lenses to correct any refractive error and occlusion therapy to treat strabismus (squint) – mainly using eye patches.

In 2018-19,12,714 children aged between four to five years old were identified using the Community Health Index System as being eligible for pre-school vision screening.

Overall uptake was 85.4% (10,853). Highest uptake was in Inverclyde 93.8% (712) and the lowest in Glasgow South 79.6% (2134). The highest uptake was among children of Chinese ethnicity at 89.1% (204), followed by White British (7160) and White Irish (1265) where uptake was 87.5%. The lowest uptake was among the group whose ethnic origin could not be classified at 72.7% (194)

Of the 10,853 children screened, 7,317 (67.4%) had a normal result, this ranged from 74% (1221) in Renfrewshire to 59.2% (1009) in Glasgow North East.

Of the 2,652 (24.4%) children referred for further assessment, 1,276 (29.2%) were from the most deprived area. The highest proportion of children screened that were referred for further investigation was in Glasgow South 30.3% (646) and Glasgow North East 30.2% (514). The lowest was 15.9% (113) in Inverciple.

695 (6.4%) children were already attending an eye clinic service ranging from 4.4% (49) in East Dunbartonshire to 9.1% (65) in Inverclyde.

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

In 2018-19, 12,503 Primary 7 school children were eligible for a vision test and 8,331 (66.6%) were tested. Highest uptake was in Inverclyde 87.9% (747) and the lowest uptake in West Dunbartonshire 54.6% (595). The uptake was highest among children living in the least deprived areas (80.9%) compared to 56.9% for children living in the most deprived areas. Highest uptake was among children of Asian or Asian British Indian origin 72.0% (152) and the lowest uptake 48.6% (90) among children in the group whose ethnic origin could not be classified.

Of the 8,331 children screened for vision testing, 1,434 (17.2%) were already wearing prescription spectacles. The highest percentage wearing glasses was in Glasgow South 20.5% (304) and the lowest in East Dunbartonshire 13.7% (127).

The highest percentage of pupils identified with visual defects was in Glasgow South 22.9% (340) compared to 7.8% (94) in Renfrewshire. Visual defects were nearly

double in percentage; 19.6% (553) in children from the most deprived quintile compared to the most affluent quintile 10.4% (209).

Of the 6899 (82.8%) children screened using the Snellen test, 81.6% (5633) were recorded with an acuity of 6/6 which is normal. The highest percentage of children not wearing glasses and identified with poor acuity of 6/9 lived in Glasgow South (22.3%) compared to the lowest percentage in Renfrewshire (5.7%).

The highest percentage of children already wearing glasses and identified with poor acuity of 6/12 or worse was in East Renfrewshire 7.2% of and the lowest in Inverclyde 2.2%.

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#### **Pre-school Vision Screening Programme**

#### 4.1. Background

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

Amblopia 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 can develop in adulthood. 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.

The most common cause of poor vision is refractive error.

### 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 2014 and 28 February 2015 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 2017/18

In 2018-19, 12,714 children aged between four to five years old were identified using the Community Health Index System as being eligible for pre-school vision screening.

5,282 (41.5%) of all pre-school children within NHSGGC live in the most deprived quintile. The majority of these children are resident within the Glasgow City sectors 3849 (72.8%) (Table 4.1)

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

	SIMD Quintile 2016								
	Most de	prived	1	T	Least deprived				
HSCP	1	2	3	4	5	Total			
East Dunbartonshire	73	193	60	205	693	1224			
East Renfrewshire	64	104	88	153	764	1173			
Glasgow North East	1490	198	207	212	12	2119			
Glasgow North West	1036	276	191	161	341	2005			
Glasgow South	1323	527	416	247	168	2681			
Inverclyde	368	104	99	86	102	759			
Renfrewshire	490	358	288	293	365	1794			
West Dunbartonshire	438	278	114	89	40	959			
Total	5282	2038	1463	1446	2485	12714			
% of Total	41.5	16.0	11.5	11.4	19.5				

Source: Child Health - Pre-School

Date Extracted: July 2019

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 95.0% (911) and South Glasgow the lowest, 84.7% (2270 (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	1224	1126	92.0	98	8.0
East Renfrewshire	1173	1103	94.0	70	6.0
Glasgow North East	2119	1811	85.5	308	14.5
Glasgow North West	2005	1739	86.7	266	13.3
Glasgow South	2681	2270	84.7	411	15.3
Inverclyde	759	717	94.5	42	5.5
Renfrewshire	1794	1696	94.5	98	5.5
West Dunbartonshire	959	911	95.0	48	5.0
Total	12714	11373	89.5	1341	10.5

Source: Child Health - Pre-

School Date Extracted: July 2019

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 89.1% (204), followed by White British (7160) and White Irish (1265) where uptake was 87.5%. The lowest uptake was among the group whose ethnic origin could not be classified at 72.7% (194) (Table 4.3).

Table 4.3 Pre-school Vision Screening Uptake by Ethnicity

2001 Census Ethnic Group	Not Screened	Screened	Total	% Screened
White - British	1027	7160	8187	87.5
White - Irish	180	1265	1445	87.5
White - any other white background	205	640	845	75.7
Asian or Asian British - Indian	54	202	256	78.9
Asian or Asian British - Pakistani	111	490	601	81.5
Asian or Asian British - Bangladeshi	12	48	60	80.0
Asian or Asian British - Other Asian	2	12	14	85.7
Black or Black British - Caribbean	2	10	12	83.3
Black or Black British - African	38	163	201	81.1
Other ethnic groups - Chinese	25	204	229	89.1
Other ethnic groups - any other ethnic group	132	465	597	77.9
Unclassified	73	194	267	72.7
TOTAL	1861	10853	12714	

10,853 (85.4%) children were screened in 2018-19 representing a decrease of 1.4% from the previous year. The highest uptake was in Inverclyde HSCP 93.8% (712) and the lowest in Glasgow North East 80.5% (1705).

67.4% (7310) children screened had a normal result, this ranged from 74% (1221) in Renfrewshire to 59.2% (1010) in Glasgow North East.

Overall 24.4% (2,652) children screened were referred for further investigations. The referral rates varied from 15.9% (113) in Inverciyde to 30.3% (646) in Glasgow South.

The percentage of children screened that were already attending an eye clinic was 6.4% (693), ranging from 4.4% (49) in East Dunbartonshire to 9.1% (65) in Inverciyde. (Table 4.4).

Table 4.4 Pre-school Vision Screening Uptake and Outcomes by HSCP Area 2018 to 2019

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	% Already attending Eye Clinic
East Dunbartonshire	1224	1123	101	91.7	71.7	22.3	1.7	4.4
East Renfrewshire	1173	1050	123	89.5	72.6	21.0	0.8	5.6
Glasgow North East	2119	1705	414	80.5	59.2	30.2	2.9	7.7
Glasgow North West	2005	1639	366	81.7	64.0	27.5	2.0	6.5
Glasgow South	2681	2134	547	79.6	62.5	30.3	1.1	6.1
Inverclyde	759	712	47	93.8	72.2	15.9	2.8	9.1
Renfrewshire	1794	1650	144	92.0	74.0	17.7	2.3	6.0
West Dunbartonshire	959	840	119	87.6	73.3	19.5	0.8	6.3
Total	12714	10853	1861	85.4	67.4	24.4	1.8	6.4

Source: Child Health - Pre-School

School Date Extracted: July 2019

The uptake of screening was highest among children living in the most deprived areas 4363(82.6%) compared to 2252 (90.6%) among children living in the least deprived areas.

The proportion of children with a normal result ranged from 60.6% (2644) among children living in the most deprived area to 76.4% (1720) in the least deprived area.

A significantly larger proportion of children living in the most deprived areas were referred for further assessment, recalled or were already attending a clinic. Of the 2,652 (24.4%) children referred for further assessment, 29.2% (1,276) were from the most deprived area compared to 18% (406) from the least deprived area.

198 (1.8%) children were recalled back to be screened due to difficulties screening their vision during the first screen.

Of the 693 (6.4%) children already attending an eye clinic, 333 (7.6%) were from the most deprived area **(Table 4.5).** 

Table 4.5 Pre-school Vision Screening Uptake and Outcomes by SIMD 2018-19

	No. of Eligible	Number of Children		No Abnormality Detected			%		%	Already Attending	% Already Attending
SIMD	Children	Screened	% Uptake	(NAD)	% NAD	Referred	Referred	Recall	Recall	Clinic	Clinic
1 (Most Deprived)	5282	4363	82.6	2644	60.6	1276	29.2	110	2.5	333	7.6
2	2038	1739	85.3	1160	66.7	435	25.0	34	2.0	110	6.3
3	1463	1231	84.1	848	68.9	290	23.6	14	1.1	79	6.4
4	1446	1268	87.7	938	74.0	245	19.3	19	1.5	66	5.2
5 (Least Deprived)	2485	2252	90.6	1720	76.4	406	18.0	21	0.9	105	4.7
Total	12714	10853	85.4	7310	67.4	2652	24.4	198	1.8	693	6.4

Source: Child Health - Pre-School

Date Extracted: July 2019

The Pre- school vision screening summary of activity for the service in NHS Greater Glasgow and Clyde for the school year 2018-19 is in Figure 4.1.

9429 children were screened in Nurseries and 6,366 (67.1%) had a normal result, 2,276 (24.1%) were referred and 643(6.8%) were already attending an eye clinic.

Those not screened in nursery were invited to attend the hospital based service. 1391 children were screened within a hospital setting, 952 (68.4%) had a normal result, 367 (26.3%) were referred and 49 (3.5%) were already attending an eye clinic.

The uptake of screening was highest among children living in the most deprived areas 4363 (82.6%) compared to 2252 (90.6%) among children living in the least deprived areas.

The proportion of children with a normal result ranged from 60.6% (2644) among children living in the most deprived area to 76.4% (1720) in the least deprived area.

A significantly larger proportion of children living in the most deprived areas were referred for further assessment, recalled or were already attending a clinic. Of the

2,652 (24.4%) children referred for further assessment, 29.2% (1,276) were from the most deprived area compared to 18% (406) from the least deprived area.

198 (1.8%) children were recalled back to be screened due to difficulties screening their vision during the first screen.

Of the 693 (6.4%) children already attending an eye clinic, 333 (7.6%) were from the most deprived area (**Table 4.5**).

Table 4.5 Pre-school Vision Screening Uptake and Outcomes by SIMD 2018-19

	No. of Eligible Children	Number of Children Screened	% Uptake	No Abnormality Detected (NAD)	% NAD	Referred	% Referred	Recall	% Recall	Already Attending Clinic	% Already Attending Clinic
1 (Most Deprived)	5282	4363	82.6	2644	60.6	1276	29.2	110	2.5	333	7.6
2	2038	1739	85.3	1160	66.7	435	25.0	34	2.0	110	6.3
3	1463	1231	84.1	848	68.9	290	23.6	14	1.1	79	6.4
4	1446	1268	87.7	938	74.0	245	19.3	19	1.5	66	5.2
5 (Least Deprived)	2485	2252	90.6	1720	76.4	406	18.0	21	0.9	105	4.7
Total	12714	10853	85.4	7310	67.4	2652	24.4	198	1.8	693	6.4

Source: Child Health - Pre-School

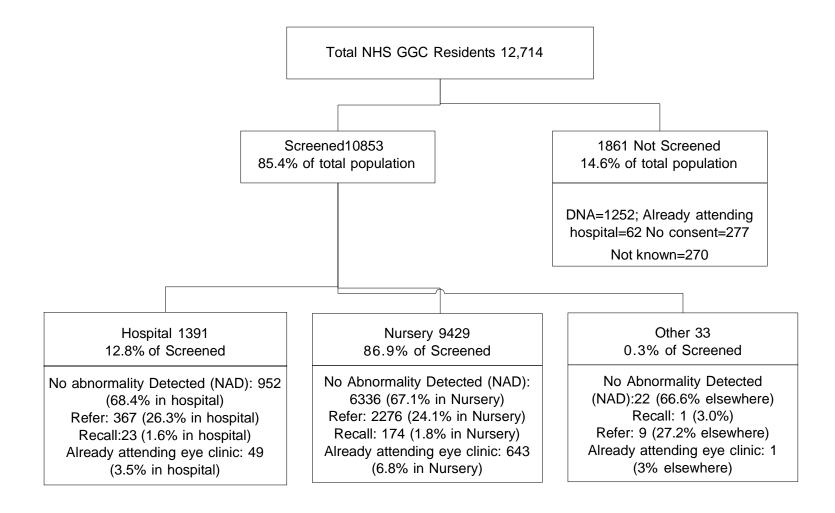
Date Extracted: July 2019

The Pre- school vision screening summary of activity for the service in NHS Greater Glasgow and Clyde for the school year 2018-19 is in Figure 4.1.

9429 children were screened in Nurseries and 6,366 (67.1%) had a normal result, 2,276 (24.1%) were referred and 643 (6.8%) were already attending an eye clinic.

Those not screened in nursery were invited to attend the hospital based service. 1391 children were screened within a hospital setting, 952 (68.4%) had a normal result, 367 (26.3%) were referred and 49 (3.5%) were already attending an eye clinic.

Figure 4.1 Summary of NHSGGC Pre-School Vision Screening Activity 2018-19



Source: Child-Health-Pre-School Data extracted: September 2019

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

### 4.7. P7 Eligible Population

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

### 4.8. 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 also carried out on children who already have glasses.

### 4.9. P7 Vision Screening Pathway

P7 vision screening takes place in school and is carried out by a Healthcare 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.

The referral pathway for those with abnormal results is to the local community optometrist:

- 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.
- Children who have specific visual abnormalities leading to visual impairment, if not already known are also 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 needs urgent assessment and management.

### 4.10. Delivery of Primary 7 School Vision Screening Programme 2017 to 2018

In 2018-19, 12,503 Primary 7 school children were eligible for a vision test of which 8331 (66.6%) were tested. The highest delivery was in Inverclyde 87.9% (747) and the lowest was in East Dunbartonshire at 54.6% (595). **(Table 4.6).** 

Table 4.6 NHSGGC Primary 7 vision screening uptake by HSCP, 2018-19

	Not			
HSCP (School)	Screened	Screened	Total	% Uptake
East Dunbartonshire	350	926	1276	72.6
East Renfrewshire	265	1097	1362	80.5
Glasgow North East	663	1039	1702	61.0
Glasgow North West	694	1243	1937	64.2
Glasgow South	916	1482	2398	61.8
Inverclyde	103	747	850	87.9
Renfrewshire	686	1202	1888	63.7
West	495	595	1090	
Dunbartonshire				54.6
Total	4172	8331	12503	66.6

Source: CHSP\_PS, August 2019

Analysis of the number and percentage of children screened by ethnicity shows that the highest uptake was among children of Asian or Asian British Indian children at 72% (152) and the lowest uptake was among those unclassified by ethnic group 48.6% (90) (Table 4.7)

Table 4.7 NHSGGC Primary 7 Screening Uptake by ethnicity, 2018 to 2019

2001 Census Ethnic Group	Not Screened	Screene	Total	% Screened
White - British	2756	5766	8522	67.7
White - Irish	532	1081	1613	67.0
White - any other white	241	38	627	61.6
background		6		01.0
Asian or Asian British - Indian	59	15	211	72.0
Asian or Asian British -	19	36	562	64.9
Pakistani		5		04.9
Asian or Asian British -	23	23	4	50.0
Bangladeshi			6	30.0
Asian or Asian British - Any	5	4	9	44.4
Other Asian Background				77.7
Black or Black British -	2	2	4	50.0
Caribbean				00.0
Black or Black British - African	61	10	167	63.5
Other ethnic groups - Chinese	45	83	128	64.8
Other ethnic groups - any other	156	27	429	63.6
ethnic group		3		03.0
Unclassified	95	90	185	48.6
Total	4172	8331	12503	66.6

P7 vision screening varied according to SIMD (child) with the most deprived quintile uptake recorded as 56.9% (2819) compared to 80.9% (2012) in the most affluent areas.

Table 4.8 NHSGCC Primary 7 Screening uptake by SIMD (child) 2018-19

SIMD Quintile	Not			%
2016 (Child)	Screened	Screened	Total	Uptake
1 (Most Deprived)	2139	2819	4958	56.9
2	749	1269	2018	62.9
3	443	1057	1500	70.5
4	365	1174	1539	76.3
5 (Least Deprived)	476	2012	2488	80.9
Total	4172	8331	12503	66.6

Source: CHSP\_PS, August 2019

Of the 12,503 children eligible for vision testing, 17.2% (1434) were already wearing prescription spectacles. The highest percentage wearing glasses was in Glasgow South 20.5% (304) and the lowest in East Dunbartonshire 13.7% (127) (Table 4.9).

Table 4.9 NHSGGC mainstream schools primary 7 vision screened pupils 2018-19: wearing spectacles

	No			%
HSCP (School)	Spectacles	Spectacles	Total	Spectacles
East Dunbartonshire	799	127	926	13.7
East Renfrewshire	936	161	1097	14.7
Glasgow North East	861	178	1039	17.1
Glasgow North West	1013	230	1243	18.5
Glasgow South	1178	304	1482	20.5
Inverclyde	603	144	747	19.3
Renfrewshire	1016	186	1202	15.5
West Dunbartonshire	491	104	595	17.5
Total	6897	1434	8331	17.2

Source: CHSP\_PS, August

2019

Visual defects identified as part of the primary 7 screening process indicate that Glasgow South had the highest percentage of pupils 22.9% (340) with defects compared to 7.8% (94) in Renfrewshire. **Table 4.10** 

Table 4.10 NHSGGC primary 7 vision screened pupils (mainstream schools) 2018-2019: visual defect identified

	No Visual	Visual		% Visual
HSCP (School)	Defect	Defect	Total	Defect
East Dunbartonshire	832	94	926	10.2
East Renfrewshire	969	128	1097	11.7
Glasgow North East	804	235	1039	22.6
Glasgow North West	1045	198	1243	15.9
Glasgow South	1142	340	1482	22.9
Inverclyde	678	69	747	9.2
Renfrewshire	1108	94	1202	7.8
West Dunbartonshire	514	81	595	13.6
Total	7092	1239	8331	14.9

Source: CHSP\_PS, August 2019

Visual defects were nearly double in percentage; 19.6% (553) in children from the most deprived quintile compared to the most affluent quintile 10.4% (209)

**Table 4.11** 

Table 4.11 NHSGGC primary 7 vision screened pupils by SIMD 2018-2019: visual defect identified

SIMD Quintile 2016	No visual	Visual		% visual
(Child)	defect	defect	Total	defect
1 (Most Deprived)	2266	553	2819	19.6
2	1050	219	1269	17.3
3	918	139	1057	13.2
4	1055	119	1174	10.1
5 (Least Deprived)	1803	209	2012	10.4
Total	7092	1239	8331	14.9

Source: CHSP\_PS, August 2019

Of the 8331 children screened, 6899 (82.8%) were screened using the Snellen test and 81.6% (5633) of these children were recorded with an 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 percentage of children not wearing glasses and identified with poor acuity of 6/9 lived in Glasgow South 22.3% and the lowest percentage in Renfrewshire 5.7%.

East Renfrewshire had the highest percentage of 7.2% of children already wearing glasses and identified with poor acuity of 6/12 or worse and Inverclyde had the lowest percentage at 2.2%. **Table 4.12** 

Table 4.12 NHSGGC residents primary 7 vision screened pupils (mainstream schools) 2018-19 poor acuity identified

	Total Number of children	Snellen	% Snellen	Acuity	% Acuity	Acuity	% Acuity	Acuity 6/12 or	% Acuity 6/12 or
HSCP (School)	Screened	Test	Test	6/6	6/6	6/9	6/9	worse	worse
East Dunbartonshire	926	799	86.3	704	88.1	70	8.8	25	3.1
East Renfrewshire	1097	938	85.5	805	85.8	65	6.9	68	7.2
Glasgow North East	1039	861	82.9	621	72.1	184	21.4	56	6.5
Glasgow North West	1243	1013	81.5	809	79.9	158	15.6	46	4.5
Glasgow South	1482	1178	79.5	832	70.6	263	22.3	83	7.0
Inverclyde	747	603	80.7	534	88.6	56	9.3	13	2.2
Renfrewshire	1202	1016	84.5	921	90.6	58	5.7	37	3.6
West Dunbartonshire	595	491	82.5	407	82.9	63	12.8	21	4.3
Total	8331	6899	82.8	5633	81.6	917	13.3	349	5.1

Source: CHSP\_PS, August 2019

### 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 re-procured by NHS Scotland.

### 4.12. Pre- school and P7 Vision Screening Challenges and Future Priorities

- Ensure the co-operation of all nurseries to allow screening to take place taking into account GDPR requirements. Uptake is far higher in children who attend nursery (87.3%) compared to those not in nursery who are asked to attend hospital (12.4%).
- Improve the recording of children who attend an Optometrist as a result of prevision or Primary 7 vision screening.
- 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 (March 2018)

Dr Emilia Crighton Head of Health Services Section (Chair)

Mrs Denise Bratten Optometrist

Mr Paul Burton Information Manager

Mrs Sandra Simpson Assistant Screening Programme Manager

Ms Samara Hodi Head of Optometry

Mrs Patricia Mackay Team Lead Children & Families, South Glasgow

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

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

Mrs Uzma Rehman Programme Manager, Public Health

Mrs Diane Russell Lead Orthoptist

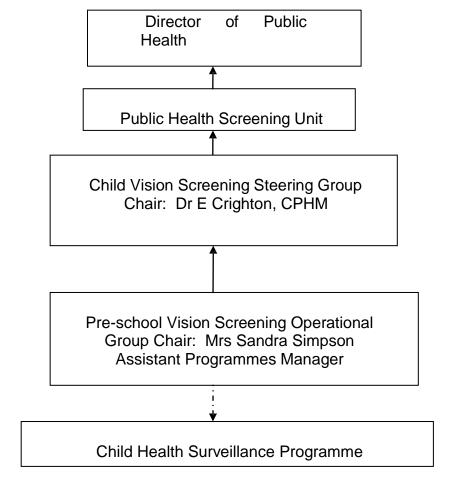
Ms Elaine Salina Principal Optometrist

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**



Key:
\_\_\_\_Direct Reports
---- Network Link

# **Section 2**

# **Adult Screening**

## **Chapter 5 - Abdominal Aortic Aneurysm (AAA) 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.

The aim of AAA screening is the early detection and elective repair of symptomatic AAA in order to prevent spontaneous rupture. Screening is associated with a 40% reduction in aneurysm related mortality. All men aged 65 years in the NHSGGC 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. In 2018-2019 NHSGGC met all of the 10 programme KPIs.

In 2018-2019, 6,119 men aged 65 were invited to participate in the AAA screening programme. 4,942 (80.8%) took up screening, exceeding the minimum uptake standard of 70%. Forty one of these men (0.8%) were found to have an aneurysm measuring between 3.00 cm and 5.49 cm and are currently on surveillance. Less than 5 men (0.1%) had an aneurysm measuring 5.5 cm or more that required surgical assessment and intervention.

Uptake is poorest in the most socio-economically deprived areas (75.3% in SIMD 1 vs. 89.2% in SIMD 5) and among ethnic minorities (68.6% for Asian or Asian British and vs. 81.5% for White British). There are also lower uptake rates in some HSCPs that are not wholly explained by socio-economic deprivation.

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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.

Studies have found that approximately 7% of men aged 65 were found to have an AAA. 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. 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. 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 performance and quality of the programme is monitored via defined National AAA Screening Standards<sup>1</sup> and Key Performance Indicators (KPIs)<sup>2</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 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

<sup>&</sup>lt;sup>1</sup>http://www.healthcareimprovementscotland.org/our work/cardiovascular disease/screening for aaa /aaa\_screening\_standards.aspx (accessed October 2019)

<sup>&</sup>lt;sup>2</sup> http://www.isdscotland.org/Health-Topics/Public-Health/AAA-Screening/2018-03-06-AAA-KPI-Definitions.pdf (accessed October 2019)

(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

For the period 1st April 2018 to 31st March 2019, 6,119 men were eligible for screening. Of these, 4,942 men (80.8%) were screened before age 66 and 3 months. A further 52 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 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.

