

# **Public Health Screening Programme**

Annual Report

1 April 2020 to 31 March 2021

Health Services
Public Health Directorate
January 2022

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Published by: NHSGGC Public Health Directorate

Date: January 2022

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# Section 1

**Pregnancy & Newborn and Child Vision 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. Trisomies and other congenital anomalies screening aims to detect Down's syndrome (T21), Edwards' syndrome (T18), or Patau's syndrome (T13) 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 2020/21, 10,472 NHSGGC residents booked to attend antenatal clinics and 9,562 (91.3%) of first antenatal booking appointments were offered before or equal to 12 weeks and 6 days gestation.

Using OnoMap software, the ethnic origin of pregnant women was identified as follows, Scottish 7,105 (67.8%), Other British 524 (5%), Pakistani 572 (5.5%), Indian 234 (2.2%), African 345 (3.3%), Chinese 99 (0.9%) and 104 (1.0%) of any other ethnic group

In November 2017 NHSGGC introduced BadgerNet, a new maternity Clinical 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. Just over a third of pregnant women 3,768 (36.2%) were recorded as having 'any risk' of GDM and were eligible to be offered an OGTT at 24-28 weeks gestation.

At the time of their booking appointment, 4,281 (40.9%) of pregnant women had a normal weight, 1,707 (16.3%) were overweight and 2,937 (28%) obese. The total number of women who were within the severely obese categories of (35<=BMI >=45) was 1,122 (10.7%). The BMI was not recorded for 192 women (1.8%)

#### Haemoglobinopathies Screening

Of the 10,472 women booked for their first antenatal booking, 10,446 (99.7%) were offered haemoglobinopathies screening and 29 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. 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.

Across NHSGGC, 8,412 (80.3%) samples had a completed FOQ recorded on BadgerNet and this varied across sites with the Princess Royal Maternity only completing the FOQ for 73.1% of the pregnant women.

#### Infectious diseases

Uptake across NHSGGC was greater than 99% for all the screening tests. The screening identified 9 women infected with HIV (7 were previously known) and 40 infected with HBV (30 were previously known) and 8 women infected with syphilis

#### Trisomies and other congenital anomalies screening

Of the 10,472 women booked at antenatal clinics, 7,849 (77.8%) were tested in the 1<sup>st</sup> Trimester and 2,263 (22.1%) in the 2<sup>nd</sup> Trimester. 208 (2.7%) high chance results were recorded for the 1<sup>st</sup> Trimester and 116 (5.1%) for the 2<sup>nd</sup> Trimester Down's syndrome screening.

#### **Amniocentesis**

Of the 229 amniocentesis samples analysed 53 abnormalities were detected (23%) and of these 36 had a diagnosis of Trisomy 21 (Down's syndrome)

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

99 chorionic villus biopsies were analysed and 30 abnormalities were detected (30.3%) and 22 had a diagnosis of Trisomy 21 (Down's syndrome)

#### Congenital anomalies screening

9,390 (89.7%) pregnant women consented for a fetal anomaly scan. 9,322 (99.3%) of scans were performed and 206 anomalies were detected.

#### **COVID Pandemic and impact on Pregnancy and Newborn Screening**

A national assessment was undertaken by NSD in March 2020 as part of the response to COVID and lockdown measures for all screening programmes across Scotland. (Appendix 1.11) The recommendation based on guidance from RCOG and the risk assessment was to continue Pregnancy & Newborn screening as this was part of routine appointments. Health Boards were asked to develop contingency plans around resource and resilience in order to ensure that services were able to continue.

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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.

Trisomy and other congenital anomalies screening aims to detect Down's syndrome chromosomal conditions (Down's syndrome (T21), Edwards' syndrome (T18), or Patau's syndrome (T13)) 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.

#### 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.

#### Trisomy (T13, T18, T21) and other congenital anomalies

Screening for **trisomy** 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 chromosomal condition. Following a higher-chance screening result for one of