An overview of NHGGC AAA screening programme activity during 2018/19 is provided in **Figure 5.1**.

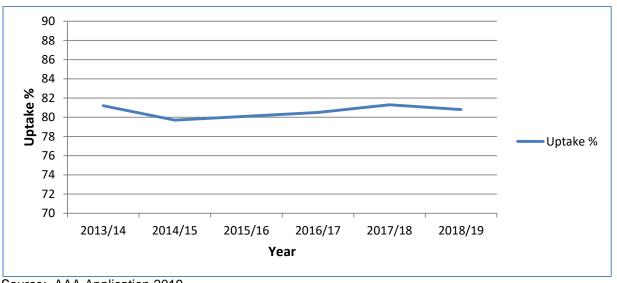
AAA screening was implemented across NHS Greater Glasgow and Clyde in February 2013. Uptake rate has remained consistent since then at about 80% (Figure 5.2).

INITIAL SCREEN Number of Discharged men declining / Number of men with from failing to an aorta <3cm programme respond to 4,860 4,860 screening invite Number of 1,177 Number of men with eligible men Surveillance an aorta 6,119 ≥ 3cm to 5.49cm 41 41 Number of men screened 4,942 Referral to Number of men vascular with an aorta ≥5.5cm services Number of men where the aorta could not be visualised/technical fail 35

Figure 5.1 Overview NHSGGC AAA screening programme activity, 2018/19

Source: AAA Application, September 2019

Figure 5.2 Uptake of AAA in NHSGGC from 2013/14 - 2018/19



Source: AAA Application 2019

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 13.9% lower than men residing in the least deprived areas (75.3% vs. 89.2% respectively) (**Table 5.1**).

Table 5.1 Uptake of AAA screening among eligible population by SIMD quintile for NHSGGC, 2018-2019

SIMD Quintile 2016	Not	Screened	Total	%
	Screened			Screened
1 (Most Deprived)	508	1,549	2,057	75.3
2	238	731	969	75.4
3	138	658	796	82.7
4	143	771	914	84.4
5 (Least Deprived)	150	1,233	1,383	89.2
Total	1,177	4,942	6,119	80.8

Source: AAA Application, September 2019

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

The majority (93.3%) of men invited were of white ethnic origin **(Table 5.2).** 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 5.2 Uptake of AAA screening among eligible population by ethnicity for NHSGGC, 2018-2019

2001 Census Ethnic Group	Not Screened	Screened	Total	% Screened
White - British	932	4,096	5,028	81.5
White - Irish	132	594	726	81.8
White - any other white background	34	81	115	70.4
Asian or Asian British	44	96	140	68.6
Black or Black British	2	5	7	71.4
Other ethnic groups - Chinese	10	35	45	77.8
Other ethnic groups - any other ethnic group	17	28	45	62.2
Unclassified	6	7	13	53.8
Total	1,177	4,942	6,119	80.8

Source: AAA Application, OnoMap, September 2019

The essential threshold for screening uptake (70%) was met in all HSCPs, with a highest uptake rate of 88.4% in East Dunbartonshire HSCP and the lowest uptake rate of 75.1% in Glasgow City HSCP North East & West Sectors, a difference in uptake of 13.3%.

However, when the known effects of deprivation and ethnicity are taken into account by standardisation (Standardised Uptake Rate – SUR), the variation in uptake within HSCPs persist, although slightly reduced (10.4% difference between highest and

lowest), with 86.4% SUR in Inverclyde HSCP compared to 76.0% SUR in Glasgow City HSCP – North West Sector **(Table 5.3).** This suggests that differences in local factors as well as demographic factors are also important in AAA screening uptake.

Table 5.3 Indirectly standardised uptake of AAA screening among eligible population by Health & Social Care Partnership in NHSGGC, 2018-2019

	Not Screened	Screened	Total	% Screened	SUR %	SUR %	SUR %
HSCP						LCI	UCI
East Dunbartonshire	77	587	664	88.4	83.4	76.7	90.2
East Renfrewshire	73	455	528	86.2	80.7	73.3	88.2
Glasgow North East Sector	211	637	848	75.1	78.3	72.2	84.3
Glasgow North West Sector	225	680	905	75.1	76.0	70.3	81.7
Glasgow South Sector	257	878	1135	77.4	80.0	74.8	85.3
Glasgow City	693	2,195	2,888	76.0	78.2	75.0	81.5
Inverclyde	63	395	458	86.2	86.4	77.8	94.9
Renfrewshire	183	867	1,050	82.6	81.1	75.7	86.5
West Dunbartonshire	88	443	531	83.4	85.2	77.3	93.2
Total	1,177	4,942	6,119	80.8		•	

Source: AAA Application, September 2019; OnoMap

SUR = Standardised Uptake Rate; UCI = Upper Confidence Intervals; LCI = Lower Confidence Intervals

To enable further local analysis of uptake rates, geographical mapping at data zone level was undertaken in 2017/18, revealing uptake in some pockets of NHSGGC were considerably lower than the overall rate of the HSCP Data zone maps for NHSGGC and by HSCP are available on the PHSU website<sup>3</sup>. Work continues with the service and HSCPs to develop actions to address geographical variation in uptake, as outlined in inequalities action plan (Appendix 5.3).

**Table 5.4** shows that 39 of the 6,119 men eligible for screening were registered with a learning disability (0.6%). Men who were registered with a learning disability were less likely to take up screening, compared to men who were not registered with a learning disability, (74.4% vs. 80.8%). This is an increase in uptake compared to 2017/18 programme statistics. However, it should be noted that numbers of individuals registered with a learning disability are low, therefore it caution should be taken when interpreting annual uptake data.

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<sup>&</sup>lt;sup>3</sup> AAA Screening Uptake Data Zone maps: <a href="https://www.nhsggc.org.uk/your-health/public-health/public-health-screening-unit/reports/">https://www.nhsggc.org.uk/your-health/public-health/public-health-screening-unit/reports/</a>

Table 5.4 Uptake of AAA by Learning Disability in NHSGGC, 2018-2019

<b>Learning Disability</b>	Not Screened	Screened	Total	% Screened
Rest of population	1,167	4,913	6,080	80.8
Registered	10	29	39	74.4
Total	1,177	4,942	6,119	80.8

Source: AAA Application, Learning Disability, September 2019 Chi-Square Tests Linear-by-Linear Association p = 0.026

People registered on PsyCIS have had at least one episode of psychosis which is typically seen in patients with a severe or enduring mental illness. **Table 5.5** shows that 61 of the 6,119 men eligible for screening were registered on PsyCIS (0.9%). These individuals had poorer uptake of AAA Screening, 65.6% compared to 80.9% in the rest of the population. However, as previously noted, numbers are small therefore caution should be applied when interpreting annual uptake data.

Table 5.5 Uptake of AAA among people with severe and enduring mental illness in NHSGGC, 2018-2019

PYSCIS	Not Screened	Screened	Total	% Screened
Rest of population	1,156	4,902	6,058	80.9
Registered	21	40	61	65.6
Total	1,177	4,942	6,119	80.8

Source: AAA Application, PSYCIS, September 2019 Chi-Square Tests Linear-by-Linear Association p = 0.006

### 5.5. Abdominal Aneurysm Screening Results

**Table 5.6** shows that 44 men (0.9%) had an enlarged aorta (≥3cm). Of these, 41 men (0.8%) had an aorta measuring between 3cm to 5.49cm, requiring surveillance scans and 3 men (0.1%) had a large aneurysm measuring 5.5 cm or more, requiring surgical assessment and intervention.

Table 5.6 Abdominal Aneurysm screening results for NHSGGC, 2018-2019

				Not	
Result Type	<3	3 - 5.49	>=5.5	Known	Total
External	3	0	0	0	3
Negative	4,860	0	0	0	4,860
Non Visualisation	0	0	0	30	30
Positive	0	41	3	0	44
Technical Fail	0	0	0	5	5
Total	4,863	41	3	35	4,942

Source: AAA Application, September 2019

### 5.6. AAA Mortality and Incident Audit

The Public Health Screening Unit leads a programme of audit of AAA screening. A multi-disciplinary group reviews all AAA related mortality and incidents in relation to the screening programme. This is an addition to the already established system of reviewing the cases of patients who have died from a ruptured aorta at regular Morbidity and Mortality meetings.

The Mortality and Incident Audit was established in autumn 2018 and all relevant cases since the programme began in 2013 were reviewed following national guidance. During 2018/19 audit, no further AAA related deaths were identified, in addition to those reported in 2017/18 annual report. The Audit group will continue to review AAA mortality annually following publication (August) National Records for Scotland Mortality data.

### 5.7. AAA Key Performance Indicators

The AAA programme KPIs cover information on: invitation and attendance at screening, the quality of screening, and vascular referrals. NHSGGC met all desirable /essential threshold for seven of the 10 KPIs for the year ending March 2019 (Appendix 5.2).

### 5.8. Quality Improvement

Healthcare Improvement Scotland's 2017 external quality assurance review of the AAA programme in Scotland<sup>4</sup> made a number of recommendations. In 2018 NHSGGC put plans in place to implement and monitor these, which are reviewed at each AAA steering group meeting. Key areas progressed are: robust governance and monitoring arrangements, job plans to include protected time to support the programme, patient experience is included, clinics risk assessed for lone working, mortality and incident audit, regular consideration of screening pathway data, and outcome data from vascular treatment is discussed by local governance groups.

### 5.9. 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.

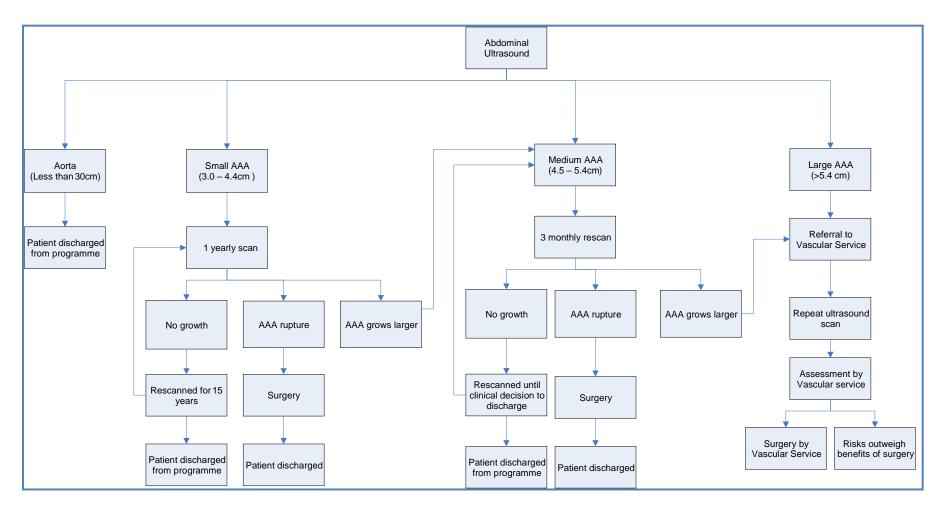
To undertake patient experience with men under surveillance for AAA.

The ongoing review and implementation of the NHSGGC Adult Screening Inequalities Action Plan (Appendix 5.3) to enable a more coordinated approach to reducing inequalities in uptake through targeted intervention plans.

<sup>&</sup>lt;sup>4</sup>http://www.healthcareimprovementscotland.org/our\_work/cardiovascular\_disease/screening\_for\_aaa /aaa\_screening\_review.aspx (Accessed 26th October 2018)

### Appendix 5.1

## **Positive Abdominal Aortic Aneurysm Screening Pathway**



# Abdominal Aortic Aneurysm Key Performance Indicators, NHS Greater Glasgow & Clyde (2015 – 2019)

KPI	Description	Essential Threshol d	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	Year ending 31 <sup>st</sup> March 2018	Year ending 31 <sup>st</sup> March 2019*
	ation and atten	dance				1		
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%	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%	80.1%	81.2%
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%	73.6%	75.4%
1.4a	Percentage of annual surveillance appointment s due where men are tested within 6 weeks of due date	≥ 90%	100%	93.3%	93.0%	94.0%	92.5%	95.3%

		1			ı	T	T	
1.4b	Percentage of quarterly surveillance							
	appointment							
	s due where	≥ 90%	100%	96.7%	98.6%	92.1%	87.4%	91.7%
	men are							
	tested within							
	4 weeks of							
	due date							
Quali	ty of screening	9						
2.1a	Percentage							
	of screening							
	encounters	< 3%	< 1%	1.6%	2.4%	2.8%	3.3%	2.5%
	where aorta	< 370	<b>170</b>	1.070	2.7/0	2.070	3.370	2.570
	could not be							
	visualised							
2.1b	Percentage							
	of men							
	screened	< 3%	< 1%	1.4%	2.1%	2.3%	2.6%	2.1%
	where aorta							
	could not be							
2.2	visualised							
2.2	Percentage							
	of screened							
	images that failed the							
	quality assurance	< 4%	< 1%	0.4%	1.4%	1.0%	1.1%	0.9%
	audit and							
	required							
	immediate							
	recall							
Refer	ral, clinical int	ervention an	d outcomes					
3.1	Percentage							
5.1	of men with							
	AAA≥5.5cm							
	seen by				400.0			400.0
	vascular	≥ 75%	≥ 95%	81.8%	100.0	100.0%	91.7%	100.0
	specialist				%	120.070		%
	within two							
	weeks of							
	screening							
3.2	Percentage							
	of men with							
	AAA≥5.5cm							
	deemed							
	appropriate							
	for							
	intervention/	≥ 60%	≥ 80%	77.8%	53.8%	62.5%	57.1%	60.0%
	operated on							
	by vascular							
	specialist							
	within eight							
	weeks of							
	screening							

<sup>\*2018-19</sup> KPI data awaiting validation

Source: ISD May 2019

Appendix 5.3

### **Inequalities Action Plan**

## **Progress report:**

# Widening access and addressing inequalities in adult screening programmes. Action plan for 2019-21

NHS Greater Glasgow and Clyde (NHS GGC)'s Public Health Directorate is responsible for co-ordinating and monitoring screening programmes across Greater Glasgow and Clyde, and Argyll & Bute (part of NHS Highland).

The Widening Access and Addressing Inequalities in Adult Screening Programmes Action Plan for 2019-21 outlined priorities and actions to widen access and address inequalities in relation to adult screening programmes.

This paper provides an update on progress of the actions and relevant developments in adult screening programmes.

# 2. Developments in the Scottish Breast Screening Programme

- (a) In July 2019, the Scottish Government announced a review of the Scottish Breast Screening Programme. The review, which is expected to take around a year, will be carried out by National Services Division (NSD), a part of NHS National Services Scotland, which commissions and coordinates the programme. The review will involve an appraisal of the programme, current pressures and future options for delivery. It will also look at advances in technology and ways to increase participation and address health inequalities.
- (b) In October 2019, the Information Services Division released **Scottish Breast Screening Programme Statistics** to 31 March 2018. This is the first release of statistics since April 2017 due to the implementation of the new digital mammography Scottish Breast Screening System. For the period 2015/16-17/18, 514,083 women aged 50-70 attended a routine breast screen appointment which equates to around 7 in 10 women (71.2%) taking up the invitation for screening. For the period 2015/16 -17/18, NHS Greater Glasgow & Clyde uptake was 65.8%. This meant it was one of four NHS Boards which did not meet the minimum acceptable uptake standard of 70%. The national uptake rate has been falling consistently since

2008/09-10/11 when it was 74.9%. Women from more deprived areas are less likely to attend for breast screening, with under 6 in 10 women from the most deprived areas going for screening compared with almost 8 in 10 women living in the least deprived areas. Currently, we are not able to access more detailed local data but it is hoped that this will follow in the near future.

### 3. Review of actions

### **ALL SCREENING**

- 1. Provide support to GP practices to access, analyse and use their data for planning and quality improvement purposes.
  - HSCPs and GP clusters are now able to access support for using their data through Local Intelligence Support Teams (LIST) employed through ISD Scotland. In addition to this national resource, NHS GGC Primary Care Development Officers continue to support GP clusters. Data sharing agreements to support the use of primary care intelligence are in progress. See also action 4.
- 2. Provide support to GP practices to maintain patient records including mobile number, appropriate read coding, identification and articulation of support needs.
- 3. Identify and address coding actions which may impact on eligibility status and patient communication.

The new GP contract has moved away from a detailed specification of requirements in relation to LD, but maintaining comprehensive disease registers in general practice remains an expectation. Further work is required to ensure consistency and quality of data in relation to recording of LD, and to agree how data will be extracted and used from practice systems to enable this to continue to be used to identify and address any inequalities in screening uptake. This will be taken forward in line with the forthcoming national template for data sharing with practices, a review of disease registers and the further development of primary care information for reporting on quality indicators.

4. Specify calls to action related to priority groups in screening when data sharing with GP practices and clusters.

This year, for the first time, standardised cluster level cervical and bowel screening uptake data has been shared with GP clusters among other public health priorities in cluster intelligence reports. Where uptake is lower than expected, clusters have been directed to resources which support quality improvement including health improvement teams and third sector

organisations as well as toolkits which can help practice staff to understand the barriers to attendance and use methods which could increase attendance. More than half of clusters also met Public Health Directorate staff in order to discuss reports further and help prioritise areas for quality improvement.

- 5. Utilise mapping of resources to develop patient and carer information pathways.
- 6. Increase use (distribution and support for understanding) of accessible patient information and digital displays as tools to aid informed participation.

All adult screening resources have been mapped. These include NHS and third sector resources. This has allowed us to identify information gaps more easily and to raise awareness of alternative formats through HSCPs and third sector organisations. In line with our Accessible Information Policy, we are able to have materials produced in additional alternative formats where a need has been identified or a patient has requested this. For example, in developing work related to cervical screening with women in Chinese communities, we have identified the need for patient information in Simplified Chinese.

Renfrewshire have utilised social media to promote cancer screening programmes through campaigns.

A national communications and engagement plan is in development to inform women of changes in the cervical screening programme. This will include updating Health Inequalities Impact Assessment for cervical screening communications to ensure the national communications strategy helps reduce inequalities and improve reach of our screening programme. See also Clyde Gateway actions 15 and 16 for campaigning work.

7. Develop a Learn Pro module to improve access to CPD on adult screening programmes for staff who are in a position to support informed participation.

Preliminary work on this has begun. A project brief and a costing have been undertaken.

8. Update protocols for providing access to screening adults from travelling communities and armed forces personnel.

Work on this is currently in progress.

9. Monitor screening uptake and engagement with the screening programmes in prisons within NHSGGC.

# 10. Support the implementation of the National Prison Healthcare Network recommendations for engagement with the population screening programmes in the prison setting.

A new practitioner post has been provisionally approved. This post will provide single point of contact for screening services. The post holder will also deliver training and cascade information about screening programmes to prison health care staff (and other staff as appropriate). We are currently working with screening services to update standard operating procedures regarding sub-population groups, including prisons. New national posters summarising screening programmes according to gender have been developed and distributed for use in prisons.

## 11. Work with third sector to support and promote screening programmes.

Cancer Research UK, Jo's Trust and Bowel Cancer UK (Scotland) continue to be our main third sector partners in relation to adult screening programmes. These organisations participate in our programme steering groups and deliver work in primary and acute care, working closely with both Public Health and HSCP Health Improvement teams.

A number of training and information sessions have been delivered by NHS GGC and third sector partners to NHS staff who work with people with learning disabilities and those who have severe and enduring mental illness.

In addition to the third sector organisations with a specific remit for cancer, HSCPs work with many third sector and community oranisations. Work with these organisations is important in order to raise awareness of adult screening programmes and to understand more about access barriers to screening. People First, for example, have contributed to the Clyde Gateway work and there is further work with the third sector planned for next year. See also action 26.

### **CERVICAL**

### 12. Clarify service specification on programme re GMS contract.

The cervical screening programme continues to be delivered in GP practices. Following the disbanding of the Quality and Outcomes Framework (QOF), the payment for cervical screening services is now included in GP Practices' Global Sum.

A new approach to cervical screening has been approved by the Scottish Government and will be introduced in early 2020. High risk HPV screening involves the same clinical examination but only women whose virology results are positive for specific types of HPV will have cervical cytology.

13. Introduce a steering group process to link the analysis of demographic data to to ensure campaigns and projects are targeted at areas with the lowest uptake rates or identify where a different course of action may be required.

Following an internal review of cervical screening was undertaken by Price Waterhouse Cooper as part of the 2017-18 internal audit plan approved by the Audit and Risk Committee. The Cervical Screening Governance Group has established a mechanism to use data to target targeting of promotional activities to those with low uptake including vulnerable or excluded groups.

14. Monitor the impact of the new GMS contract on screening uptake.

The new contract was introduced in April 2018. It is early yet to monitor impact; however, a broader evaluation of the Primary Care Improvment Plans agreed by the Primary Care Programme Board is underway and will look at issues including equality of access in primary care.

### **CERVICAL / BREAST**

- 15. Support peer to peer learning for adults with a learning disability in cervical and breast screening in the Clyde Gateway area.
- 16. Conduct tests of change in peer learning programme as part of the Clyde Gateway area project.

The Clyde Gateway programme of work is funded under the Screening Inequalities Fund. There have been three tests of change In GGC:

- Sandyford pop-up clinics: Use of data from the Scottish Cervical Call Recall System to invite non-engager to Saturday pop-up clinics to increase uptake of cervical screening.
- A peer learning approach to screening for women with learning disabilities using coproduction methods based on EMBRACES: ID, an evidence based programme.
- A marketing communications campaign to increase local awareness and knowledge of screening programmes.

The work is due to be completed by March 2020. Glasgow Centre for Population Health is working with Clyde Gateway to evaluate this work.

### **CERVICAL**

17. Test the use of teaser communication via a randomised control trial.

Development work for this action is ongoing. The proposal has been subject to changes following suggestions by the Scottish Government during the ongoing application process for the Screening Inequalities Fund. The main proposed change has been from teaser letter to SMS text

reminder aimed at women under 30 who may be in their first or second invitation cycle. In developing this work in line with this change, it has become clear that much of the learning will come from testing the legal and ethical processes involved in this work as well as the current limitations of our information and communication systems subject to ethical approval. This will help us to identify what would need to be changed in order to scale up the use of SMS technologies in screening programmes. Recent results from similar work undertaken by Public Health England in London suggest that the use of mobile technologies can increase engagement in cervical screening. Our proposed work aims to explore this further in relation to deprivation and HPV vaccination status.

# 18. Monitor the impact of HPV vaccination on uptake of cervical screening programme.

This will be undertaken as part of the routine reporting in the Screening Annual Report. Cervical screening uptake is highest in HPV vaccinated women when compared to the non-vaccinated women.

# 19. Review and update cervical screening toolkit following primary care staff focus groups.

The toolkit is currently on hold because a national one to due to be published.

# 20. Test of change: Increase appointment availability for cervical screening outwith standard office hours.

Also see actions 15 and 16. In addition, Health Improvement staff worked with two GP practicies to provide cervical screening drop-in clinics in East Dunbartonshire. These were successful in engaging women who had been identified as non-engagers. An important aspect of the tests of change, particularly for pop-up clinics is whether the approach is sustainable. Similar previous work in North East Glasgow identified operational barriers to providing an out of hours services in health centres.

# 21. Develop content and deliver staff learning and development to GP practice staff.

# 22. Provide opportunities for third sector organisations to contribute to NHS staff training.

Primary Care Support and Development continue to staff deliver cervical skills training. This training incorporates inequalities content such as supporting with women with learning disabilities. Cancer Research UK staff have also contributed training on increasing uptake and reducing

barriers to participation and programme updates. Cervical skill training has been delivered to practices nurses, colposcopy staff and Sandyford Sexual Health Services.

### 23. Provide targeted education to groups with lower uptake status.

See actions 15 and 16. There are also plans to deliver education to BME communities in 2020.

#### **BOWEL SCREENING**

### 24. Teaser letters for bowel screening.

NHSGGC reinstated the teaser letter to first time participants to coincide with the introduction of the FIT test.

### 25. Monitor the impact of FIT on uptake of the screening programme.

Monitoring of the impact of FIT is ongoing. Following the implementation of FIT, there has been a 3.9% increase in uptake of bowel screening across Scotland and a 4.1% increase within NHSGGC. This increase is evident for both sexes and across all deprivation quintiles. A research study of clinical outcomes associated with symptomatic FIT is currently being conducted by the University of Glasgow in partnership with NHS GGC.

### 26. Conduct tests of change in West Dunbartonshire.

West Dunbartonshire undertook a multi agency test of change aimed at improving the bowel screening uptake rates for people with learning disabilities. Following Caldicott approval, the National Bowel Screening Service was able to provide live updated data to the Learning Disability Team on the current cancer screening status of those individuals known to its service. This allowed staff within both the Learning Disabilities Team and staff from the Third Sector support agencies to provide a personalised letter, face to face health check and offer support to complete the screening test kit. This resulted in screening test kit completion or a recording of informed decision to decline to participate. For those individuals who were part of the baseline group and received our basic evidence-based intervention, 30% (14) went on to complete a screening test kit or made an informed decision to decline to participate. Of the individuals who were part of our PDSA, 70% (7) went on to complete a screening test kit or make an informed decision to decline to participate. The Learning Disabilities Team participated in bowel cancer awareness training provided by Cancer Research UK. Eleven local third sector agencies attended cancer awareness training provided by Bowel Cancer UK. The Learning Disability Team as part of West

Dunbartonshire's commissioning of third sector services, have written a number of new service contact specifications which will embed screening support activities and the recording of screening status as part of future third sector service contracts.

- 27. Support primary care awareness of FIT and symptomatic FIT.
- 28. Support GPs to use a test of change approach to promote bowel screening uptake.

Cancer Research UK have raised awareness of the role of symptomatic FIT in their work with primary care.

### **BREAST**

29. Assess feasibility of programme of service and community development where uptake is low.

A muli-agency programme of work to raise awareness and increase participation in screening in Govanhill is in progress. As part of this, the West of Scotland Breast Screening Service agreed to pilot the location a breast screening mobile unit close to the area, however, there was a lack of any suitable location for the mobile unit. This issue has now been resolved by the demolition of a wall at the New Victoria Hospital which has now created sufficient and appropriate space.

30. Support breast screening visits for women with disabilities.

Inequalities of access will be addressed in the current national Breast Screening Review. Work is also planned for next year in West Dunbartonshire to look at supporting women with learning disabilities to access breast screening. (It is recognised that many women with learning disabilities also have physical disabilities.)

### BREAST / AAA / DIABETIC RETINOPATHY

31. Routinely send a list of clinic venues with all initial invitation letters, so that people are aware that can change venue.

Options for this action will be raised with service managers at programme steering groups.

### AAA

32. Implement the evidence based recommendations from Public Health England to reduce inequalities.

We are currently improving local intelligence in order to inform evidence based recommendations at a local level. Inhouse research is being conducted on individuals under AAA surveillance. This will seek information on experience of the AAA monitoring process, how AAA has

impacted on their life, and suggestions for improvement with current process. Participant demographic questions will be based on the demographics known to affect engagement with AAA screening (e.g. comorbidities, learning disability or mental health issues, relationship status, scanning venue/distance to, postcode for SIMD/HSCP, etc). This will help us to identify issues linked to inequalities.

### **AAA / DIABETIC RETINOPATHY**

- 33. Increase awareness of programmes in primary care and in the most deprived communities.
- **34.** Analyse uptake by deprivation through datazone mapping.

  We undertook geographical mapping of uptake rates for cervical, bowel,

  AAA and DRS screening programmes at data-zone level.
- 35. Scope out potential to resource health improvement support at screening facilities.
- 36. Work with RNIB to promote DRS.
- 37. Support GP practices to use of SCI diabetes and accurately code patients.

These actions link to a broader programme of work linked to Moving Forward Together and to the Health Improvement Diabetes Prevention Programme. These are in development and will be reported in more detail once plans have been agreed.

## Members of Abdominal Aortic Aneurysm Screening Steering Group (at March 2018)

Dr Emilia Crighton Consultant in Public Health Medicine (Chair)

Mrs Karen Bell Clinical Services Manager, Surgery & Anaesthetics

Ms Lisa Buck Public Health Programme Manager

Mr Paul Burton Information Manager

Mrs Lin Calderwood HI&T Service Delivery Manager

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Mrs Lynn Ross General Manager, Diagnostics

Mr Wesley Stuart Lead Clinician

## **Chapter 6 – Bowel Screening Programme**

### **Summary**

Colorectal (Bowel) Cancer was the third most common cancer in Scotland for both men and women in 2017. Ninety four percent of bowel cancers detected are among people aged over 50 years of age. In 2017, 780 people (425 men and 355 women) residing in the Greater Glasgow and Clyde area were diagnosed with bowel cancer. In the same year, 364 people (190 men and 174 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 2017-19, 365,834 NHSGGC residents were invited to participate in the bowel screening programme. The overall uptake of screening was 56.8% (207,737), against a target of 60%. Uptake is poorest among men (54.34%), younger participants (aged 50-54 was 48.4%), socio-economically deprived residents (SIMD 1 was 47.1%), people with learning disabilities (38.9%), and among ethnic minorities (Asian or Asian British was 38.3%). There are also lower uptake rates in some HSCPs that are not wholly explained by socio-economic deprivation.

Overall, 3.0% (6,265 of 207,737) of completed screening tests were reported positive, meriting further investigation. Men have a higher positivity than women (3.6% vs. 2.5%); older people have higher positivity than younger people (4.1% aged 70-74 vs. 2.2% aged 50-54); and those living in our most deprived communities have higher positivity rates than the least deprived (4.1% vs. 2.1%).

Following the implementation of FIT in November 2017, there has been a 4.1% increase in uptake of bowel screening in NHSGGC.

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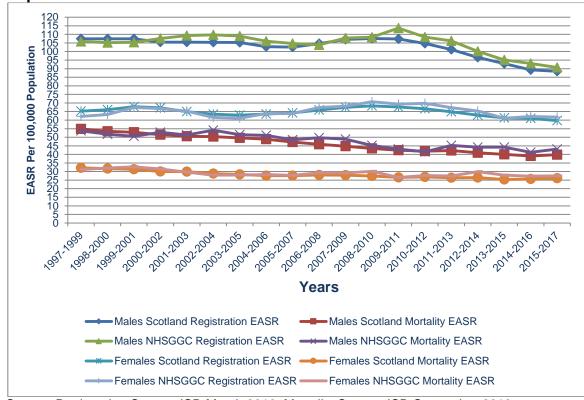
### 6.1. Background

Colorectal (Bowel) Cancer is the third most common cancer in Scotland for both men and women accounting for 11.7% of all cancers <sup>5</sup>. In 2017, the most recent year for which completed data is available, approximately 3,776 people in Scotland were newly diagnosed with the disease. Ninety four percent of bowel cancers detected are among people aged over 50 years of age<sup>6</sup>.

In 2017, 780 people (425 men and 355 women) residing in the NHSGGC area were diagnosed with bowel cancer. This gives an age-standardised incidence rate of 95.5 per 100,000 of the population for men, higher than the Scotland rate of 91.2 per 100,000. For women the age-standardised incidence rate is 60.9 per 100,000 of the population, higher than the Scotland rate of 56.1 per 100,000. In the same year, 364 people in NHSGGC (190 men and 174 women) with a diagnosis of bowel cancer died, giving an age-standardised mortality rate of 46.7 per 100,000 population for men and 29.1 per 100,000 population for women.

Standardised incidence and mortality rates over rolling 3 year periods for bowel cancer for NHSGGC and Scotland are illustrated in **Figure 6.1**.

Figure 6.1 Colorectal Cancer Registration & Mortality 1997-2017 (Rolling 3 Years) European Age Standardised Rate (EASR) Per 100,000 Population.



Source: Registration Source: ISD March 2019, Mortality Source: ISD September 2018

(Accessed November 2019)

<sup>&</sup>lt;sup>5</sup> https://www.isdscotland.org/Health-Topics/Cancer/Publications/2019-04-30/2019-04-30-Cancer-Incidence-Report.pdf (Accessed November 2019)

<sup>&</sup>lt;sup>6</sup> https://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables2017.asp?id=2276#2276

In the time period between 2007 and 2017, the age-standardised incidence rate of bowel cancer in Scotland decreased in both men and women (17.3% and 11.5% respectively) and mortality rates of bowel cancer in Scotland decreased in both men and women (11.0% and 6.4% respectively).

Recent decreases in incidence might reflect the removal of pre-malignant polyps at colonoscopies resulting from the Bowel Screening Programme.

The main preventable risk factors for bowel cancer are consumption of red and processed meats, overweight, alcohol consumption and smoking<sup>7</sup>.

### 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>8</sup> and National Bowel Screening Standards<sup>9</sup>.

### 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. 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

In November 2017 the quantitative Faecal Immunochemical Test (FIT) was introduced 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>10</sup>. Previous to this date, the Guaiac Faecal Occult Blood test (gFOBt) testing kit was used. The FIT is easier to do, requiring only one sample (rather than the three for gFOBt), and

<sup>&</sup>lt;sup>7</sup> https://www.isdscotland.org/Health-Topics/Cancer/Publications/2019-04-30/Cancer\_in\_Scotland\_summary\_m.pdf (Accessed November 2019)

<sup>8 &</sup>lt;a href="http://isdscotland.org/Health-Topics/Cancer/Bowel-Screening/">http://isdscotland.org/Health-Topics/Cancer/Bowel-Screening/</a> (Accessed November 2019)
9 <a href="http://www.healthcareimprovementscotland.org/our\_work/cancer\_care\_improvement/programme\_resources/bowel\_screening\_standards.aspx">http://www.healthcareimprovementscotland.org/our\_work/cancer\_care\_improvement/programme\_resources/bowel\_screening\_standards.aspx</a> (Accessed November 2019)
10 <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4482205/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4482205/</a> (accessed November 2019)

this gives it higher user acceptability. FIT is also more accurate meaning 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 the results to patient, GP Practice and Health Board. The patient is informed by letter, an electronic notification is sent to the patient's general practitioner and results of all positive tests are sent to the Health Board via an IT system.

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 as an alternative where appropriate to do so. If required, patients are then referred for further diagnostic investigations and treatment. Some patients may not be offered a colonoscopy, common reasons being an inability to tolerate any form of bowel prep, a recent change to health, a previous failed colonoscopy, or unsuitability due to physical incapability.

Anyone who has a positive result will automatically be invited again in 2 years time, unless a permanent exclusion is placed on their record. **Figure 6.2** provides an overview of the 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 patient will be invited to take part in bowel screening in two years' time.

Identify eligible residents Send test kit Perform screening Positive Process test kit and return result If positive – Refer to NHS Board to patient SCI Gateway Information Negative Pre-assessment Recall 2 years Colonoscopy CT Colonography Follow up as agreed in failsafe Other pathology Positive Surgery/oncology radiology Pathology Key: Scottish Bowel Screening Practices NHS Greater Glasgow and

Figure 6.2 Bowel Screening Pathway

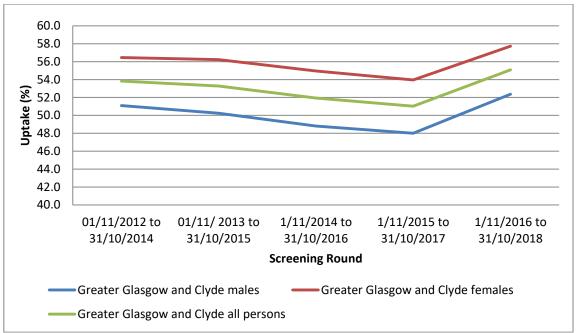
#### 6.5. Programme Performance and Delivery

The bowel screening programme KPIs 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 2016 and 31st October 2018.

NHSGGC does not meet the screening uptake KPI of 60%; the proportion of people with a positive screening result is higher than in the rest of Scotland resulting in higher proportional demand for colonoscopies; the waiting times for colonoscopy are longer than in the rest of Scotland and the quality of endoscopy (evidenced by completion rate and adenoma detection rate) is higher than the rest of Scotland.

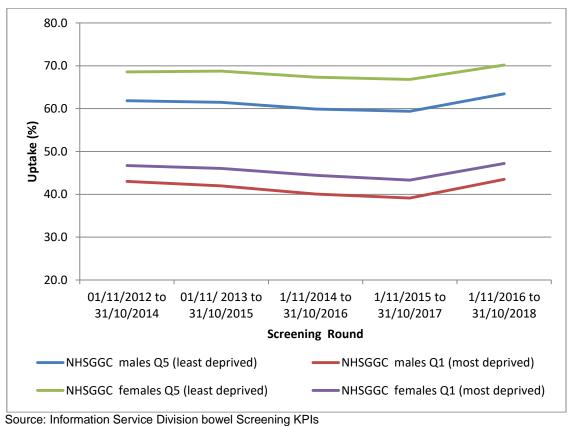
Following the implementation of FIT in November 2017, there has been a 4.1% increase in uptake of bowel screening in NHSGGC between screening cycle 1<sup>st</sup> November 2016 to 31<sup>st</sup> October 2018 compared with previous screening cycle. (**Figure 6.3**). This increase in uptake is evident for both sexes (**Figure 6.3**) and across all deprivation quintiles (**Figure 6.4**).

Figure 6.3 Uptake of Bowel Screening in Scotland and NHSGGC 2012 -2018 by sex



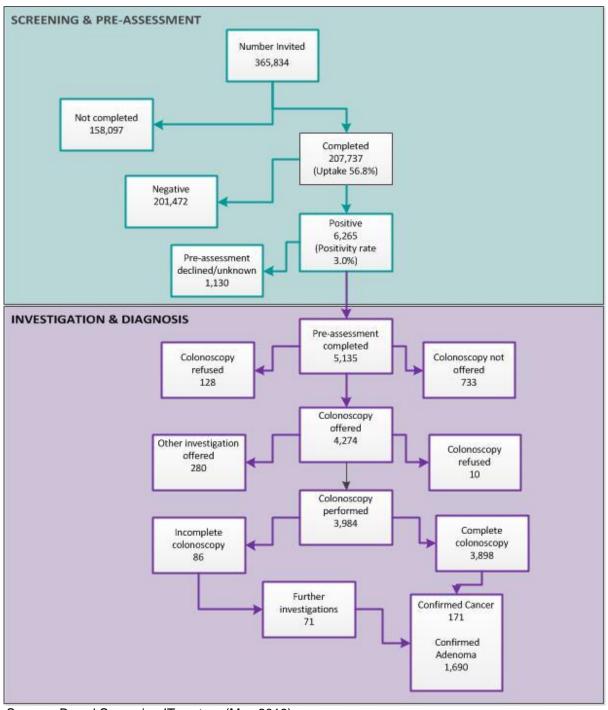
Source: Information Service Division bowel Screening KPIs

Figure 6.4 Uptake of Bowel Screening 2012 - 2018 by Deprivation (most and least deprived)



**Figure 6.5** summarises bowel screening activity between April 2017 and March 2019 by local analysis. During this time period, 365,834 NHSGGC residents were invited for bowel screening. Over half (56.8%) of those invited returned the screening test, of which 6,265 tested positive (3.0%). Of those individuals who had a positive result, 5,135 (81.9%) accepted a nurse preassessment and over three quarters (77%) had a colonoscopy. Subsequently, 171 cancers and 1,690 adenomas were detected.

Figure 6.5 Movement of eligible NHSGGC residents through bowel screening pathway (1 April 2017 to 31 March 2019)



Source: Bowel Screening IT system (May 2019)

Analysis was undertaken to explore variations in uptake by sex, age, deprivation, ethnicity, learning disability, severe and enduring mental illness and Health and Social Care Partnership (HSCP) area.

Men were significantly less likely to return a bowel screening test than women (54.3% vs. 59.2% respectively) **(Table 6.1)**, showing an increase in uptake in both sexes in 2017-19 screening round compared to 2016-18 (49.4% in males and 55.1% in females).

Table 6.1 Uptake of bowel screening by sex in NHSGGC, 2017-19

				%
Sex	Not Screened	Screened	Total	Screened
Male	82,460	97,849	180,309	54.3
Female	75,637	109,888	185,525	59.2
Total	158,097	207,737	365,834	56.8

Source: Bowel Screening IT system (May 2019)

Chi-Square Tests p < 0.0001

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 46.9% and increased to 63.7% between 70 and 74 years. However, this shows an improvement in uptake across all age groups compared to 2016-18 screening round, with both the 65-69 and the 70-74 age groups again achieving the target.

Table 6.2 Uptake of bowel screening by age in NHGGC, 2017-19

Age Group	Not Screened	Screened	Total	% Screened
50-54	47,633	44,614	92,247	48.4
(50-52)	28,994	25,639	54,633	46.9
55-59	40,570	46,407	86,977	<i>53.4</i>
60-64	31,892	47,555	79,447	59.9
65-69	17,400	33,048	50,448	65.5
70-74	20,602	36,113	56,715	63.7
Total	158,097	207,737	365,834	56.8

Source: Bowel Screening IT system (May 2019)

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

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 (47.1%) and highest in the least deprived areas (68.3%). As previously noted in figure 6.4, uptake has increased across all deprivation quintiles compared with previous screening rounds.

Table 6.3 Uptake of Bowel screening by SIMD in NHS Greater Glasgow and Clyde, 1st April 2017-31st March 2019

SIMD Quintile				
2016	Not Screened	Screened	Total	% Screened
1 (Most Deprived)	66,757	59,475	126,232	47.1
2	27,760	33,058	60,818	54.4
3	20,091	28,516	48,607	58.7
4	18,942	33,885	52,827	64.1
5 (Least Deprived)	24,547	52,803	77,350	68.3
Total	158,097	207,737	365,834	56.8

Source: Bowel Screening IT system (May 2019)

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

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**), however uptake has improved across all ethnic groups compared with previous screening rounds following implementation of FIT.

Table 6. 4 Uptake of Bowel screening by ethnicity in NHS Greater Glasgow and Clyde, 1st April 2017-31st March 2019

2001 Census Ethnic				
Group	Not Screened	Screened	Total	% Screened
White - British	128,696	178,127	306,823	58.1
White - Irish	15,613	19,300	34,913	55.3
White - any other white background	4,321	3,809	8,130	46.9
Asian or Asian British	5,276	3,279	8,555	38.3
Black or Black British	487	334	821	40.7
Other ethnic groups - Chinese	1,035	1,151	2,186	52.7
Other ethnic groups - any other ethnic group	2,012	1,328	3,340	39.8
Unclassified	657	409	1,066	38.4
Total	158,097	207,737	365,834	56.8

Source: Bowel Screening IT system (May 2019); OnoMap

Variations in bowel screening uptake across HSCPs persist **(Table 6.5).** They range from 50.6% in Glasgow City HSCP North East Sector to 67.0% in East Dunbartonshire HSCP. Only two HSCPs meet 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 uptake across HSPCs are much smaller (SUR% ranging from 54.4% to 59.1%). This tells us that most of the differences in uptake across HSCP's are explained by their differences in population demographics rather than local practice. Following

the implementation of FIT, all HSCPs have shown an increase in uptake during 2017-19 screening round.

Table 6.5 Indirectly Standardised Uptake of Bowel screening by HSCP in NHS Greater Glasgow and Clyde, 2017-19

	Not Screene	Screen		% Scre ene	su	SUR	SUR
HSCP	d	ed	Total	d	R %	% LCI	% UCI
East Dunbartonshire HSCP	12,804	25,991	38,795	67.0	59. 1	58.3	59.8
East Renfrewshire HSCP	10,879	20,478	31,357	65.3	57. 5	56.7	58.3
Glasgow North East Sector	26,410	27,011	53,421	50.6	55. 8	55.2	56.5
Glasgow North West Sector	26,261	29,094	55,355	52.6	54. 4	53.8	55.0
Glasgow South Sector	32,352	34,399	66,751	51.5	54. 9	54.3	55.5
(Glasgow City)	85,023	90,504	175,527	51.6	55. 0	54.6	55.4
Inverciyde HSCP	11,878	16,721	28,599	58.5	57. 6	59.4	56.2
Renfrewshire HSCP	24,011	36,056	60,067	57.8	57. 2	58.4	55.8
West Dunbartonshire HSCP	13,502	17,987	31,489	58.6	57. 7	59.4	56.3
Total	158,097	207,737	365,834	56.8			

Source: Bowel Screening IT system (May 2019), OnoMap

SUR = Standardised Uptake Rate; UCI = Upper Confidence Intervals; LCI = Lower Confidence Intervals

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**Table 6.6** shows that 2,406 of the 365,834 individuals eligible for screening were registered with a learning disability (0.7%). People who were registered with a learning disability had poorer uptake of bowel screening, 38.9% compared to 56.8% in the rest of the population.

Table 6.6 Uptake of bowel screening by learning disability in NHGGC, 2017-19

Learning Disability	Not Screened	Screened	Total	% Screened
Rest of population	156,628	206,800	363,428	56.9
Registered with a LD	1,469	937	2,406	38.9
Total	158,097	207,737	365,834	56.8

Source: Bowel Screening IT system (May 2019), Learning Disability Register (September 2017)

Chi-Square Tests p < 0.0001

People registered on PsyCIS have had at least one episode of psychosis which is typically seen in patients with a severe or enduring mental illness. Table 6.7 shows that 3,065 of the 365,834 people eligible for screening were registered on PsyCIS (0.8%). These individuals had poorer uptake of Bowel Screening, 38.5% compared to 58.9% in the rest of the population.

Table 6.7 Uptake of Bowel screening among people with severe and enduring mental illness in NHS Greater Glasgow and Clyde, 1st April 2017-31st March 2019

Severe and Enduring Mental Illness	Not Screened	Screened	Total	% Screened
Not Registered	156,213	206,556	362,769	56.9
Registered on PsyCIS	1,884	1,181	3,065	38.5
Total	158,097	207,737	365,834	56.8

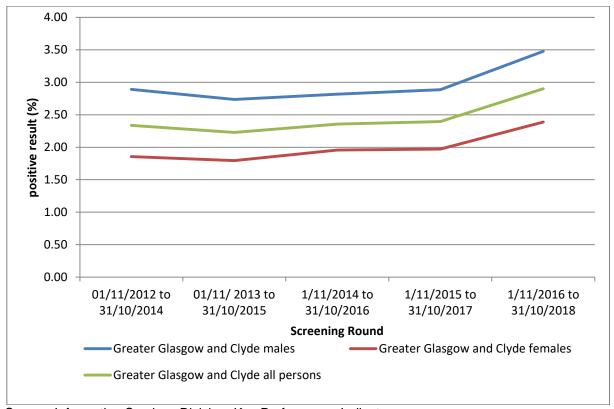
Source: Bowel Screening IT system (May 2019)

Chi-Square Tests p < 0.0001

#### 6.6. Screening Test Positivity

The increased sensitivity of the new FIT test compared with previous FOBt, has consequently led to an increase in the percentage of people with a positive test result (**Figure 6.6**).

Figure 6.6 Positivity rate by sex, 2012-2018



Source: Information Services Division, Key Performance Indicators

Overall, 3.0% (6,265 of 207,737) of completed screening test were reported positive, meriting further investigation. Men have a higher positivity than women (3.6% vs. 2.5%, respectively); older people have higher positivity than younger people (4.1% aged 70-74 vs. 2.2% aged 50-54); and those living in our most deprived communities have higher positivity than the least deprived (4.1% vs. 2.1%, respectively) **(Tables 6.8 and 6.9).** 

Table 6.8 Uptake for Bowel screening and positivity rate by age and sex for NHS Greater Glasgow and Clyde, 1st April 2017-31st March 2019

		% Screened	% Positive				
Age Group	Male	Female	Total	Male	Female	Total	
50-54	44.8	52.1	48.4	2.5	1.9	2.2	
55-59	50.4	56.3	53.4	3.0	2.3	2.6	
60-64	57.8	61.9	59.9	3.7	2.5	3.0	
65-69	64.0	66.9	65.5	4.3	2.8	3.5	
70-74	63.4	63.9	63.7	5.0	3.3	4.1	
Total	54.3	59.2	56.8	3.6	2.5	3.0	

Source: Bowel Screening IT system (May 2019)

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

Table 6.9 Bowel screening positivity rate by SIMD for NHS Greater Glasgow and Clyde, 1st April 2017-31st March 2019

SIMD Quintile 2016	Negative	Positive	Total	% Screened
1 (Most Deprived)	57,013	2,462	59,475	4.1
2	31,987	1,071	33,058	3.2
3	27,672	844	28,516	3.0
4	33,099	786	33,885	2.3
5 (Least Deprived)	51,701	1,102	52,803	2.1
Total	201,472	6,265	207,737	3.0

Source: Bowel Screening IT system (May 2019)

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

#### 6.7. Adenoma and Polyp Detection

Of the 6,265 people who had a positive screening test, 3,984 people underwent a colonoscopy. Of these, 2,403 people (60.3%) had a polyp detected, 1,690 people (42.4%) had a confirmed adenoma detected and 171 (4.3%) people had a confirmed colorectal cancer diagnosis.

**Table 6.10** shows the proportion of polyps identified at colonoscopy and the adenoma pathology diagnosis. 68.2% of men and 50.5% of women who underwent colonoscopies had polyps detected. Adenomas were diagnosed in 49.0% of men and 34.2% of women, and 4.7% of men and 3.8% of women had a confirmed cancer diagnosis.

Table 6.10 Adenoma and polyp detection rate by age and gender in NHS GGC, 2017-19 (M=Male; F=Female)

	inve	ents havestigation	ns*	% Polyps Detected		% Adenomas Detected			% Cancer Detected			
Age Grou			<b>+</b>			Tota		ı	Tota		ı	Tota
р 50-54	M 338	F 302	Total 640	M 62.4	F 41.7	52.7	M 43.5	F 24.8	34.7	2.4	F 2.0	2.2
55-59	442	374	816	65.4	46.0	56.5	48.0	31.8	40.6	3.2	2.7	2.9
60-64	517	393	910	69.8	49.4	61.0	50.9	32.3	42.9	4.4	2.5	3.6
65-69	437	299	736	70.0	56.9	64.7	51.7	41.1	47.4	5.7	7.4	6.4
70-74	484	398	882	71.3	57.5	65.1	49.2	40.2	45.1	7.0	4.8	6.0
Total	2,218	1,766	3,984	68.2	50.5	60.3	49.0	34.2	42.4	4.7	3.8	4.3

Source: Bowel Screening IT system (Data extracted: May 2019)

**Table 6.11** shows the detection rate by gender and deprivation. Whilst more people from areas of greatest deprivation have had investigations performed, the detection rate of polyps, adenomas and cancers is roughly similar across the SIMD quintiles with higher polyp and adenoma detection rates among males.

Table 6.11 Polyp, Adenoma and Cancer detection rate by SIMD and gender in NHS GGC, 2017-19 (M=Male; F=Female)

	inve	ents hav estigatio erformed	ns*	% Polyps Detected		% Adenomas Detected			% Cancer Detected			
SIMD Quintile 2016	М	F	Tota I	M	F	Total	M	F	Tota I	М	F	Tota I
1 (Most Deprived)	720	605	1,32 5	67.9	52.0	60.8	51.1	35.3	44.1	2.8	3.8	3.3
2	314	286	600	68.0	43.2	56.4	47.7	29.6	39.2	5.7	3.4	4.6
3	246	198	444	67.4	56.1	62.2	47.8	35.2	42.1	7.9	4.1	6.2
4	276	186	462	69.6	52.1	62.1	48.4	35.5	42.9	3.8	3.7	3.8
5 (Most Deprived)	323	256	579	68.4	49.0	60.4	46.9	34.8	41.9	5.9	4.1	5.1
Total	1,879	1,531	3,41 0	68.2	50.5	60.3	49.0	34.2	42.4	4.7	3.8	4.3

Source: Bowel Screening IT system (Data extracted: May 2019)

Data presented in **Table 6.12** shows the Dukes staging of the 171 people who had a confirmed colorectal cancer diagnosis.

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

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

Table 6.12 Dukes' stage of colorectal cancel for NHSGGC, 2018

DUKES		
Staging	Number	%
Α	67	39.2
В	33	19.3
C1	32	18.7
C2	3	1.8
D	10	5.8
Unknown	26	15.2
Total	171	

Source: Local Cancer Audit, December 2019

#### 6.8. Quality Improvement in Colonoscopy

The Public Health Screening Unit leads a programme of bowel screening audit. It has been focused on the quality of colonoscopy services. 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. It is expected that all bowel screening colonoscopists will undertake a minimum of 200 unselected colonoscopies per year, and that they will have a minimum completion rate of 90% and a minimum adenoma detection rate of 35% in bowel screening colonoscopies. Any complications identified are flagged to sectoral clinical management teams for discussion at local Morbidity and Mortality meetings, and it is expected that outcomes will be shared across the health board. Post colonoscopy cancer rates are now being audited.

#### 6.9. Challenges and Future Priorities

An increase in uptake of bowel screening and increase in positivity following the implementation of FIT has increased colonoscopy waiting times during 2018/19. A significant amount of work was undertaken to increase screening colonoscopy capacity, reducing waiting times now less than 21 days at the time of this report. Waiting times continue to be closely monitored.

Undertake review and options appraisal of current NHSGGC Bowel Screening Application to streamline programme administration and integration with existing clinical systems where appropriate.

To continue to work in partnership with CRUK and Bowel Cancer UK to support GP practices and communities to support eligible patients to participate in bowel screening programme and facilitate opportunities to share learning from successful initiatives.

Continue to progress of actions identified within NHSGGC Inequalities Plan for Adult Screening programmes (Appendix A) to enable a more coordinated approach to reducing inequalities in uptake through targeted activities.

### Appendix 6.1

## **Key Performance Indicators: May 2019 data submission Invitations between 1st November 2016 and 31st October 2018**

KPI	Key Performance: Indicator Description	Target	Scotland %	NHSGCC %	
Scre	Screening Uptake				
1.	Overall uptake of screening - percentage of people with a final outright screening test result, out of those invited.	60%	59.5%	55.1%	
2.	Overall uptake of screening by deprivation category *- percentage of people with a final outright screening test result for which a valid postcode is available,  *by Scottish Index of Multiple Deprivation (SIMD)	60%	Q1 46.5% Q2 54.4% Q3 60.9% Q4	Q1 45.3% Q2 52.6% Q3 57.4% Q4	
	quintile 1 (Q1 most deprived) to quintile 5 (Q5 least deprived)		65.3% Q5 68.9%	62.8% Q5 66.9%	
3.	Percentage of people with a positive test result, out of those with a final outright screening test result.	N/A	2.6%	2.9%	
Refe	rral, clinical intervention and outcomes				
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	37.9% 34.3% 27.8%	22.9% 32.4% 44.7%	
5.	Percentage of people with a positive screening test result going on to have a colonoscopy performed.	N/A	77.3%	74.3%	
6.	Percentage of people having a completed colonoscopy, out of those who had a colonoscopy performed.	90%	95.4%	98.1%	
7.	Percentage of people requiring admission for complications arising directly from the colonoscopy, out of those who had a colonoscopy performed.	N/A	0.45%	0.35%	
8.	Percentage of people with colorectal cancer, out of those with a final outright screening test result.	N/A	0.115%	0.100%	
9- 14.	Percentage of people with colorectal cancer staged as 9. Dukes' A. 10. Dukes' B. 11*. Dukes' C 13. Dukes' D. 14. Dukes' Not known. * indicator 11 includes indicator 12 (previously Dukes' C2)	N/A	38.6% 21.7% 26.2% 6.3% 6.2%	44.5% 19.4% 24.6% 5.7% 3.8%	

15 - 16.	Percentage of people with colorectal cancer 15. Where the stage has not yet been supplied. 16. That has a recorded stage.	N/A	1.0% 99.0%	1.9% 98.1%
17.	Percentage of people with polyp cancer out of those with a final outright screening test result.	N/A	0.023%	0.009%
18.	Percentage of people with polyp cancer, out of those with colorectal cancer.	N/A	20.0%	9.5%
19.	Percentage of people with adenoma as the most serious diagnosis, out of those with a final outright screening test result.	N/A	0.842%	0.894%
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	0.119%	0.117%
21.	Positive Predictive Value of current screening test for colorectal cancer.	N/A	5.7%	4.6%
22.	Positive Predictive Value of current screening test for adenoma as the most serious diagnosis.	N/A	42.2%	41.5%
23.	Positive Predictive Value of current screening test for high risk adenoma as the most serious diagnosis.	N/A	6.0%	5.4%
24.	Positive Predictive Value of current screening test for high risk adenoma as the most serious diagnosis or colorectal cancer.	N/A	11.7%	10.0%
25.	Positive Predictive Value of current screening test for adenoma as the most serious diagnosis or colorectal cancer.	N/A	47.9%	46.1%
26 - 28	Percentage of people with a colorectal cancer that is a malignant neoplasm of the: 26. colon (ICD-10 C18) 27. rectosigmoid junction (ICD-10 C19) 28. rectum (ICD-10 C20)	N/A	65.9% 3.2% 31.0%	68.2% -% 31.8%

#### Members of Bowel Screening Steering Group (as at March 2018)

Dr Emilia Crighton Deputy Director of Public Health, Chair

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

Ms Lisa Buck Public Health Programme Manager

Mr Paul Burton Information Manager

Mrs Lin Calderwood H&IT Service Delivery Manager

Mrs Lisa Cohen CRUK, Facilitator Manager: West of Scotland

Mrs Ailsa Connelly Lead Nurse, New Victoria Hospital

Dr Fraser Duthie Lead Clinician for Pathology
Mr Patrick Finn Consultant Surgeon, RAH

Ms Ailsa Forsyth Lead Nurse, GGH

Miss Irene Fyfe Health Records Manager
Dr Rachel Green Chief of Medicine, Diagnostics

Dr Rob Henderson CPHM, NHS Highland Ms Janice Hosie Deputy Site Manager, GRI

Ms Julie Huntly Lead Nurse, Clyde

Ms Heather Jarvie Public Health Programme Manager

Mrs Alyson Goodwin Lead Nurse, QEUH

Dr Graeme Marshall Clinical Director, Glasgow City HSCP, North East

Sector

Ms Natalie McMillan 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 Mrs Lorna Reid Lead Nurse, RAH

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

Dr Andrew Renwick Consultant, RAH

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

### **Chapter 7 - Breast Screening Programme**

### Summary

Breast cancer is the most common cancer in women in Scotland accounting for 28.8% of all new cancers diagnosed in women. In 2017, 897 new breast cancers were registered among women residing in NHSGGC. In the same year, 193 women with a diagnosis of breast cancer died. Between 2007 and 2017, age-standardised incidence rate of breast cancer in Scotland increased by 1.4%, however age-standardised mortality rate decreased by 13.4%.

During 2015-2016, the Scottish Breast Screening Programme implemented a new Scottish Breast Screening System (SBSS) IT system. Information Service Division published annual programme statistics in October 2019, relating to breast screening uptake and outcomes up to 31<sup>st</sup> March 2018, which are presented in this report.

The purpose of breast screening by mammography is to detect breast cancers early. It is believed that very early detection of breast cancers in this way can result in more effective treatment, which may 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 patient request.

The number of women eligible for breast screening in the 3 year screening round from 1st April 2015 to 31st March 2018 was 151,176 of which 99,399 attended (65.8%), lower than the national uptake rate of 71.2% and breast screening acceptable and achievable standards of 70% & 80% respectively.

The West of Scotland Breast Screening Service (WoSBSS) has optimised their appointing system, increasing the number of booked clients. Appointing figures have risen from approximately 8,000 screening slots per month to 10,000.

The Breast Screening Community Liaison Officer continues to work in partnership with Public Health, Primary Care, HSCP Health Improvement and 3<sup>rd</sup> Sector organisations to support participation in screening, including staff training, health road shows and community talks.

The Scottish Government announced a fundamental review of the Scottish Breast Screening Programme during 2019/20. The review will be carried out by National Services Division and will involve a comprehensive appraisal of the current programme, current pressures and future options for delivery. It will also look at advances in technology and ways to increase participation and address health inequalities.

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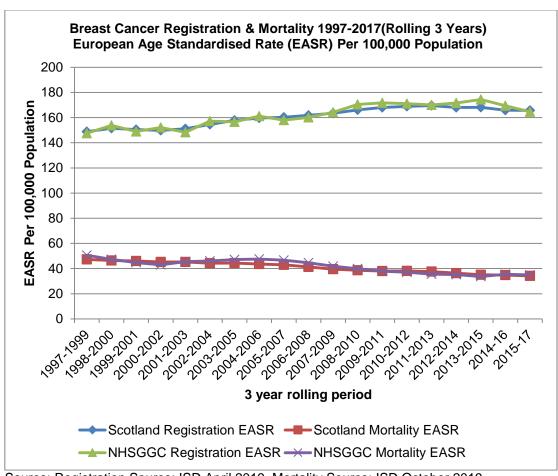
#### 7.1. Background

Breast cancer is the most common cancer in women in Scotland, accounting for 28.8% of all new cancers diagnosed in women<sup>11</sup>.

In 2017, the most recent year for which completed data are available, 897 new breast cancers were registered among women residing in NHSGGC. This gives an age-standardised incidence rate of 153.3 per 100,000 per population, as compared with the Scotland rate of 164.6 per 100,000. In the same year, 193 women with a diagnosis of breast cancer died in NHSGGC, giving a standardised mortality rate of 32.6 per 100,000 population, comparable with the Scotland rate of 32.5 per 100,000<sup>12</sup>.

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 and Mortality 1997-2017 (Rolling 3 Years) European Age Standardised Rate (EASR) Per 100,000 Population



Source: Registration Source: ISD April 2019, Mortality Source: ISD October 2019

<sup>&</sup>lt;sup>11</sup> https://www.isdscotland.org/Health-Topics/Cancer/Publications/2019-04-30/2019-04-30-Cancer-Incidence-Report.pdf (accessed November 2019)

https://www.isdscotland.org/Health-Topics/Cancer/Publications/2019-10-29/2019-10-29-Cancer-Mortality-Report.pdf (accessed November 2019)

In the time period between 2007 and 2017, the age-standardised incidence rate of breast cancer in women in Scotland increased by 1.4%, however age-standardised mortality rate decreased by 13.4%. 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, smaller number of children, post-menopausal obesity and alcohol consumption11.

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

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 early. It is believed that very early detection of breast cancers in this way can result in more effective treatment, which may reduce deaths from breast cancer.

Women aged 50 until age 70 years + 364 days who are registered with a GP, and those women not registered with a GP but whom the screening programme is made aware of (e.g. women in long-stay institutions) are eligible for a routine screen once every three years. Women aged over 70 years are screened on patient request. Some women are excluded from routine invitation, for example those who have had bilateral mastectomy or who have signed a disclaimer form to remove themselves from the Scottish Breast Screening Programme call-recall system.

The Scottish Government announced a fundamental review of the Scottish Breast Screening Programme during 2019/20. The review will be carried out by National Services Division and will involve a comprehensive appraisal of the current programme, current pressures and future options for delivery. It will also look at advances in technology and ways to increase participation and address health inequalities.

#### 7.3. Programme Monitoring

The Scottish Breast Screening Programme (SBSP) delivery and quality is monitored against key programme statistics<sup>13</sup> and (new) National Breast Screening Service Standards<sup>14</sup>.

#### 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).

14http://www.healthcareimprovementscotland.org/our\_work/standards\_and\_guidelines/stnds/breast\_screening\_standards.aspx\_(accessed November 2019)

<sup>&</sup>lt;sup>13</sup> https://www.isdscotland.org/Health-Topics/Cancer/Publications/2019-10-08/2019-10-08-Breast-Screening-Report.pdf? (accessed November 2019)

The WoSBSS screens NHSGGC residents in either the static facility in Nelson Mandela Place or, in the majority of cases, in mobile units that visit preestablished sites across the NHSGGC area. Eligible women registered within a GP practice within range of Glasgow city centre will be invited to attend appointments for screening in the static facility. For the 2018/19 screening round, the service has been active in NHSGGC areas detailed in **Table 7.1** 

Table 7.1: 2018/19 screening locations / facility

HSCP	Mobile Unit	Static (Nelson Mandela Place)
East	Kirkintilloch,	N/A
Dunbartonshire	Bishopbriggs	
East Renfrewshire	Barrhead	Newton Mearns, Clarkston
Glasgow City	Castlemilk, Pollock, Govan, Drumchapel	Anniesland, Knightswood Partick, Scotstoun Yoker, Kinning Park, Maryhill, New Gorbals
Inverclyde	N/A in screening round	N/A
Renfrewshire	Renfrew, Paisley	N/A
West	Clydebank	N/A
Dunbartonshire		

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 until age 70 + 364 days when women in her Practice are screened. A woman can request a screening appointment from the age of 50, however if her GP practice is being screened in the next six months she will be advised to attend there. The WoSBSS 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. Women 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. These usually involve surgery. This could be either a lumpectomy to remove the lump and a small amount of surrounding tissue or a mastectomy to remove the entire breast. Surgery is likely to be followed by radiotherapy, chemotherapy, hormone therapy or a combination 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 WoSBSS situated in Glasgow. The surgical treatment is carried out by designated teams in QEUH, New Victoria Hospital, New Stobhill Hospital and Royal Alexandra Hospital. A small proportion of women with palpable tumours are referred for treatment to local breast teams. **Figure 7.2** illustrates the breast screening pathway.

Breast Screening Pathway Invitation of women Screening by mammography Film processing: Results abnormal read and analysed Assessment will include clinical examination which may also involve: Further films Results normal Ultrasound Core biopsy MRI (referral to diagnostics required) Benign Malignant Indeterminate Routine recall (invite 3 years later) Patient choice -Repeat biopsy or Treatment excise open biopsy Benign

Figure 7.2 Breast screening Pathway

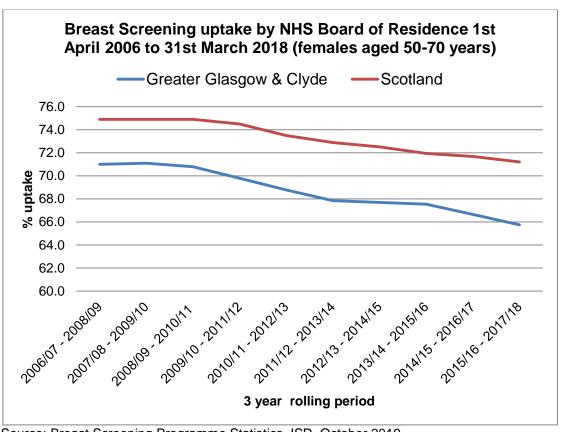
#### 7.5. Delivery of Breast Screening Programme

The SBSP implemented a new Scottish Breast Screening System (SBSS) IT system in line with the change to digital mammography during 2015/16. Information Service Division published annual programme statistics in October 2019 for the year 2017-2018, relating to breast screening uptake and

outcomes<sup>15</sup>. Updated annual programme statistics reflecting activity to the end March 2019 is expected early 2020. Unfortunately at the time of this report, it was still not possible to run further local analysis from the SBSS system (e.g. further demographic breakdown of uptake).

Uptake of breast screening has been consistently falling over the last decade (Figure 7.3).

Figure 7.3: Breast screening uptake by NHS Board of Residence 1st April 2006 to 31st March 2018 (females aged 50-70 years)



Source: Breast Screening Programme Statistics, ISD, October 2019

The number of women aged 50-70 years residing in NHSGGC who were eligible for breast screening in March 2018 was 151,176 (Table 7.2). A total of 99,399 of these women attended screening, an overall uptake rate of 65.8%, lower than the national uptake rate of 71.2% and breast screening minimum standard of 70% / target of 80%. Uptake was lowest among women invited for their initial screen aged 50-52 years (63.2%) compared to women invited for subsequent screen, aged between 53-70 (83.3%).

<sup>15</sup> https://www.isdscotland.org/Health-Topics/Cancer/Breast-Screening/ (accessed November 2019)

Table 7.2: Breast screening uptake covering screening round 2015/16 to 2017/18, NHSGGC & Scotland

	Greater Glasgow & Clyde	Scotland
Prevalent uptake (Age 50-52)		
No of women screened	15,896	80,148
No of women invited	25,142	116,059
% Uptake (Age 50-52)	63.2	69.1
Incident uptake (Age 53-70)		
No of women screened	70,043	371,145
No of women invited	84,056	428,202
% Uptake (Age 53-70)	83.3	86.7
Overall uptake (Age 50-70)		
No of women screened	99,399	514,083
No of women invited	151,176	721,934
% Uptake (Age 50-70)	65.8	71.2

Source: ISD Breast Screening Programme report statistics (KC62) October 2019

The national SBSP statistics published in October 2019, it is evident that women from more deprived areas are less likely to attend for breast screening, with 58.5% of women from the most deprived areas going for screening compared with 79.1% women living in the least deprived areas <sup>16</sup>.

As women are invited to attend screening once every three years and it is more informative to examine trends by NHS Board of residence for three-year rolling periods rather than single years. It is envisaged that Board level uptake data by deprivation quintile will be available in April 2020 upon publication of 2018/19 data.

#### 7.6. Breast Screening Outcomes

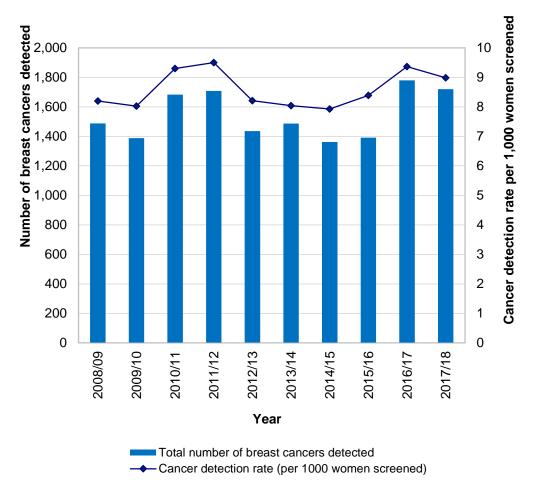
The national SBSP statistics published in October 2019 noted the number of screen-detected breast cancers in women of all ages in Scotland in 2017/18 was 1,720, a rate of 9 per 1,000 women screened<sup>17</sup>. This represents an increase in numbers and rates compared against the previous 4 years (2012/13 – 2015/16) (Figure 7.2).

It is proposed that this may be due to the introduction of digital mammography in Scotland during 2015/16, potentially improving the programmes ability to detect breast cancer.

<sup>&</sup>lt;sup>16</sup> https://www.isdscotland.org/Health-Topics/Cancer/Publications/2019-10-08/2019-10-08-Breast-Screening-Report.pdf (accessed November 2019)

<sup>&</sup>lt;sup>17</sup> https://www.isdscotland.org/Health-Topics/Cancer/Publications/2019-10-08/2019-10-08-Breast-Screening-Report.pdf (accessed November 2019)

Figure 7.2 Trends in the number of breast cancers detected, and cancer detection rates per 1,000 women screened: Scotland, 2008/09 to 2017/18 (All appointment types)



Source: Scottish Breast Screening Programme (SBSP) Statistics, October 2019 The 2015/16 data for Scotland is 9% incomplete due to the Breast Screening Programme implementing a new SBSS IT system

Outcomes specific to NHSGGC residents will be reported in next year's annual report.

#### 7.7. Challenges and Future Priorities

Following difficulties faced by WoSBSS in securing accessible locations capable of accommodating the mobile units a paper was submitted to NHSGGC Corporate Management Team in July 2019, recommending support from HSCP and Acute facilities to work with WoSBSS to identify suitable locations for the mobile units, with a preference for NHS/Council locations.

Following this, work is ongoing with support from NHSGGC Estates and Facilities Senior Management to secure locations for future screening rounds, enabling enhanced forward planning of appropriate community and GP practice engagement.

WoSBSS continue to actively monitor slippage in the system, overbooking appointments, and being sensitive to local uptake rates, the available

screening appointments have now been optimised. The service now regularly has 10,000 screening slots per month where previously this figure was approximately 8,000.

The Community Liaison Officer appointed in 2004 is working in partnership with GPs, Public Health, HSCP Health Improvement colleagues, and the community to improve understanding and uptake of the Screening Programme, and inform development of priority actions in NHSGCC inequalities action plan (Appendix 7.2). This will include actions as a matter of priority, targeting women invited for their initial screened aged 50-52 years

WoSBSS has secured approval to implement new telephony within the Service which will enable SMS and telephone reminders. This will be implemented during 2020.

Limited access to local reporting environment persists, however it is envisaged that this will be resolved during 2020 to enable further demographic breakdown of NHSGGC resident population in relation to uptake and outcomes.

Practice based calling that can lead to a women missing screening invitations remains a challenge, however this will be considered in the scope of the National Review of Breast Screening during 2019/20.

### Appendix 7.1

### Members of Breast Screening Steering Group (As at March 2018)

Dr Emilia Crighton
Carol Beckwith
Celia Briffa-Watt
Lisa Buck
Deputy Director of Public Health (Chair)
CRUK Facilitator, CRUK – West of Scotland
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Sandra Cairney Associate Director of Public Health, Argyll & Bute

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Margo Carmichael Health Improvement Lead for Breast Screening,

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Dr Marzi Davies Director, WoSBSS Dr Rob Henderson CPHM, NHS Highland

Dr Aileen Holliday Clinical Effectiveness Coordinator, NHS Forth

Valley

Marion Inglis Administration Manager, WoSBSS

Janice Tannock Superintendent Radiographer/Operational Ms Joan Main Assistant General Manager, Diagnostics

Dr Graeme Marshall Clinical Director, NE HSCP

Elaine Murray Community Liaison Officer, WoSBSS, Lorna Nimmo Superintendent Radiographer, WoSBSS,

Dr Tasmin Sommerfield CPHM, NHS Lanarkshire

Manager, WoSBSS

### **Inequalities Action Plan**

### **Progress report:**

# Widening access and addressing inequalities in adult screening programmes. Action plan for 2019-21

NHS Greater Glasgow and Clyde (NHS GGC)'s Public Health Directorate is responsible for co-ordinating and monitoring screening programmes across Greater Glasgow and Clyde, and Argyll & Bute (part of NHS Highland).

The Widening Access and Addressing Inequalities in Adult Screening Programmes Action Plan for 2019-21 outlined priorities and actions to widen access and address inequalities in relation to adult screening programmes.

This paper provides an update on progress of the actions and relevant developments in adult screening programmes.

## 2. Developments in the Scottish Breast Screening Programme

- (a) In July 2019, the Scottish Government announced a review of the Scottish Breast Screening Programme. The review, which is expected to take around a year, will be carried out by National Services Division (NSD), a part of NHS National Services Scotland, which commissions and coordinates the programme. The review will involve an appraisal of the programme, current pressures and future options for delivery. It will also look at advances in technology and ways to increase participation and address health inequalities.
- (b) In October 2019, the Information Services Division released **Scottish Breast Screening Programme Statistics** to 31 March 2018. This is the first release of statistics since April 2017 due to the implementation of the new digital mammography Scottish Breast Screening System. For the period 2015/16-17/18, 514,083 women aged 50-70 attended a routine breast screen appointment which equates to around 7 in 10 women (71.2%) taking up the invitation for screening. For the period 2015/16 -17/18, NHS Greater Glasgow & Clyde uptake was 65.8%. This meant it was one of four NHS Boards which did not meet the minimum acceptable uptake standard of 70%. The national uptake rate has been falling consistently since 2008/09-10/11 when it was 74.9%. Women from more deprived areas are less likely to attend for breast screening, with under 6 in 10 women from

the most deprived areas going for screening compared with almost 8 in 10 women living in the least deprived areas. Currently, we are not able to access more detailed local data but it is hoped that this will follow in the near future.

#### 3. Review of actions

#### ALL SCREENING

38. Provide support to GP practices to access, analyse and use their data for planning and quality improvement purposes.

HSCPs and GP clusters are now able to access support for using their data through Local Intelligence Support Teams (LIST) employed through ISD Scotland. In addition to this national resource, NHS GGC Primary Care Development Officers continue to support GP clusters. Data sharing agreements to support the use of primary care intelligence are in progress. See also action 4.

- 39. Provide support to GP practices to maintain patient records including mobile number, appropriate read coding, identification and articulation of support needs.
- 40. Identify and address coding actions which may impact on eligibility status and patient communication.

The new GP contract has moved away from a detailed specification of requirements in relation to LD, but maintaining comprehensive disease registers in general practice remains an expectation. Further work is required to ensure consistency and quality of data in relation to recording of LD, and to agree how data will be extracted and used from practice systems to enable this to continue to be used to identify and address any inequalities in screening uptake. This will be taken forward in line with the forthcoming national template for data sharing with practices, a review of disease registers and the further development of primary care information for reporting on quality indicators.

41. Specify calls to action related to priority groups in screening when data sharing with GP practices and clusters.

This year, for the first time, standardised cluster level cervical and bowel screening uptake data has been shared with GP clusters among other public health priorities in cluster intelligence reports. Where uptake is lower than expected, clusters have been directed to resources which support quality improvement including health improvement teams and third sector organisations as well as toolkits which can help practice staff to understand the barriers to attendance and use methods which could

increase attendance. More than half of clusters also met Public Health Directorate staff in order to discuss reports further and help prioritise areas for quality improvement.

- 42. Utilise mapping of resources to develop patient and carer information pathways.
- 43.Increase use (distribution and support for understanding) of accessible patient information and digital displays as tools to aid informed participation.

All adult screening resources have been mapped. These include NHS and third sector resources. This has allowed us to identify information gaps more easily and to raise awareness of alternative formats through HSCPs and third sector organisations. In line with our Accessible Information Policy, we are able to have materials produced in additional alternative formats where a need has been identified or a patient has requested this. For example, in developing work related to cervical screening with women in Chinese communities, we have identified the need for patient information in Simplified Chinese.

Renfrewshire have utilised social media to promote cancer screening programmes through campaigns.

A national communications and engagement plan is in development to inform women of changes in the cervical screening programme. This will include updating Health Inequalities Impact Assessment for cervical screening communications to ensure the national communications strategy helps reduce inequalities and improve reach of our screening programme. See also Clyde Gateway actions 15 and 16 for campaigning work.

44. Develop a Learn Pro module to improve access to CPD on adult screening programmes for staff who are in a position to support informed participation.

Preliminary work on this has begun. A project brief and a costing have been undertaken.

45. Update protocols for providing access to screening adults from travelling communities and armed forces personnel.

Work on this is currently in progress.

- 46. Monitor screening uptake and engagement with the screening programmes in prisons within NHSGGC.
- 47. Support the implementation of the National Prison Healthcare Network recommendations for engagement with the population screening programmes in the prison setting.

A new practitioner post has been provisionally approved. This post will provide single point of contact for screening services. The post holder will also deliver training and cascade information about screening programmes to prison health care staff (and other staff as appropriate). We are currently working with screening services to update standard operating procedures regarding sub-population groups, including prisons. New national posters summarising screening programmes according to gender have been developed and distributed for use in prisons.

## 48. Work with third sector to support and promote screening programmes.

Cancer Research UK, Jo's Trust and Bowel Cancer UK (Scotland) continue to be our main third sector partners in relation to adult screening programmes. These organisations participate in our programme steering groups and deliver work in primary and acute care, working closely with both Public Health and HSCP Health Improvement teams.

A number of training and information sessions have been delivered by NHS GGC and third sector partners to NHS staff who work with people with learning disabilities and those who have severe and enduring mental illness.

In addition to the third sector organisations with a specific remit for cancer, HSCPs work with many third sector and community oranisations. Work with these organisations is important in order to raise awareness of adult screening programmes and to understand more about access barriers to screening. People First, for example, have contributed to the Clyde Gateway work and there is further work with the third sector planned for next year. See also action 26.

#### CERVICAL

#### 49. Clarify service specification on programme re GMS contract.

The cervical screening programme continues to be delivered in GP practices. Following the disbanding of the Quality and Outcomes Framework (QOF), the payment for cervical screening services is now included in GP Practices' Global Sum.

A new approach to cervical screening has been approved by the Scottish Government and will be introduced in early 2020. High risk HPV screening involves the same clinical examination but only women whose virology results are positive for specific types of HPV will have cervical cytology.

50. Introduce a steering group process to link the analysis of demographic data to to ensure campaigns and projects are targeted

## at areas with the lowest uptake rates or identify where a different course of action may be required.

Following an internal review of cervical screening was undertaken by Price Waterhouse Cooper as part of the 2017-18 internal audit plan approved by the Audit and Risk Committee. The Cervical Screening Governance Group has established a mechanism to use data to target targeting of promotional activities to those with low uptake including vulnerable or excluded groups.

#### 51. Monitor the impact of the new GMS contract on screening uptake.

The new contract was introduced in April 2018. It is early yet to monitor impact; however, a broader evaluation of the Primary Care Improvment Plans agreed by the Primary Care Programme Board is underway and will look at issues including equality of access in primary care.

#### **CERVICAL / BREAST**

- 52. Support peer to peer learning for adults with a learning disability in cervical and breast screening in the Clyde Gateway area.
- 53. Conduct tests of change in peer learning programme as part of the Clyde Gateway area project.

The Clyde Gateway programme of work is funded under the Screening Inequalities Fund. There have been three tests of change In GGC:

- Sandyford pop-up clinics: Use of data from the Scottish Cervical Call Recall System to invite non-engager to Saturday pop-up clinics to increase uptake of cervical screening.
- A peer learning approach to screening for women with learning disabilities using coproduction methods based on EMBRACES: ID, an evidence based programme.
- A marketing communications campaign to increase local awareness and knowledge of screening programmes.

The work is due to be completed by March 2020. Glasgow Centre for Population Health is working with Clyde Gateway to evaluate this work.

#### **CERVICAL**

#### 54. Test the use of teaser communication via a randomised control trial.

Development work for this action is ongoing. The proposal has been subject to changes following suggestions by the Scottish Government during the ongoing application process for the Screening Inequalities Fund. The main proposed change has been from teaser letter to SMS text reminder aimed at women under 30 who may be in their first or second invitation cycle. In developing this work in line with this change, it has

become clear that much of the learning will come from testing the legal and ethical processes involved in this work as well as the current limitations of our information and communication systems subject to ethical approval. This will help us to identify what would need to be changed in order to scale up the use of SMS technologies in screening programmes. Recent results from similar work undertaken by Public Health England in London suggest that the use of mobile technologies can increase engagement in cervical screening. Our proposed work aims to explore this further in relation to deprivation and HPV vaccination status.

## 55. Monitor the impact of HPV vaccination on uptake of cervical screening programme.

This will be undertaken as part of the routine reporting in the Screening Annual Report. Cervical screening uptake is highest in HPV vaccinated women when compared to the non-vaccinated women.

## 56. Review and update cervical screening toolkit following primary care staff focus groups.

The toolkit is currently on hold because a national one to due to be published.

## 57. Test of change: Increase appointment availability for cervical screening outwith standard office hours.

Also see actions 15 and 16. In addition, Health Improvement staff worked with two GP practicies to provide cervical screening drop-in clinics in East Dunbartonshire. These were successful in engaging women who had been identified as non-engagers. An important aspect of the tests of change, particularly for pop-up clinics is whether the approach is sustainable. Similar previous work in North East Glasgow identified operational barriers to providing an out of hours services in health centres.

## 58. Develop content and deliver staff learning and development to GP practice staff.

## 59. Provide opportunities for third sector organisations to contribute to NHS staff training.

Primary Care Support and Development continue to staff deliver cervical skills training. This training incorporates inequalities content such as supporting with women with learning disabilities. Cancer Research UK staff have also contributed training on increasing uptake and reducing barriers to participation and programme updates. Cervical skill training

has been delivered to practices nurses, colposcopy staff and Sandyford Sexual Health Services.

#### 60. Provide targeted education to groups with lower uptake status.

See actions 15 and 16. There are also plans to deliver education to BME communities in 2020.

#### **BOWEL SCREENING**

#### 61. Teaser letters for bowel screening.

NHSGGC reinstated the teaser letter to first time participants to coincide with the introduction of the FIT test.

#### 62. Monitor the impact of FIT on uptake of the screening programme.

Monitoring of the impact of FIT is ongoing. Following the implementation of FIT, there has been a 3.9% increase in uptake of bowel screening across Scotland and a 4.1% increase within NHSGGC. This increase is evident for both sexes and across all deprivation quintiles. A research study of clinical outcomes associated with symptomatic FIT is currently being conducted by the University of Glasgow in partnership with NHS GGC.

#### 63. Conduct tests of change in West Dunbartonshire.

West Dunbartonshire undertook a multi agency test of change aimed at improving the bowel screening uptake rates for people with learning disabilities. Following Caldicott approval, the National Bowel Screening Service was able to provide live updated data to the Learning Disability Team on the current cancer screening status of those individuals known to its service. This allowed staff within both the Learning Disabilities Team and staff from the Third Sector support agencies to provide a personalised letter, face to face health check and offer support to complete the screening test kit. This resulted in screening test kit completion or a recording of informed decision to decline to participate. For those individuals who were part of the baseline group and received our basic evidence-based intervention, 30% (14) went on to complete a screening test kit or made an informed decision to decline to participate. Of the individuals who were part of our PDSA, 70% (7) went on to complete a screening test kit or make an informed decision to decline to participate. The Learning Disabilities Team participated in bowel cancer awareness training provided by Cancer Research UK. Eleven local third sector agencies attended cancer awareness training provided by Bowel Cancer UK. The Learning Disability Team as part of West Dunbartonshire's commissioning of third sector services, have written a

number of new service contact specifications which will embed screening support activities and the recording of screening status as part of future third sector service contracts.

- 64. Support primary care awareness of FIT and symptomatic FIT.
- 65. Support GPs to use a test of change approach to promote bowel screening uptake.

Cancer Research UK have raised awareness of the role of symptomatic FIT in their work with primary care.

#### **BREAST**

66. Assess feasibility of programme of service and community development where uptake is low.

A muli-agency programme of work to raise awareness and increase participation in screening in Govanhill is in progress. As part of this, the West of Scotland Breast Screening Service agreed to pilot the location a breast screening mobile unit close to the area, however, there was a lack of any suitable location for the mobile unit. This issue has now been resolved by the demolition of a wall at the New Victoria Hospital which has now created sufficient and appropriate space.

67. Support breast screening visits for women with disabilities.

Inequalities of access will be addressed in the current national Breast Screening Review. Work is also planned for next year in West Dunbartonshire to look at supporting women with learning disabilities to access breast screening. (It is recognised that many women with learning disabilities also have physical disabilities.)

#### **BREAST / AAA / DIABETIC RETINOPATHY**

68. Routinely send a list of clinic venues with all initial invitation letters, so that people are aware that can change venue.

Options for this action will be raised with service managers at programme steering groups.

#### **AAA**

69. Implement the evidence based recommendations from Public Health England to reduce inequalities.

We are currently improving local intelligence in order to inform evidence based recommendations at a local level. Inhouse research is being conducted on individuals under AAA surveillance. This will seek information on experience of the AAA monitoring process, how AAA has impacted on their life, and suggestions for improvement with current

process. Participant demographic questions will be based on the demographics known to affect engagement with AAA screening (e.g. comorbidities, learning disability or mental health issues, relationship status, scanning venue/distance to, postcode for SIMD/HSCP, etc). This will help us to identify issues linked to inequalities.

#### AAA / DIABETIC RETINOPATHY

- 70. Increase awareness of programmes in primary care and in the most deprived communities.
- **71.** Analyse uptake by deprivation through datazone mapping.

  We undertook geographical mapping of uptake rates for cervical, bowel,

  AAA and DRS screening programmes at data-zone level.
- 72. Scope out potential to resource health improvement support at screening facilities.
- 73. Work with RNIB to promote DRS.
- 74. Support GP practices to use of SCI diabetes and accurately code patients.

These actions link to a broader programme of work linked to Moving Forward Together and to the Health Improvement Diabetes Prevention Programme. These are in development and will be reported in more detail once plans have been agreed.

### **Chapter 8 - Cervical Screening**

#### **Summary**

Cervical cancer was the eleventh most common cancer in females in 2017 in Scotland but also the most common cancer in women under the age of 35 years. In 2017, 61 new cervical cancers were registered among NHSGGC residents. This gives an age-standardised incidence rate of 10.5 per 100,000 population, comparable to the Scotland rate of 10.1 per 100,000. In the same year, 26 women who had a diagnosis of cervical cancer died in NHSGGC, giving a standardised mortality rate of 4.4 per 100,000 population higher than the Scotland rate of 3.7 per 100,000.

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.

Uptake in NHSGGC for 2018/2019 was 72.0% against a target of 80%, a total of 239,255 women being adequately screened within the specified period. Uptake is poorest among women aged between 25-29 (63.3%), women with learning disabilities (28.0%), and among women from ethnic minorities (for Chinese women it was 38.4%). Uptake for women living in the least deprived areas was 77.4% compared with 69.4% in the most deprived areas however there is not a clear trend across socio-economic groups. The lower uptake rates in some HSCPs are not wholly explained by socio-economic deprivation.

Queen Elizabeth University Hospital processes all smear test specimens for NHSGGC and in 2018/19 processed 103,942 cervical screening tests. Of all tests processed 97.1% 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, 8.9% had a borderline/low grade cell changes and the remaining 1.1% had high grade cell changes.

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 2018, 40% of all invasive cervical cancers were screen detected.

A new approach to cervical screening has been approved by the Scottish Government and will be introduced in early 2020. 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.

In response to an NHSGGC internal audit of the Cervical Screening Programme, clear mechanisms have been established to use data to target promotional activities to vulnerable or excluded groups.

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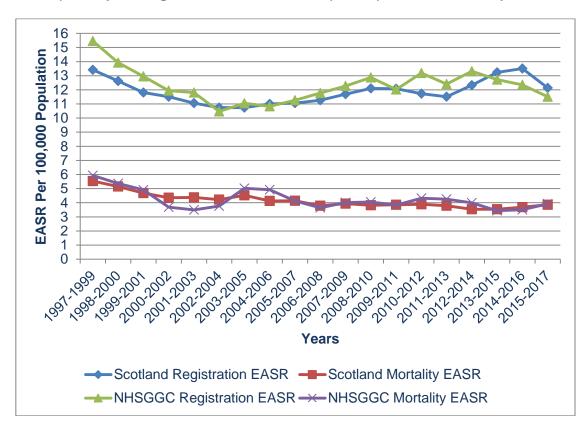
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#### 8.1. Background

Cervical cancer was the eleventh most common cancer in females in 2017 in Scotland and most common cancer in women under the age of 35 years<sup>18</sup>. In 2017, the most recent year for which completed data is available<sup>19</sup>, 61 new cervical cancers (cancer of the cervix uteri) were registered among NHSGGC residents. This gives an age-standardised incidence rate of 10.5 per 100,000 population, comparable to the Scotland rate of 10.1 per 100,000. In the same year, 26 women with a diagnosis of cervical cancer died, giving a standardised mortality rate of 4.4 per 100,000 population higher than the Scotland rate of 3.7 per 100,000.

Standardised incidence and mortality rates over rolling 3 year periods for cervical cancer for NHSGGC and Scotland are illustrated in **Figure 8.1**. There has been a 3.8% increase in standardised incidence rate in the decade from 2007-2017, and a 2.0% reduction in standardised mortality rates of cervical cancer during the same time period.

Figure 8.1 Cervical Cancer Registration & Mortality 1997-2017 (Rolling 3 Years) European Age Standardised Rate (EASR) Per 100,000 Population



Source: ISD September 2018

<sup>&</sup>lt;sup>18</sup> https://www.isdscotland.org/Health-Topics/Cancer/Publications/2019-04-30/2019-04-30-Cancer-Incidence-Report.pdf (accessed November 2019)

<sup>&</sup>lt;sup>19</sup>https://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Female-Genital-Organ/#cervix (accessed November 2019)

#### 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 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. From June 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>20</sup> and National Cervical Screening Standards<sup>21</sup>.

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

1. National and Health Board level uptake: this method identifies all women in the Health Board area in the eligible age groups minus those

20 https://www.isdscotland.org/Health-Topics/Cancer/Publications/2019-09-03/2019-09-03-Cervical-Screening-Report.pdf (accessed November 2019)

<sup>&</sup>lt;sup>21</sup>http://www.healthcareimprovementscotland.org/our\_work/standards\_and\_guidelines/stnds/cervical\_scr\_eening\_standards.aspx (accessed November 2019)

who have no cervix (for example, following a total or radical hysterectomy).

2. 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 plastic vial containing preservative fluid, or rinsed directly into the preservative fluid.

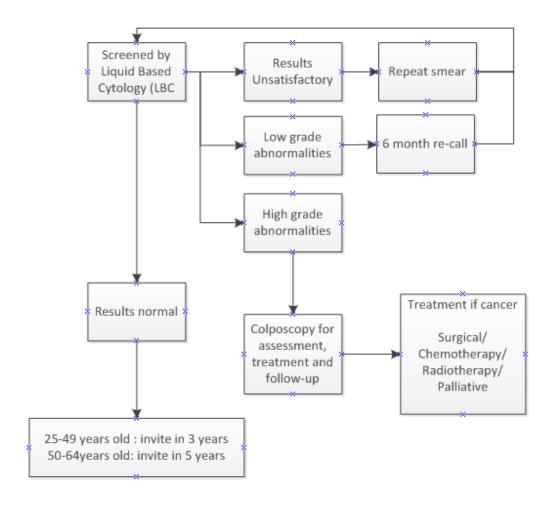
The sample is sent to the laboratory where it is spun and treated to remove obscuring material, for example mucus or pus and a random sample of the remaining cells is taken. A thin layer of the cells is deposited onto a slide. The slide is then screened automatically and if there is evidence of any abnormality, 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 and low grade results); 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.

Figure 8.2 Cervical screening pathway

#### **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.

A new approach to cervical screening, High risk HPV primary screening, will be introduced in early 2020. 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.

#### 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 the school year of 2018/19, vaccination uptake amongst S1 girls in NHSGGC was 91.2% (1st dose) and 91.3% in S2 girls (2nd 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 2018/19 by NHS Board of school. Girls in S3

		First	dose	Second	d dose
NHS Board of school	Number eligible	Number immunised	Uptake rate (%)	Number immunised	Uptake rate (%)
Ayrshire & Arran	1,835	1,651	90.0	1,404	76.5
Borders	589	559	94.9	530	90.0
Dumfries & Galloway	785	710	90.4	653	83.2
Fife	1,861	1,624	87.3	1,478	79.4
Forth Valley	1,674	1,576	94.1	1,480	88.4
Grampian	2,749	2,482	90.3	2,377	86.5
Greater Glasgow & Clyde	5,896	5,583	94.7	5,382	91.3
Highland	1,617	1,397	86.4	1,276	78.9
Lanarkshire	3,752	3,499	93.3	3,301	88.0
Lothian	4,117	3,721	90.4	3,398	82.5
Orkney	92	78	84.8	73	79.3
Shetland	116	105	90.5	102	87.9
Tayside	2,072	1,883	90.9	1,734	83.7
Western Isles	113	100	88.5	94	83.2
Scotland	27,268	24,968	91.6	23,282	85.4

Source: CHSP School/SIRS

https://www.isdscotland.org/Health-Topics/Child-Health/Publications/2019-11-26/2019-11-26-HPV-Report.pdf (accessed December 2019)

#### 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). QOF was disbanded in 2016/17 and payment to practices continued based on their previous three year average achievement. There were previously two parts to the payments. The first was QOF, which remunerated practices for having a protocol for the management of screening, carrying out the screening test and reaching a target and auditing their inadequate smears. This payment is now included in GP Practices' 'Global Sum'.

The second was 'Additional Services' which remunerated practices for:

- The provision of any necessary information and advice to assist women identified by the Health Board as recommended nationally for a cervical screening test in making an informed decision as to participation in the NHS Scotland Cervical Screening Programme;
- 2. The performance of screening tests on women who have agreed to participate in the Programme;
- 3. Arranging for women to be informed of the results of the test; and
- 4. Ensuring the test results are followed up appropriately

'Additional Services' remains part of the new contract, however and if GP Practices chose to "opt out" of delivering this their 'Global Sum' would be reduced by 0.84%.

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 2018/19 contract year.

Table 8.2 Number and proportion of women excluded from GMS cervical screening programme by exclusion category, 2018/19

GP list size (all women	25-64 yrs)	347,569
Exclusion reason	Number	% of those excluded
Defaulter	76,539	79.14
No Cervix	15,415	15.94
Opted Out	3,282	3.39
Pregnant	546	0.56
Not clinically appropriate	532	0.55
No Further Recall	324	0.34
Terminally III	25	0.03
Co morbidity	23	0.02
Anatomically Impossible	22	0.02
Total	96,708	100.0
% of women with GMS exclusion	applied	27.8%
Total number of eligible women	332,154	
(GP list size minus no cervix excl	usion only)	

Source: SCCRS (August 2019)

During 2018/19 contract year, there were 347,569 women aged 25 to 64 years residing in NHSGGC area and registered with an NHSGGC GP practice. Of these, 27.8% (96,708) had a GMS exclusion applied, of which 15,415 women were recorded as having no cervix, and not eligible for cervical screening. Therefore 332,154 women were eligible for cervical screening in the 2018/19 contract year. The highest proportion of those excluded under GMS exception reporting was classified as Defaulters (79.1%), 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**).

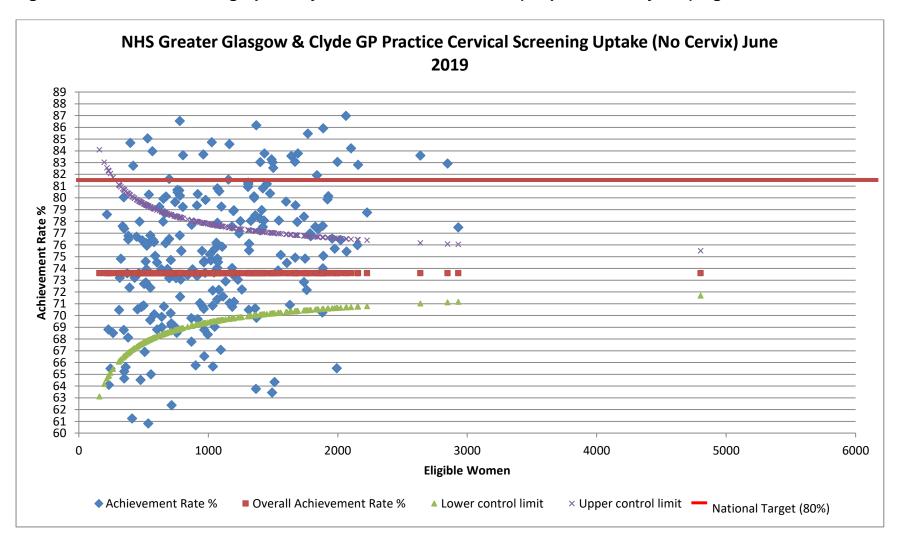
**Figure 8.3** shows uptake by individual GP Practice against the National KPI target of 80%. The majority of Practices did not achieve the target figure.

Table 8.3 No Cervix uptake rates, GMS uptake rates, unsatisfactory smear rates and percentage of defaulters by HSCP in 2018/19

No Ce			No Cervix Uptake			GMS Contract Uptake			% Unsatisfactory				% Defaulters (of List Size)							
	Jun -18	Sep -18	Dec -18	Mar -19	Jun -19	Jun -18	Sep -18	Dec -18	Mar -19	Jun -19	Jun -18	Sep -18	Dec -18	Mar -19	Jun -19	Jun -18	Sep -18	Dec -18	Mar -19	Jun -19
East																				
Dunbarton shire	81.8	81.8	81.8	82.1	82.3	93.4	92.9	93.2	94.0	94.8	2.5	3.0	2.4	2.6	3.0	16.7	16.1	16.5	16.5	16.9
East	01.0	01.0	01.0	02.1	02.0	50.4	02.0	50.2	54.0	54.0	2.0	0.0		2.0	0.0	10.7	10.1	10.0	10.0	10.5
Renfrewsh																				
ire	80.6	80.5	80.6	80.8	80.7	93.2	92.8	92.7	93.4	93.8	2.6	3.3	2.1	1.5	2.9	18.0	17.9	17.9	17.8	18.0
Glasgow																				
North East	72.1	71.8	71.5	71.6	71.8	87.4	87.4	87.6	88.5	89.1	2.4	2.5	2.3	2.5	3.1	23.6	23.7	24.5	24.7	24.8
Glasgow North																				
West	65.3	65.2	64.7	65.1	65.4	84.9	84.5	84.8	85.2	85.7	2.2	2.5	2.6	2.1	3.0	28.1	27.8	28.8	28.3	28.3
Glasgow																				
South	72.9	72.8	72.7	72.8	72.9	88.9	88.4	88.5	89.3	90.0	2.9	2.8	2.3	2.0	4.3	23.0	22.5	23.1	23.2	23.5
Inverclyde	75.0	74.8	74.5	75.2	75.8	90.6	89.8	89.8	91.0	91.5	3.6	2.9	2.5	2.7	2.9	22.8	22.1	22.3	22.1	21.7
Other <sup>1</sup>	69.0	63.6	61.3	65.6	65.8	75.0	66.7	68.8	81.3	80.0	0.0	0.0	0.0	0.0	0.0	31.0	44.1	45.5	48.5	30.8
Renfrewsh		_	_								_								_	
ire	77.8	77.7	77.6	77.9	78.2	91.6	91.3	91.1	91.9	92.5	2.6	2.3	2.0	2.1	1.9	19.8	19.3	19.5	19.7	19.7
West																				
Dunbarton	76.0	76.0	75.0	76.2	76 A	00.6	90.4	90.4	00.7	01.6	2.2	2.2	2.4	2.2	2.0	21 5	20 F	20 F	20.0	21.2
shire	76.0	76.0	75.9	76.3	76.4	90.6	89.4	89.4	90.7	91.6	3.2	3.3	2.4	2.2	2.9	21.5	20.5	20.5	20.9	21.3
GGC	73.5	73.4	73.1	73.4	73.6	89.2	88.8	88.9	89.7	90.3	2.7	2.7	2.3	2.2	2.8	22.7	22.3	22.8	22.9	23.0

<sup>&</sup>lt;sup>1</sup> Other = Challenging Behaviour, Nursing Homes Practice, Homelessness Unit; Source: SCCRS (August 2019)

Figure 8.3 Cervical Screening Uptake by GP Practice at June 2019 (for previous 5.5 years), against National KPI



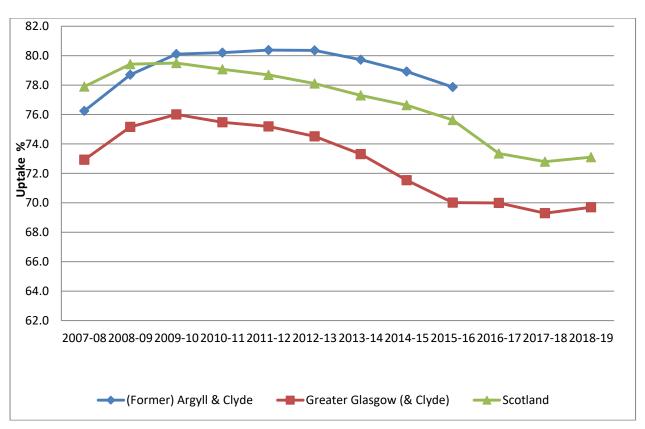
#### 8.8. Programme Performance and Delivery

National 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 national statistics for the time period 1st April 2018 and 31st March 2019.

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). There has been a decline over time in uptake of cervical screening in Scotland and NHS Greater Glasgow and Clyde, and the overall uptake target of 80% has not been reached nationally (Figure 8.4). From 2016, the rate of decline in uptake has levelled off, however this is likely due to the implementation of CARAF in June 2016 (where previously the youngest age groups had the lowest uptake rate)

Figure 8.4 Uptake rate of cervical screening in NHSGGC and Scotland by year (2007-2019)



Source: Information Services Division, cervical screening programme statistics \* 2007-16 data are based on the pre-2006 Health Board configuration (former Argyll & Clyde); From 2016 figures for NHS Greater Glasgow include the Clyde area.

In addition to national performance monitoring via annually published programme statistics, local monitoring is 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 statistics (Appendix 8.2).

Younger women have a poorer uptake of cervical screening than older women **(Table 8.4).** Among women aged 25 to 29, the uptake rate was 63.3% compared to women aged over 40, whose overall uptake rate was 73.9%. No age group achieves the 80% target uptake.

Table 8.4 Uptake of cervical screening among eligible population by age for NHS Greater Glasgow and Clyde, 2018-19 in previous 5.5 years

Age Group	Not Screened	Screened	Total	% Uptake
25-29	16,136	27,867	44,003	63.3
30-34	14,809	35,644	50,453	70.6
35-39	11,863	33,594	45,457	73.9
40-44	8,813	28,392	37,205	76.3
45-49	9,008	30,664	39,672	77.3
50-54	10,209	32,164	42,373	75.9
55-59	11,172	29,007	40,179	72.2
60-64	10,889	21,923	32,812	66.8
Total	92,899	239,255	332,154	72.0

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

Source: SCCRS (August 2019)

Uptake was higher in areas of lower deprivation. Uptake for women aged 25 to 64 in the least deprived areas was 77.4% compared with 69.4% in the most deprived areas. The target of 80% was not met in any deprivation quintile **(Table 8.5).** 

Table 8.5 Uptake of cervical screening among eligible population by SIMD for NHS Greater Glasgow and Clyde, 2018-19 in previous 5.5 years

SIMD Quintile 2016	Not Screened	Screened	Total	% Uptake
1 (Most Deprived)	37,002	83,856	120,858	69.4
2	15,413	40,257	55,670	72.3
3	13,890	32,912	46,802	70.3
4	12,593	34,147	46,740	73.1
5 (Least Deprived)	14,001	48,083	62,084	77.4
Total	92,899	239,255	332,154	72.0

Source: SCCRS (August 2019)

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 target of 80% was not met by any ethnic group. The highest uptake was among White – British ethnic category at 76.2%, and the lowest uptake of 38.4% was among Chinese women.

Table 8.6 Uptake of cervical screening among eligible population by ethnicity for NHS Greater Glasgow and Clyde, 2018-19 in previous 5.5 years

2001 Census Ethnic Group	Not Screened	Screened	Total	% Screened
White - British	60,525	193,692	254,217	76.2
White – Irish	5,550	15,462	21,012	73.6
White - any other white background	9,205	10,734	19,939	53.8
Asian or Asian British	6,233	9,120	15,353	59.4
Black or Black British	1,156	1,559	2,715	57.4
Other ethnic groups - Chinese	4,532	2,820	7,352	38.4
Other ethnic groups - any other group	3,372	4,073	7,445	54.7
Unclassified	2,326	1,795	4,121	43.6
Total	92,899	239,255	332,154	72.0

Source: SCCRS (August 2019); OnoMap

The target for cervical screening uptake (80%) was met only in East Dunbartonshire HSCP (81.0%). The lowest uptake rate of 63.0% was in Glasgow City HSCP North West Sector, a difference in uptake of 17.0% (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 75.8.% SUR in East Dunbartonshire HSCP compared to 65.9% 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.

Table 8.7 Indirectly Standardised Uptake of Cervical Screening by HSCP in NHS Greater Glasgow and Clyde, 2018-19

НЅСР	Not Screened	Screened	Total	% Screened	SUR %	SUR % LCI	SUR % UCI
East Dunbartonshi re	5,426	23,184	28,610	81.0	75.8	74.8	76.8
East Renfrewshire	4,899	19,478	24,377	79.9	75.2	74.1	76.2
Glasgow North East Sector	16,463	37,073	53,536	69.2	71.5	70.7	72.2
Glasgow North West Sector	24,396	41,514	65,910	63.0	65.9	65.3	66.5
Glasgow South Sector	19,637	47,533	67,170	70.8	72.3	71.7	73.0
Glasgow City	60,496	126, 120	186,616	67.6	69.8	69.5	70.2
Inverclyde	5,218	15,414	20,632	74.7	72.9	71.8	74.1
Renfrewshire	10,840	36,483	47,323	77.1	74.5	73.7	75.3
West Dunbartonshi re	6,020	18,576	24,596	75.5	74.3	73.3	75.4
Total	92,899	239,255	332,154	72.0			

Source: SCCRS (August 2019), OnoMap.

SUR = Standardised Uptake Rate; UCI = Upper Confidence Intervals; LCI = Lower Confidence Intervals

To enable further local analysis of uptake rates, geographical mapping at datazone level was undertaken during 2017/18. Data zone maps for NHSGGC and by HSCP are available on the PHSU website<sup>22</sup>. These maps provide further insight to geographical variation in uptake and have been used to inform activities outlined in the inequalities action plan (Appendix 8.3).

Of those eligible for cervical screening, 1,359 were registered as having a Learning Disability (LD) **(Table 8.8)**. Women who were registered with a learning disability had poorer uptake of cervical screening (28.0%) compared to the rest of the population (72.0%).

<sup>22</sup> Cervical Screening Uptake Data Zone maps: <a href="https://www.nhsggc.org.uk/your-health/public-health-public-health-screening-unit/reports/">https://www.nhsggc.org.uk/your-health/public-health-public-health-screening-unit/reports/</a>

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Table 8.8 Uptake of cervical screening among eligible population with learning disability for NHS Greater Glasgow and Clyde 2018-19, in previous 5.5 years

Learning Disability	Not Screened	Screened	Total	% Uptake
Rest of population	91,540	238,726	330,266	<i>7</i> 2.3
Registered with a LD	1,359	529	1,888	28.0
Total	92,899	239,255	332,154	72.0

Source: SCCRS; Learning Disability Register (August 2019)

Pearson Chi-Square p < 0.0001

People registered on PsyCIS have had at least one episode of psychosis which is typically seen in patients with a severe or enduring mental illness. These individuals had poorer uptake of screening (66.8%) compared to in the rest of the population (72.1%) **(Table 8.9)**.

Table 8.9 Uptake of screening among eligible population among people with severe and enduring mental illness for NHS Greater Glasgow and Clyde 2018-19, in previous 5.5 years

Severe and Enduring Mental Illness	Not Screened	Attended Screening	Total	% Uptake
Rest of population	92,267	237,983	330,250	72.1
Registered on PsyCIS	632	1,272	1,904	66.8
Total	92,899	239,255	332,154	72.0

Source: SCCRS; PSYCIS (August 2019)

Pearson Chi-Square p < 0.0001

#### 8.9. NHSGGC Cytopathology Laboratories

**Table 8.10** provides an overview of the number of cervical screening tests processed and the results of cervical screening tests carried out at NHSGGC laboratory for the period 1st April 2018 to 31st March 2019. This data is sourced from nationally produced annual reports from SCCRS Laboratory Reports.

The total number of smear tests processed in NHSGGC laboratory in 2018/19 was 103,942. 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 103,943 cervical samples processed, 2,979 (2.9%) 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 2018/19 (2.9%) was similar to other years in the past decade.

A total of 100,963 smears tests received by the laboratories (97.1%) were satisfactory and processed. Of these 90,983 (89.9%) were reported to be negative (normal).

In 2018/19, 10,170 (10.1%) of satisfactory smears were reported as abnormal. Abnormal smears results include: borderline, low grade, moderate and severe dyskaryosis, severe and invasive dyskaryosis, glandular abnormality and adenocarcinoma. Of the Abnormal smears, 8.9% had a borderline/low grade cell change and the remaining 1.1% had high grade cell changes. **Appendix 8.1** shows the management and follow up advice for cytology results.

The introduction of High risk HPV screening in early 2020 will impact the workload of the NHSGGC Cytopathology laboratories. The Glasgow laboratory will be one of the two laboratories that will deliver the new pathway. Planning is ongoing at national, Board, and local team levels to enable a smooth transition.

Table 8.10 Cervical screening tests processed and results of cervical screening tests carried out at NHSGGC Laboratory: 1st April 2018 – 31st March 2019

				Result of satisfactory screens								
All	Unsatis-			Borde	rline		Dyskaryosis					
screens	factory	Total Negativ		Change in endocervical cells	Change in squamous cells	Low grade	High grade (moderate)	High grade (severe)	High grade dyskaryosis invasive	Glandular abnormality	Endocervical Adeno- carcinoma	Endometrial or other malignancy
103,942	2,979 (2.9%)	100,963	90,793 (89.9%)	237 (0.2%)	4,645 (4.6%)	4,138 <i>(4.1%)</i>	644 (0.6%)	422 (0.4%)	20 (0.02%)	56 (0.06%)	1 (0.00%)	7 (0.01%)

Source: ISD, SCCRS Laboratory Report 09A

#### 8.10. Colposcopy

**Table 8.11** shows the activity data across NHSGGC colposcopy services. In 2018/19, there were 6,167 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 8.11 NHSGGC Colposcopy Services Workload 1 April 2018 to 31 March 2019

	Ту	pe of Episode	9	Total
Attendance Status	New Outpatients	Return/ Follow Up Outpatients	Inpatients	Episodes (Types 1-3)
Patient was Seen		•		
(Attended)	3,781	2,330	56	6,167
<b>Cancelled by Patient</b>	248	273	1	522
Cancelled by Clinic or Hospital	11	118	1	130
Patient attended but was not seen (CNW)	1	1	0	2
Patient Did Not Attend	267	340	0	607

Source: National Colposcopy Clinical Audit System (Extracted November 2019) Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

New Healthcare Improvement Scotland Cervical Screening Standards<sup>23</sup>, set out nationally agreed time frames for individuals referred to colposcopy following an abnormal screening test:

- 1. no later than 2 weeks for urgent referrals (glandular, suspicion of invasion)
- 2. no later than 4 weeks for high grade referral, and
- 3. no later than 8 weeks for low grade referrals that do not require urgent assessment.

**Table 8.12** presents the waiting times of patients referred to NHSGGC colposcopy services. For patients who are identified as having high grade abnormalities, most women were seen within the timeframe with 86 women (11%) waiting more than 4 weeks.

<sup>23</sup> http://www.healthcareimprovementscotland.org/our\_work/standards\_and\_guidelines/stnds/cervical\_sc reening\_standards.aspx [Accessed December 2019]

Table 8.12: Referrals to Colposcopy by Time Waited from Referral to First Appointment by Referral Cytology or Reason for Referral, time period 1 April 2018 to 31 March 2019

	New	New Referrals by Time Waited from Referral to First Appointment									
	equa	han or I to 4 (s (a)	Greate 4 weel <= 8 v	er than ks and weeks o)	Greate 8 we	er than eeks c)	Total New Referrals				
Referral Cytology	No %		No	%	No	%	(a + b + c)				
Unsatisfactory	25	27.2	51	55.4	16	17.4	92				
Borderline change in squamous cells	103	25.0	185	44.9	124	30.1	412				
Low grade dyskaryosis	231	24.5	441	46.9	269	28.6	941				
Borderline change in endocervical cells	8	33.3	8	33.3	8	33.3	24				
High grade dyskaryosis (moderate)	407	87.2	49	10.5	11	2.4	467				
High grade dyskaryosis (severe)	277	91.4	23	7.6	3	1.0	303				
High grade dyskaryosis? Invasive	11	73.3	4	26.7	0	0.0	15				
Glandular Abnormality	33	86.8	4	10.5	1	2.6	38				
Endocervical Adenocarcinoma	1	100.0	0	0.0	0	0.0	1				
Endometrial or other malignancy	3	75.0	0	0.0	1	25.0	4				
No Referral Cytology											
Clinical Indication	234	58.9	123	31.0	40	10.1	397				
Other	291	37.1	356	45.4	138	17.6	785				
Total	1624	46.7	1244	35.8	611 17.6		3,479				

Source: NHSGGC local waiting times reports amalgamated, Extracted Nov 2019

#### 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 2018, we reviewed the notes of 55 women who developed invasive cervical cancer and had a pathology diagnosis made in NHS Greater Glasgow and Clyde laboratories.

**Table 8.13** shows numbers and the distribution of women's age at diagnosis for years 2010 to 2018. The largest number of cervical cancers occurred in women aged between 30 and 39 years.

Table 8.13 Number of NHSGGC residents with invasive cervical cancers by age at diagnosis and year of diagnosis

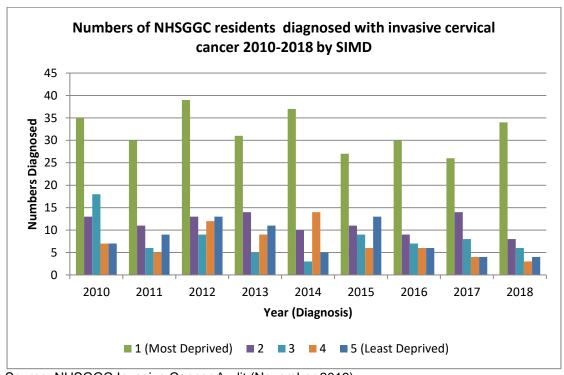
	Year (Diagnosis)									
Age Group	2010	2011	2012	2013	2014	2015	2016	2017	2018	Total
20-29	10	7	12	6	9	8	16	7	7	82
30-39	23	16	27	23	21	18	9	20	14	171
40-49	22	10	17	17	14	16	10	13	13	132
50-59	7	10	9	10	11	9	10	6	13	85
60-69	≤5	7	11	3	6	10	8	≤5	≤5	59
70-79	10	8	7	7	≤5	≤5	≤5	≤5	≤5	52
80+	≤5	≤5	≤5	≤5	≤5	≤5	≤5	≤5	≤5	20
Total	80	61	86	70	69	66	58	56	55	601

Source: NHSGGC Invasive Cancer Audit (November 2019)

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 2018. The highest proportion of cervical cancers occurred in women living in the most deprived (SIMD1) areas.

Figure 8.5 Numbers of NHSGGC residents diagnosed with invasive cervical cancer 2010-2018.



Source: NHSGGC Invasive Cancer Audit (November 2019)

**Table 8.14** shows the distribution of clinical stage at diagnosis over an eight year period from 2010 to 2018.

Table 8.14 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	2017	2018	Total
Not Known	4	≤5	≤5	≤5	≤5	≤5	≤5	≤5	≤5	10
1a1 (less than 3mm deep and >=7mm wide)	21	12	20	19	14	11	19	13	17	146
1a2 (3-5mm deep and <7mm wide)	≤5	≤5	≤5	≤5	≤5	≤5	≤5	≤5	≤5	11
1b (confined to cervix)	14	14	24	19	26	21	10	15	16	159
2 or Greater (spread outwith cervix)	39	33	38	30	29	33	26	27	20	275
Total	80	61	86	70	69	66	58	56	55	601

Source: NHSGGC Invasive Cancer Audit (Extract updated May 2022)
Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

**Table 8.15** shows that, in 2018, 22 of the 55 (40%) cases were screen detected. The rest of the cases presented to the service with symptoms or were incidental findings.

Table 8.15 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	2017	2018	Total
Not Known	24	20	≤5	≤5	≤5	≤5	≤5	≤5	≤5	48
Smear detected	29	20	39	31	33	28	27	20	22	249
Symptomatic	27	21	46	38	34	36	26	35	33	296
Incidental Finding	≤5	≤5	≤5	≤5	≤5	≤5	≤5	≤5	≤5	8
Total	80	61	86	70	69	66	58	56	55	601

Source: NHSGGC Invasive Cancer Audit (November 2019)

Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

In 2018, 13 of 55 (23.6%) women diagnosed with invasive cervical cancer had a complete smear history compared to 39 (70.9%) women who had incomplete smear histories (**Table 8.16**). Over the nine years audited, 65 (10.8%) women out of the 601 that developed cancer had never had a smear; 210 (34.9%) had complete smear histories and 318 (52.9%) of women had incomplete smear histories.

Table 8.16 Smear histories of women with invasive cervical cancer

		Year (Diagnosis)								
Smear History	2010	2010 2011 2012 2013 2014 2015 2016 2017 2018								Total
Adequate	25	25	34	24	28	21	23	17	13	210
Incomplete	42	22	40	36	36	39	30	34	39	318
Not	12	14	11	10	≤5	≤5	≤5	≤5	≤5	65
Applicable										
Not Known	≤5	≤5	≤5	≤5	≤5	≤5	≤5	≤5	≤5	8
Total	80	61	86	70	69	66	58	56	55	601

Source: NHSGGC Invasive Cancer Audit (November 2019)

Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

**Table 8.17** 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 8.17 Follow up status of women with invasive cervical cancer

		Year (Diagnosis)								
<b>Current Status</b>	2010	2011	2012	2013	2014	2015	2016	2017	2018	Total
Lost to colposcopy service	≤5	≤5	≤5	≤5	≤5	≤5	≤5	≤5	≤5	6
On follow up at colposcopy	21	8	24	18	13	11	15	10	9	129
On follow up at oncology/Beatson	47	38	46	46	52	48	31	16	11	335
Early recall	≤5	≤5	≤5	≤5	≤5	≤5	≤5	≤5	≤5	≤5
Death	7	9	11	≤5	≤5	≤5	≤5	≤5	≤5	42
No further recall	≤5	≤5	≤5	≤5	≤5	≤5	8	24	28	63
Unknown	≤5	≤5	≤5	≤5	≤5	≤5	≤5	≤5	≤5	22
Total	80	61	86	70	69	66	58	56	55	601

Source: NHSGGC Invasive Cancer Audit (November 2019)

Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

#### 8.12. Quality Improvement

An internal review of cervical screening was undertaken by Price Waterhouse Cooper as part of the 2017-18 internal audit plan approved by the Audit and Risk Committee. Recommendations of this report included:

'A clear process should be created which links the analysis of demographic data back to the campaigns and projects/other actions being undertaken. Demographic data should be discussed at every steering group meeting to ensure campaigns and projects are targeted at areas with the lowest uptake rates or identify where a different course of action may be required.'

The recently launched NHS GGC Public Health Strategy (2018)<sup>24</sup> outlines a commitment to reduce inequalities in uptake of screening programmes through targeted intervention plans. The strategy also recognises and aims to support the work of partner organisations in widening access to screening as an approach to early intervention.

In response to these drivers, a more structured approach was been developed with our key stakeholders in 2018, and NHSGGC's Screening Inequalities Action plan 2019-21 outlined priorities and actions to widen access and address inequalities in relation to all five adult screening programmes.

NHSGGC continues to work in close collaboration with Third sector partners including CRUK and Jo's Cervical Cancer Trust have worked closely to develop approaches and deliver on actions outlined in the action plan.

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<sup>&</sup>lt;sup>24</sup> http://www.stor.scot.nhs.uk/ggc/bitstream/11289/579831/1/Public+Health+Strategy+2018+-+2028+A4+-+Landscape+-+10-08-18-01.pdf [Accessed 28<sup>th</sup> December 2018]

#### 8.13. Challenges and Future Priorities

- To counter the decreasing uptake of cervical screening by implementing a planned programme of promotional activities as outlined in inequalities plan.
- To deliver implementation of Hr-HPV primary screening in 2020, including stakeholder communications and workforce development plan.
- To undertake trial of SMS reminder texts to 25 year old women eligible for cervical screening.
- 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 Cervical Cancer Trust to support GP practices to sustain good practice to support eligible women to participate in cervical screening programme.
- To continue development and delivery of the NHSGC Adult Screening Inequalities Action Plan (Appendix A) will enable a more coordinated approach to reducing inequalities in uptake through targeted intervention plans.
- To support national public health information campaigns to increase cervical screening uptake among women in younger age groups.

### **Appendix 8.1**

- 1. Management and follow-up advice for cytology results
- 2. Management and follow up for cytology results: Post Total Hysterectomy
- 3. Management and follow up for cytology post treatment cervical smear and HPV test (Test of Cure)

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

SMEAR REPORT	MANAGEMENT
Negative	36 month recall
Negative, after borderline	Further repeat at 6 months Return to
	routine recall after 2nd negative
Negative, after mild	Further repeat at 6 & 18 months. Return
	to routine recall after 3rd negative
Unsatisfactory	3 month recall. Refer after third in
	succession
Low grade abnormalities	
Borderline Squamous Changes +/-	6 month recall. Refer after third.
HPV	? High grade – Flag as such and Refer to
	Colposcopy on 1st
Borderline Glandular Changes	6 month recall. Refer after second
Low grade dyskaryosis	Repeat in 6 months Refer after second
Low grade dyskaryosis	Repeat in o months Refer after second
High grade abnormalities	
Glandular abnormality	Urgent (within 2 weeks) refer to
-	Colposcopy
Moderate Dyskaryosis	Refer to Colposcopy
Severe Dyskaryosis	Refer to Colposcopy
Severe Dyskaryosis / invasive	Urgent (within 2 weeks) refer to
	Colposcopy
Adenocarcinoma – Endocervical	Urgent (within 2 weeks) 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)**

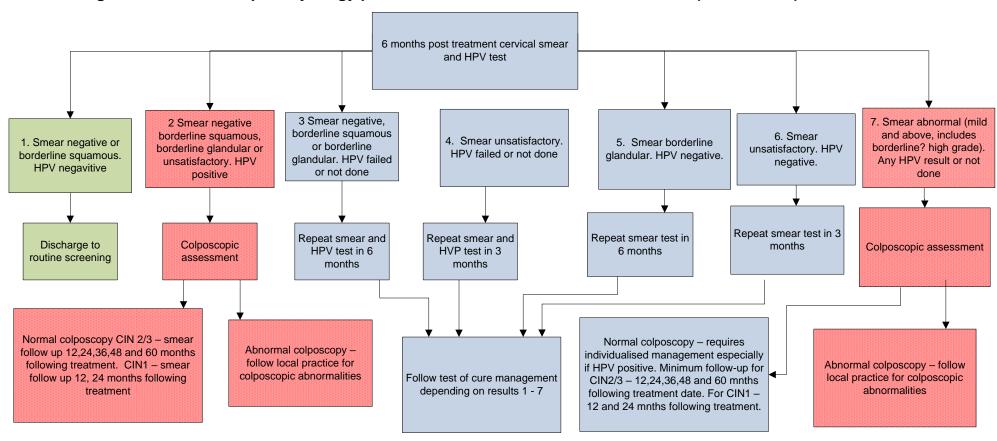
# 1. Management and follow up for cytology results: Post Total Hysterectomy

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 (any grade, completely or incompletely excised)	Vault smear and HPV Test at 6 months (Test of Cure). If both negative, no further recall. If abnormal refer back and manage outcome accordingly.
Hysterectomy as treatment for CGIN (any grade)	Vault smears at 6 and 18 months. If negative, no further recall. If abnormal refer back and manage outcome accordingly.

CIN = cervical intraepithelial neoplasia CGIN = cervical glandular intraepithelial neoplasia

#### **Appendix 8.1 (continued)**

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



#### **National Performance Standards 2018-2019**

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

### Uptake for Cervical Screening; Scotland & NHSGGC 1st April 2018 to 31st March 2019

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	73.1	69.7
Percentage uptake by depriv	vation quintile		
SIMD 1 (most deprived)		67.2	67.0
SIMD 2		70.8	69.1
SIMD 3	80	73.4	69.1
SIMD 4		76.5	70.9
SIMD 5 (least deprived)		78.0	75.6

### Uptake for Cervical Screening by HPV vaccinated: Scotland & NHSGGC 1st April 2018 to 31st March 2019

Percentage uptake of females who had a record of a previous screening test taken within last 3.5 years by age

	Age						
HPV vaccination status	22	23	24	25	26	27	22-27
ŀ	IPV Imn	nunisati	on statu	s (Full <sup>1</sup> )			
Scotland	52.7	63.7	67.2	70.3	75.3	76.7	69.4
Greater Glasgow & Clyde	48.0	61.5	65.3	68.9	73.7	76.1	67.8
Н	PV Immi	unisatio	n status	(Incom	olete¹)		
Scotland	43.0	48.0	57.8	66.1	70.7	73.1	67.2
Greater Glasgow & Clyde	32.0	41.0	57.4	62.2	72.5	71.6	66.0
	No HPV Immunisation status						
Scotland	24.5	32.0	28.6	30.7	38.7	45.2	36.4
Greater Glasgow & Clyde	20.5	26.2	23.1	25.7	33.7	40.5	31.2

<sup>1.</sup> The Immunisation Status of FULL is where the individual has been Fully Immunised, i.e. had all HPV doses. 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 2018 to 31st March 2019

Year/ quarter	Scotland	Greater Glasgow & Clyde
Q4	117,982	30,152
Q3	93,870	24,395
Q2	95,240	23,998
Q1	100,762	25,397
TOTAL	407,854	103,942

<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 2018 to 31st March 2019

Year/ quarter	Scotland	Greater Glasgow & Clyde
Q4	37	43
Q3	30	35
Q2	26	30
Q1	29	28

<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 2018 to 31st March 2019 (Mean number of days by quarter)

Year/ quarter	Scotland	Greater Glasgow & Clyde
Q4	37	38
Q3	28	37
Q2	27	32
Q1	30	31

<sup>&</sup>lt;sup>1</sup>The reporting time is defined as the number of days from the date the screening test was performed to the date the report was issued by the laboratory.

#### **Inequalities Action Plan**

### **Progress report:**

# Widening access and addressing inequalities in adult screening programmes. Action plan for 2019-21

NHS Greater Glasgow and Clyde (NHS GGC)'s Public Health Directorate is responsible for co-ordinating and monitoring screening programmes across Greater Glasgow and Clyde, and Argyll & Bute (part of NHS Highland).

The Widening Access and Addressing Inequalities in Adult Screening Programmes Action Plan for 2019-21 outlined priorities and actions to widen access and address inequalities in relation to adult screening programmes.

This paper provides an update on progress of the actions and relevant developments in adult screening programmes.

#### 2. Developments in the Scottish Breast Screening Programme

- (a) In July 2019, the Scottish Government announced a review of the Scottish Breast Screening Programme. The review, which is expected to take around a year, will be carried out by National Services Division (NSD), a part of NHS National Services Scotland, which commissions and coordinates the programme. The review will involve an appraisal of the programme, current pressures and future options for delivery. It will also look at advances in technology and ways to increase participation and address health inequalities.
- (b) In October 2019, the Information Services Division released Scottish Breast Screening Programme Statistics to 31 March 2018. This is the first release of statistics since April 2017 due to the implementation of the new digital mammography Scottish Breast Screening System. For the period 2015/16-17/18, 514,083 women aged 50-70 attended a routine breast screen appointment which equates to around 7 in 10 women (71.2%) taking up the invitation for screening. For the period 2015/16 17/18, NHS Greater Glasgow & Clyde uptake was 65.8%. This meant it was one of four NHS Boards which did not meet the minimum acceptable uptake standard of 70%. The national uptake rate has been falling consistently since 2008/09-10/11 when it was 74.9%. Women from more deprived areas are less likely to attend for breast screening, with under 6 in 10 women from the most deprived areas going for screening compared with almost 8 in 10 women living in the least deprived areas. Currently, we

are not able to access more detailed local data but it is hoped that this will follow in the near future.

#### 3. Review of actions

#### **ALL SCREENING**

75. Provide support to GP practices to access, analyse and use their data for planning and quality improvement purposes.

HSCPs and GP clusters are now able to access support for using their data through Local Intelligence Support Teams (LIST) employed through ISD Scotland. In addition to this national resource, NHS GGC Primary Care Development Officers continue to support GP clusters. Data sharing agreements to support the use of primary care intelligence are in progress. See also action 4.

- 76. Provide support to GP practices to maintain patient records including mobile number, appropriate read coding, identification and articulation of support needs.
- 77. Identify and address coding actions which may impact on eligibility status and patient communication.

The new GP contract has moved away from a detailed specification of requirements in relation to LD, but maintaining comprehensive disease registers in general practice remains an expectation. Further work is required to ensure consistency and quality of data in relation to recording of LD, and to agree how data will be extracted and used from practice systems to enable this to continue to be used to identify and address any inequalities in screening uptake. This will be taken forward in line with the forthcoming national template for data sharing with practices, a review of disease registers and the further development of primary care information for reporting on quality indicators.

## 78. Specify calls to action related to priority groups in screening when data sharing with GP practices and clusters.

This year, for the first time, standardised cluster level cervical and bowel screening uptake data has been shared with GP clusters among other public health priorities in cluster intelligence reports. Where uptake is lower than expected, clusters have been directed to resources which support quality improvement including health improvement teams and third sector organisations as well as toolkits which can help practice staff to understand the barriers to attendance and use methods which could increase attendance. More than half of clusters also met Public Health Directorate staff in order to discuss reports further and help prioritise areas for quality improvement.

- 79. Utilise mapping of resources to develop patient and carer information pathways.
- 80. Increase use (distribution and support for understanding) of accessible patient information and digital displays as tools to aid informed participation.

All adult screening resources have been mapped. These include NHS and third sector resources. This has allowed us to identify information gaps more easily and to raise awareness of alternative formats through HSCPs and third sector organisations. In line with our Accessible Information Policy, we are able to have materials produced in additional alternative formats where a need has been identified or a patient has requested this. For example, in developing work related to cervical screening with women in Chinese communities, we have identified the need for patient information in Simplified Chinese.

Renfrewshire have utilised social media to promote cancer screening programmes through campaigns.

A national communications and engagement plan is in development to inform women of changes in the cervical screening programme. This will include updating Health Inequalities Impact Assessment for cervical screening communications to ensure the national communications strategy helps reduce inequalities and improve reach of our screening programme. See also Clyde Gateway actions 15 and 16 for campaigning work.

- 81. Develop a Learn Pro module to improve access to CPD on adult screening programmes for staff who are in a position to support informed participation. Preliminary work on this has begun. A project brief and a costing have been undertaken.
- 82. Update protocols for providing access to screening adults from travelling communities and armed forces personnel.

Work on this is currently in progress.

- 83. Monitor screening uptake and engagement with the screening programmes in prisons within NHSGGC.
- 84. Support the implementation of the National Prison Healthcare Network recommendations for engagement with the population screening programmes in the prison setting.

A new practitioner post has been provisionally approved. This post will provide single point of contact for screening services. The post holder will also deliver training and cascade information about screening programmes to prison health care staff (and other staff as appropriate). We are currently working with screening services to update standard operating procedures regarding sub-population groups, including

prisons. New national posters summarising screening programmes according to gender have been developed and distributed for use in prisons.

#### 85. Work with third sector to support and promote screening programmes.

Cancer Research UK, Jo's Trust and Bowel Cancer UK (Scotland) continue to be our main third sector partners in relation to adult screening programmes. These organisations participate in our programme steering groups and deliver work in primary and acute care, working closely with both Public Health and HSCP Health Improvement teams.

A number of training and information sessions have been delivered by NHS GGC and third sector partners to NHS staff who work with people with learning disabilities and those who have severe and enduring mental illness.

In addition to the third sector organisations with a specific remit for cancer, HSCPs work with many third sector and community oranisations. Work with these organisations is important in order to raise awareness of adult screening programmes and to understand more about access barriers to screening. People First, for example, have contributed to the Clyde Gateway work and there is further work with the third sector planned for next year. See also action 26.

#### **CERVICAL**

#### 86. Clarify service specification on programme re GMS contract.

The cervical screening programme continues to be delivered in GP practices. Following the disbanding of the Quality and Outcomes Framework (QOF), the payment for cervical screening services is now included in GP Practices' Global Sum.

A new approach to cervical screening has been approved by the Scottish Government and will be introduced in early 2020. High risk HPV screening involves the same clinical examination but only women whose virology results are positive for specific types of HPV will have cervical cytology.

87. Introduce a steering group process to link the analysis of demographic data to to ensure campaigns and projects are targeted at areas with the lowest uptake rates or identify where a different course of action may be required.

Following an internal review of cervical screening was undertaken by Price Waterhouse Cooper as part of the 2017-18 internal audit plan approved by the Audit and Risk Committee. The Cervical Screening Governance Group has established a mechanism to use data to target targeting of promotional activities to those with low uptake including vulnerable or excluded groups.

88. Monitor the impact of the new GMS contract on screening uptake.

The new contract was introduced in April 2018. It is early yet to monitor impact; however, a broader evaluation of the Primary Care Improvement Plans agreed by the Primary Care Programme Board is underway and will look at issues including equality of access in primary care.

#### **CERVICAL / BREAST**

- 89. Support peer to peer learning for adults with a learning disability in cervical and breast screening in the Clyde Gateway area.
- 90. Conduct tests of change in peer learning programme as part of the Clyde Gateway area project.

The Clyde Gateway programme of work is funded under the Screening Inequalities Fund. There have been three tests of change In GGC:

- Sandyford pop-up clinics: Use of data from the Scottish Cervical Call Recall System to invite non-engager to Saturday pop-up clinics to increase uptake of cervical screening.
- A peer learning approach to screening for women with learning disabilities using coproduction methods based on EMBRACES: ID, an evidence based programme.
- A marketing communications campaign to increase local awareness and knowledge of screening programmes.

The work is due to be completed by March 2020. Glasgow Centre for Population Health is working with Clyde Gateway to evaluate this work.

#### **CERVICAL**

#### 91. Test the use of teaser communication via a randomised control trial.

Development work for this action is ongoing. The proposal has been subject to changes following suggestions by the Scottish Government during the ongoing application process for the Screening Inequalities Fund. The main proposed change has been from teaser letter to SMS text reminder aimed at women under 30 who may be in their first or second invitation cycle. In developing this work in line with this change, it has become clear that much of the learning will come from testing the legal and ethical processes involved in this work as well as the current limitations of our information and communication systems subject to ethical approval. This will help us to identify what would need to be changed in order to scale up the use of SMS technologies in screening programmes. Recent results from similar work undertaken by Public Health England in London suggest that the use of mobile technologies can increase engagement in cervical screening. Our proposed work aims to explore this further in relation to deprivation and HPV vaccination status.

# 92. Monitor the impact of HPV vaccination on uptake of cervical screening programme.

This will be undertaken as part of the routine reporting in the Screening Annual Report. Cervical screening uptake is highest in HPV vaccinated women when compared to the non-vaccinated women.

## 93. Review and update cervical screening toolkit following primary care staff focus groups.

The toolkit is currently on hold because a national one to due to be published.

### 94. Test of change: Increase appointment availability for cervical screening outwith standard office hours.

Also see actions 15 and 16. In addition, Health Improvement staff worked with two GP practicies to provide cervical screening drop-in clinics in East Dunbartonshire. These were successful in engaging women who had been identified as non-engagers. An important aspect of the tests of change, particularly for pop-up clinics is whether the approach is sustainable. Similar previous work in North East Glasgow identified operational barriers to providing an out of hours services in health centres.

### 95. Develop content and deliver staff learning and development to GP practice staff.

# 96. Provide opportunities for third sector organisations to contribute to NHS staff training.

Primary Care Support and Development continue to staff deliver cervical skills training. This training incorporates inequalities content such as supporting with women with learning disabilities. Cancer Research UK staff have also contributed training on increasing uptake and reducing barriers to participation and programme updates. Cervical skill training has been delivered to practices nurses, colposcopy staff and Sandyford Sexual Health Services.

#### 97. Provide targeted education to groups with lower uptake status.

See actions 15 and 16. There are also plans to deliver education to BME communities in 2020.

#### **BOWEL SCREENING**

#### 98. Teaser letters for bowel screening.

NHSGGC reinstated the teaser letter to first time participants to coincide with the introduction of the FIT test.

#### 99. Monitor the impact of FIT on uptake of the screening programme.

Monitoring of the impact of FIT is ongoing. Following the implementation of FIT, there has been a 3.9% increase in uptake of bowel screening across Scotland and a 4.1% increase within NHSGGC. This increase is evident for both sexes and across all

deprivation quintiles. A research study of clinical outcomes associated with symptomatic FIT is currently being conducted by the University of Glasgow in partnership with NHS GGC.

#### 100. Conduct tests of change in West Dunbartonshire.

West Dunbartonshire undertook a multi agency test of change aimed at improving the bowel screening uptake rates for people with learning disabilities. Following Caldicott approval, the National Bowel Screening Service was able to provide live updated data to the Learning Disability Team on the current cancer screening status of those individuals known to its service. This allowed staff within both the Learning Disabilities Team and staff from the Third Sector support agencies to provide a personalised letter, face to face health check and offer support to complete the screening test kit. This resulted in screening test kit completion or a recording of informed decision to decline to participate. For those individuals who were part of the baseline group and received our basic evidence-based intervention, 30% (14) went on to complete a screening test kit or made an informed decision to decline to participate. Of the individuals who were part of our PDSA, 70% (7) went on to complete a screening test kit or make an informed decision to decline to participate. The Learning Disabilities Team participated in bowel cancer awareness training provided by Cancer Research UK. Eleven local third sector agencies attended cancer awareness training provided by Bowel Cancer UK. The Learning Disability Team as part of West Dunbartonshire's commissioning of third sector services, have written a number of new service contact specifications which will embed screening support activities and the recording of screening status as part of future third sector service contracts.

#### 101. Support primary care awareness of FIT and symptomatic FIT.

# 102. Support GPs to use a test of change approach to promote bowel screening uptake.

Cancer Research UK have raised awareness of the role of symptomatic FIT in their work with primary care.

#### **BREAST**

### 103. Assess feasibility of programme of service and community development where uptake is low.

A muli-agency programme of work to raise awareness and increase participation in screening in Govanhill is in progress. As part of this, the West of Scotland Breast Screening Service agreed to pilot the location a breast screening mobile unit close to the area, however, there was a lack of any suitable location for the mobile unit. This issue has now been resolved by the demolition of a wall at the New Victoria Hospital which has now created sufficient and appropriate space.

#### 104. Support breast screening visits for women with disabilities.

Inequalities of access will be addressed in the current national Breast Screening Review. Work is also planned for next year in West Dunbartonshire to look at supporting women with learning disabilities to access breast screening. (It is recognised that many women with learning disabilities also have physical disabilities.)

#### BREAST / AAA / DIABETIC RETINOPATHY

105. Routinely send a list of clinic venues with all initial invitation letters, so that people are aware that can change venue.

Options for this action will be raised with service managers at programme steering groups.

#### AAA

106. Implement the evidence based recommendations from Public Health England to reduce inequalities.

We are currently improving local intelligence in order to inform evidence based recommendations at a local level. Inhouse research is being conducted on individuals under AAA surveillance. This will seek information on experience of the AAA monitoring process, how AAA has impacted on their life, and suggestions for improvement with current process. Participant demographic questions will be based on the demographics known to affect engagement with AAA screening (e.g. comorbidities, learning disability or mental health issues, relationship status, scanning venue/distance to, postcode for SIMD/HSCP, etc). This will help us to identify issues linked to inequalities.

#### AAA / DIABETIC RETINOPATHY

- 107. Increase awareness of programmes in primary care and in the most deprived communities.
- 108. Analyse uptake by deprivation through datazone mapping.
  We undertook geographical mapping of uptake rates for cervical, bowel, AAA and DRS screening programmes at data-zone level.
- 109. Scope out potential to resource health improvement support at screening facilities.
- 110. Work with RNIB to promote DRS.
- 111. Support GP practices to use of SCI diabetes and accurately code patients.

These actions link to a broader programme of work linked to Moving Forward Together and to the Health Improvement Diabetes Prevention Programme. These are in development and will be reported in more detail once plans have been agreed.

#### Appendix 8.4

#### Members of Cervical Screening Steering Group (As at March 2018)

Dr Emilia Crighton Deputy Director of Public Health (Chair)

Ms Christine Black Consultant in Sexual and Reproductive Health

Ms Lisa Buck Public Health Programme Manager

Mr Paul Burton Information Manager

Ms Sandra Cairney Associate Director of Public Health, Argyll and Bute HSCP

Mrs Lin Calderwood HI&T Service Delivery Manager

Mrs Pam Campbell Records Manager

Ms Claire Denning General Practice Nursing Transformation Lead, Primary Care

Support

Dr Victoria Flanagan Consultant Obstetrician & Gynaecologist, RAH

Dr Morton Hair Clinical Lead, RAH

Dr Robert Henderson Consultant in Public Health Medicine, Highland

Ms Heather Jarvie Public Health Programme Manager

Mrs Kathy Kenmuir Practice Nurse Support and Development Team Manager

Dr Margaret Laing Staff Grade in Cytology/Colposcopy
Dr Graeme Marshall Clinical Director, North East Glasgow

Mrs Michelle McLachlan General Manager, Obstetrics

Dr Abigail Oakley Consultant Pathologist

Mr Graham Reid Specialty Manager, Cytology

Mrs Elizabeth Rennie Programme Manager, Screening Dept
Mrs Fiona Scott Practice Manager, Clarkston Medical Centre

Ms Alana Struthers CRUK Facilitator, West of Scotland Ms Heather Woods PHEC, Jo's Cervical Cancer Trust

## **Chapter 9 - Diabetic Retinopathy Screening (DRS)**

## **Summary**

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.

The Scottish Diabetes Survey 2018 reports that in Scotland, there were 304,375 people with known diabetes recorded on local diabetes registers in 2018, representing 5.6% of the population. In the same year in Greater Glasgow and Clyde, there were 65,174 people with known diabetes (5.5% of the population), compared to 48,602 people in 2007 (4.1% of the population) an increase of 34.1%.

In 2018-2019 screening period there were 69,637 people with known diabetes residing in NHS Greater Glasgow and Clyde. Of these, 59,625 (85.6%) were eligible for DRS screening. A total of 10,012 (14.4%) people were not eligible for screening because they were either permanently or temporarily suspended from the programme. Of those eligible for DRS screening, 46,077 (77.3%) attended screening.

Uptake is poorest in younger adults, aged 25-34 at 56.8% and among the most socioeconomically deprived residents (SIMD 1 was 73.8%). There are also lower uptake rates in some HSCPs that are primarily explained by demographic factors.

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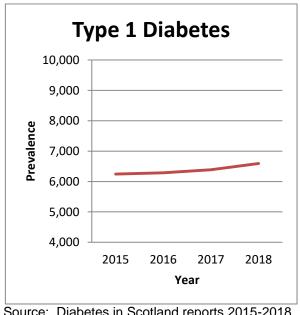
#### 9.1. **Background**

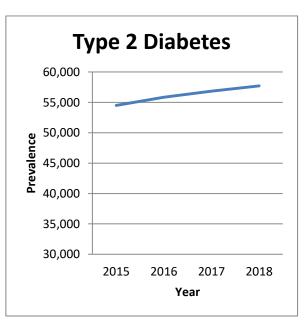
Diabetes mellitus is a long-term condition in which the level of glucose in the blood is raised leading to abnormal fat metabolism and other complications. There are two main types of diabetes: type 1 and type 2. Type 1 often develops before the age of 40 and usually during the teenage years. Type 2 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 origins are more frequently affected.

The Scottish Diabetes Survey 2018<sup>25</sup> reports that in Scotland, there were 304,375 people with known diabetes recorded on local diabetes registers in 2018, representing 5.6% of the population of all ages. 87.9% (267,615) of all people registered in Scotland with diabetes were recorded as having type 2 diabetes and 10.8% (32,828) of all registered people were recorded as having type 1 diabetes. In the same year in Greater Glasgow and Clyde, there were 65,174 people with known diabetes in 2018, (5.6% of the population) compared to 48,602 people in 2007 (4.1% of the population).

Figures 9.1 and 9.1b illustrate the increase in the number of NHSGGC residents with type 1 and type 2 diabetes in the previous four year period. In 2015 there were 6,244 people with type 1 diabetes compared to 6,592 in 2018, an increase of 5.6%. For type 2 diabetes, there has been a greater increase over the time period, 54,515 people in 2015 when compared to 57,713 in 2018, representing an increase of 5.9%.

Figures 9.1a and 9.1b Number of people with type 1 diabetes and with type 2 diabetes in NHSGGC 2015- 2018.





Source: Diabetes in Scotland reports 2015-2018

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

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<sup>&</sup>lt;sup>25</sup>http://www.diabetesinscotland.org.uk/Publications/Scottish%20Diabetes%20Survey%202018.p df Access Nov 2019

people in Scotland. Retinopathy is symptom-free until its late stages, and programmes of retinal screening can reduce the risk of blindness in the 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 (DRS) Programme was implemented across NHSGC in 2004-2005 and 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 annual Diabetic Retinopathy Screening.

The programme performance and quality of national DRS screening is monitored via defined National DRS Screening Standards<sup>26</sup> and Key Performance Indicators<sup>27</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.

- 1. VECTOR provides the call/recall, image capture, grading, quality assurance and result delivery.
- 2. 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 can be viewed here by clinical staff involved in the care of patients with diabetes.

#### 9.4. Screening Setting

Across Greater Glasgow and Clyde screening takes place at five hospital locations and 14 health centres or clinics.

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

<sup>&</sup>lt;sup>26</sup>http://www.healthcareimprovementscotland.org/our\_work/long\_term\_conditions/programme\_resources/diabetic\_retin\_opathy\_screening.aspx (Accessed November 2019)

<sup>&</sup>lt;sup>27</sup> http://www.ndrs-wp.scot.nhs.uk/?page\_id=122 (Accessed November 2019)

#### 9.5. Screening Pathway

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

**Diabetic Retinopathy Screening Pathway** Maintain Diabetes Register Update call/recall database Invite patient Attend Image Diagnosis and treatment capture Generate recall date Grading and reporting Communication to patient and Healthcare professionals Generate recall date

Figure 9.2 Diabetic Retinopathy screening pathway

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

The VECTOR system, introduced in March 2017, has been used to produce the National KPI data used in this report for the period of 1st April 2018 to 31st March 2019.

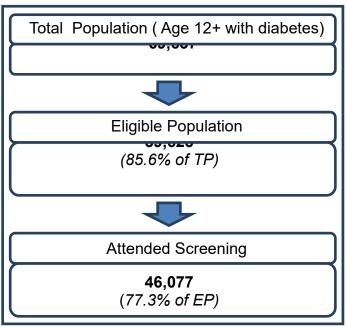
The DRS screening programme KPI's cover information on uptake of screening, screening performance, outcomes of screening and Ophthalmology performance. **Appendix 9.1**. National KPIs are reported by Board of Treatment.

Analysis of the data by Board of residence provides a localised picture of the demographic breakdown of the eligible resident population who were eligible and screened during time period 1<sup>st</sup> April 2018 to 31<sup>st</sup> March 2019. Please note that the figures below may differ from those quoted in national statistics as these relate to Board of treatment.

During 2018/2019 there were 69,637 people with known diabetes in NHS Greater Glasgow and Clyde. Of these, 59,625 (85.6%) were eligible for DRS screening. Of those eligible for DRS screening, 46,077 (77.3%) attended screening, below the national target of 80% (Figure 9.3).

A total of 10,012 (14.4%) 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; deemed clinically unfit by the general practitioner or no longer diabetic.

Figure 9.3 NHSGGC DRS Screening Programme 2018-2019 by Board of Residence



Source: VECTOR 2018/19 (1st April 2018 to 31st March 2019) provided by ISD, November 2019

**Table 9.1** shows that more than half (55.6%) of the eligible resident population were male. Males were also slightly more likely to attend screening than females (78.3% vs. 76.0%). The 80% uptake target was not met by either sex.

Table 9.1 Uptake of DRS screening by sex in NHSGGC, by Board of Residence 2018-2019

Sex	Eligible Population	% of eligible population	Attended Screening (full year)	% Attended Screening (full year)
Female	26,496	44.4	20,140	76.0
Male	33,129	55.6	25,937	78.3
Unknown	0	n/a	0	n/a
TOTAL	59,625	100.0	46,077	77.3

Source: VECTOR 2018/19 (1st April 2018 to 31st March 2019) provided by ISD, November 2019

**Table 9.2** shows that approximately half of the eligible resident population (50.9%) are aged between 55 to 74 years of age. Eligible individuals aged 65 to 74 years were most likely to attend DRS screening (83.7%) compared to other age groups. The uptake target of 80% was only met in the 65 to 74 years and 75 to 84 years age groups.

Table 9.2 Uptake of DRS screening by age in NHSGGC, by Board of Residence 2018-2019

Age	Eligible Population	% of eligible population	Attended Screening (full year)	% Attended Screening (full year)
0 to 14	135	0.2	105	77.8
15 to 24	968	1.6	633	65.4
25 to 34	1,731	2.9	983	56.8
35 to 44	3,762	6.3	2,420	64.3
45 to 54	8,760	14.7	6,219	71.0
55 to 64	15,161	25.4	11,897	78.5
65 to 74	15,199	25.5	12,718	83.7
75 to 84	10,522	17.6	8,607	81.8
85+	3,387	5.7	2,495	73.7
TOTAL	59,625	100.0	46,077	77.3

Source: VECTOR 2018/19 (1st April 2018 to 31st March 2019) provided by ISD, November 2019

Approximately 40% 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 9.3).** Uptake was lowest among people residing in the most deprived areas (73.8%) and highest among those residing in the least deprived areas (82.8%). The uptake target of 80% was only met in the least two deprived deprivation quintiles.

Table 9.3 Uptake of DRS screening by deprivation in NHSGGC, by Board of Residence 2018-2019

SIMD	Eligible Population	% of eligible population	Attended Screening (full year)	% Attended Screening (full year)
1 (most deprived)	24,150	40.5	17,830	73.8
2	10,653	17.9	8,247	77.4
3	7,068	11.9	5,614	79.4
4	6,500	10.9	5,307	81.7
5 (least deprived)	8,306	13.9	6,874	82.8
Unknown	2,948	4.9	2,205	74.8
TOTAL	59,625	100.0	46,077	77.3

Source: VECTOR 2018/19 (1st April 2018 to 31st March 2019) provided by ISD, November 2019

**Table 9.4** shows that the majority of the eligible population are White British (79.7%). DRS screening uptake among this group was 78.7%. Uptake among Asian / Asian British ethnic group was similar at 77.5%. The 80% target uptake was not met by any ethnic group.

Table 9.4 Uptake of DRS screening by ethnicity in NHSGGC, by Board of Residence 2018-2019

2001 Census Ethnic	Eligible	% of eligible	Attended Screening	% Attended Screening
Group	Population	population	(full year)	(full year)
WHITE - BRITISH	47,533	79.7	37,404	78.7
WHITE - IRISH	343	0.6	271	79.0
WHITE - ANY OTHER WHITE BACKGROUND	1,556	2.6	1,041	66.9
ASIAN OR ASIAN BRITISH	4,727	7.9	3,664	77.5
BLACK OR BLACK BRITISH	639	1.1	450	70.4
OTHER ETHNIC GROUPS - CHINESE	372	0.6	275	73.9
OTHER ETHNIC GROUPS - ANY OTHER ETHNIC GROUP	1,126	1.9	804	71.4
UNCLASSIFIED	3,329	5.6	2,168	0.7
Total	59,625	100.0	46,077	77.3

Source: VECTOR 2018/19 (1st April 2018 to 31st March 2019) provided by ISD, November 2019

In addition to the information provided above which was provided by national analysts, data was extracted locally and on a different date to enable further analysis at HSCP level, learning disabilities and individuals with severe and enduring mental health. Consequently the numbers may vary slightly from previous tables.

There are variations in screening uptake across HSCPs (**Table 9.5**). They range from 74.3% in Glasgow City HSCP North East Sector to 81.6% in East Dunbartonshire HSCP, which was the only HSCP meet the minimum target of 80%. However, when the known effects of age, sex, deprivation and ethnicity are taken into account by standardisation, the differences in uptake across HSPCs are much smaller (SUR% ranging from 76.3% to 78.8%). This tells us that most of the differences in uptake across HSCP's are explained by their differences in population demographics rather than local practice.

Table 9.5 indirectly standardised uptake of diabetic retinopathy screening by HSCP in NHGGC, 2018-19 (NHSGGC residents only)

HSCP	Not Screened	Screened	Total	% Screened	SUR %	SUR % LCI	SUR % UCI
East Dunbartonshire HSCP	905	4,021	4,926	81.6	77.8	75.4	80.2
East Renfrewshire HSCP	840	3,312	4,152	79.8	76.3	73.7	78.9
Glasgow North East Sector	2,474	7,160	9,634	74.3	76.3	74.5	78.1
Glasgow North West Sector	2,153	6,938	9,091	76.3	77.3	75.5	79.1
Glasgow South Sector	3,029	9,643	12,672	76.1	77.3	75.8	78.9
Glasgow City	7,656	23,741	31,397	75.6	77.0	76.0	78.0
Inverclyde HSCP	912	3,442	4,354	79.1	78.8	76.2	81.4
Renfrewshire HSCP	1,865	7,364	9,229	79.8	78.7	76.9	80.5
West Dunbartonshire HSCP	1,211	3,868	5,079	76.2	78.7	73.7	78.5
Total	13,389	45,748	59,137	77.4			

Source: VECTOR, OnoMap, September 2019

SUR = Standardised Uptake Rate; UCI = Upper Confidence Intervals; LCI = Lower Confidence Intervals

People who were registered with a learning disability had slightly poorer uptake of DRS **(Table 9.6)** at 74.8% compared to 77.4% in the rest of the population. This has increased slightly from previous year (69.8%), however numbers are small in comparison with rest of the population.

Table 9.6 Uptake of DRS screening among eligible population by learning disability for NHS Greater Glasgow and Clyde 2018-19, by Board of Residence.

Learning Difficulties		Attended	Total	
Register	Not Screened	Screening	Eligible	% Uptake
Rest of population	13,249	45,332	58,581	77.4
Registered with a LD	140	416	556	74.8
Total	13,389	45,748	59,137	77.4

Source: VECTOR LD, September 2019

People registered on PsyCIS have had at least one episode of psychosis which is typically seen in patients with a severe or enduring mental illness. These individuals had slightly poorer uptake of DRS **(Table 9.7)**. It was 72.8% compared to 77.4% in the rest of the population. This has increased slightly from previous year (70.5%), however numbers are small in comparison with rest of the population.

Table 9.7 Uptake of DRS screening among eligible resident population among people with severe and enduring mental illness for NHS Greater Glasgow and Clyde 2018-19

Severe and Enduring Mental Illness	Not Screened	Attended	Total Eligible	0/ Untoko
Mental lilless	Screened	Screening	Total Eligible	% Uptake
Rest of population	13,157	45,128	58,285	77.4
Registered on PsyCIS	232	620	852	72.8
Total	13,389	45,748	59,137	77.4

Source: VECTOR LD, September 2019

#### 9.7. Challenges and Future Developments

The national DRS database Vector, implemented in 2017 will become unsupported after April 2020, therefore work is ongoing to migrate to a new screening database called Optomize system in April 2020.

It is anticipated that the number of people with diabetes will continue to increase, requiring additional screening capacity and resources in the coming and future years.

In July 2020 the service will implement the UK NSC recommendation that, for patients with no retinopathy or maculopathy in 2 successive years, the screening interval will increase from one year to two years. The service will also implement DRS Optical Coherence Tomography (OCT) clinics, which will increase the specificity of referrals from DRS to ophthalmology.

By changing the screening interval for patients at low risk of sight loss from one year to two years it is predicted that there will be a reduction in DRS screening appointments. However this will be offset by an increase in new DRS OCT appointments. NHSGC Screening department is in process of scoping a new telephone system to improve the efficiency and capacity of call handling. In addition, following the

implementation of Optimize, screening department will progress virtual printing via Royal Mail for patient screening invites which will release staff capacity.

Public Health Screening Department will continue to develop and progress actions outlined in 2018 NHSGGC Inequalities Plan for Adult Screening programmes, to enable a more coordinated approach to reducing inequalities in uptake through targeted intervention plans. This includes developing opportunity for partnership work with the third sector and HSCPs will continue in order to support eligible patients to participate in the DRS programme.

Geographical mapping at data-zone level undertaken during 2018 will continue to inform opportunities for targeting community awareness and mobile unit locations as appropriate<sup>28</sup>.

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<sup>&</sup>lt;sup>28</sup> Diabetic Retinopathy Screening Uptake Data Zone maps: <a href="https://www.nhsggc.org.uk/your-health/public-health-public-health-screening-unit/reports/">https://www.nhsggc.org.uk/your-health/public-health-public-health-screening-unit/reports/</a> (access November 2019)

## Diabetic Retinopathy Screening Service reports for Quarter 4 2018/2019 By Board of Treatment

Report start date 01/04/2018 report end date 01/04/2019 Report Interval = 365 days. All data taken from Vector. Source: DRS National statistics 2019

	HIS Target		Board of Trea	atment
KPI	June 2016 (where applicable)	Description	Greater Glasgow & Clyde	Scotland
		Total Population (TP)	70,163	332,438
		Temporarily suspended (TS)	7,158 <i>(10.2%)</i>	<b>25,872</b> (7.8%)
KPI 0: Summary		Permanently suspended (PS)	4,161 (5.9%)	<b>25,646</b> (8.1%)
Statistics		Temporarily unavailable (TU)	1,215 <i>(1.7%)</i>	<b>3,834</b> (1.2%)
		Eligible Population (EP = TP-TS-PS+TU)	60,059 (85.6%)	<b>283,438</b> (85.3%)
		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.	N/A	N/A
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.	N/A	N/A
KPI 1:	100% for Q4 of eligible people,	People attending screening without invitation (API)	1,364	11,711
Screening invitation rate (HIS Standard 3)	regardless of personal circumstances or	People invited at least once (INV)	57,082	263,095
3)	characteristics are offered an opportunity to	% (100 * INV / (EP - API))	97.3%	96.8%

	attend. (HIS Standard 3.3)			
KPI 2: Screening uptake rate	NHS boards achieve an attendance of 80% for Q4.	People attending at least once (ATT)	46,515	216,233
(HIS Standard 3)	(HIS Standard 3.1)	% (100 * ATT / EP)	77.4%	76.3%
DNA rate	Indicative DNA rate by %	% (100 * INV - ATT)	19.8%	20.5%
KPI 3: Annual successful screening rate	NHS boards achieve an uptake of 80% pa. (HIS	People successfully screened in the previous year (ANN)	43,239	209,139
(HIS Standard 3)	Standard 3.2)	% (100 * SUC1 /EP)	72.0%	73.8%
KPI 4: Successful screening rate (HIS Standard	NHS boards achieve an uptake of 80% for Q4 (HIS Standard	People successfully screened in reporting period (SUC)	43,239	209,202
3)	3.2)	% (100 * SUC2 /EP)	72.0%	73.8%
KPI 5: Biennial successful screening rate (HIS Standard	NHS boards achieve an uptake of 80%	People successfully screened (biennial) (BIE)	52,058	246,115
3)	pa. (HIS Standard 3.2)	% (100 * BIE / EP)	86.7%	86.8%
KPI 6: Annual patient technical recall rate	As low as possible	People unsuccessfully screened (UNSUC)	889	5,490
recall rate		% (100 * UNSUC / EP)	1.5%	1.9%
KPI 7A: Annual	NHS boards achieve a maximum rate	Photographic screenings (PS)	44,931	213,313
photographic technical failure rate (HIS Standard 4)	of ungradeable images of 2.5% for digital	Unsuccessful photographic screening episodes (UPS)	912	5,780
,	imaging. (HIS Standard 4.3)	% (100 * UPS/ PS)	2.0%	2.7%
KPI 7B: Annual slit lamp technical failure rate	NHS boards achieve a maximum rate	Slit lamp screenings (SL)	3,935	18,781
	of ungradeable images of 2.0% for slit	Unsuccessful slit lamp screening episodes (USL)	48	549
	lamp examinations.	% (100 * USL / SL)	1.2%	2.9%

	(HIS Standard 4.3)			
KPI 7: Annual		Slit lamp screenings + photographic screenings (SLPS)	48,866	232,094
overall technical failure rate	As low as possible	Unsuccessful slit lamp screenings & photographic screenings (USLUPS)	960	6,329
		% (100 * USLUPS / SLPS)	2.0%	2.7%
		Longest recorded number of days to written report (LRD)	156	156
KPI 8: Duration to written report	A minimum of 95% of people screened are sent the result	Average of the number of days to written report (AD)	9	6
	within 20 working days of being	Median of the number of days to written report (MD)	3	4
KPI 9: Written report success	screened.	Episodes with <= 20 working days to written report (E20D)	36,943	209,213
rate		% (100 * E20D / NE)	78.62%	92.2%
		Screening outcomes		
		Successful screening episodes (excl. ophthalmology examinations) (SSE)	45,373	222,693
KPI 10: Twelve		% (100* SSE/EP)	75.5%	78.6%
Month Recall result rate		Screening episodes (excl. ophthalmology examinations) with negative result (SEN)	497	3,090
		% (100 * SEN / SSE)	1.1%	1.4%
KPI 11: Six Month Recall result rate		Screening episodes (excl. ophthalmology examinations) with observable result (SEO)	657	3,767
		% (100 * SEO / SSE)	1.4%	1.7%

KPI 12: Six	People with last result 'observable' in the first 6 month of the interval (POR)	372	1,637	
KPI 12: Six Month recall rescreen rate		People within POR who commenced an examination within 6 month (PC6M)	3,427	391
	% (100 * PC6M / POR)	11.3%	23.9%	
KPI 13: Referable Result rate		Screening episodes (excl. ophthalmology examinations) with referable result (SER)	1,910	9,119
		% (100 * SER / SSE)	4.2%	4.1%
	Op	hthalmology performan	ce	
		Patients with an outcome of 'Refer to Ophthalmology ' in the first 6 month of the interval (RO)	989	4,214
		% (100 * RO/EP)	1.6%	1.5%
		Patients within RO with a subsequent Ophthalmology examination (SOE)	565	1,816
		% (100 * SOE/RO)	57.1%	43.1%
KPI 14: Ophthalmology Report Interval		Longest recorded days to ophthalmology examination for the first qualifying episode (LRDOE)	214	217
		Longest recorded to Ophthalmology examination for the first qualifying episode (based on 30 days/month – months & days)	30 weeks 4 days	41 weeks 0 days
		Average of the number of days to Ophthalmology examination (ADOE)	75	51

KPI 15: Ophthalmology review target		Patients with an outcome of 'Refer to Ophthalmology ' in the first 6 months of the interval (RO)	989	4,207
		Number of these patients for whom the days to Ophthalmology examination is less than or equal to referral target (90 days)  (REFT)	123	757
		% (100 * REFT / RO)	12.4%	18.0%
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) Screening population	5,322	12,539
		(SP) % (100 * OPHTH / SP)	65,734 8.1%	303,856 4.1%
KPI 17: Ophthalmology suspensions rate		People temporarily suspended from screening for reason of "under the care of Ophthalmologist" (UCO)	5,675	20,418
		Screening population (SP)	65,734	303,856
		% (100 * UCO / SP)	8.6%	6.7%

#### Appendix 2

# Members of Diabetic Retinopathy Screening Steering Group (As at 31<sup>st</sup> March 2018)

Dr Emilia Crighton Deputy Director of Public Health (chair)

Mr Jim Bretherton Clinical Service Manager

Miss Lisa Buck Public Health Programme Manager

Mr Paul Burton Information Manager

Mrs Lin Calderwood HI&T Screening Service Delivery Manager

Dr Mike Gavin Consultant Ophthalmologist

Mrs Jo Gibson Head of Health & Community Care, West Dunbartonshire

**HSCP** 

Mrs Elaine Hagen Programme Support Officer, Screening Department Clinical Nurse Co-ordinator, Retinal Screening

Ms Heather Jarvie Public Health Programme Manager

Mr Stuart Laird Area Optometric Committee

Ms Gillian Kinstrie Co-ordinator for MCN for Diabetes Dr Alice McTrusty Optometrist/Lecturer GCU/AOC,

Mr Eddie McVey Optometric Advisor

Mrs Elizabeth Rennie Programme Manager, Screening Dept

Mr David Sawers DRS Service Manager

Mrs Sandra Simpson Assistant Programme Manager, Screening Department

Dr William Wykes Consultant Ophthalmologist

Dr Sonia Zachariah Specialty Doctor, Diabetic Retinal Screening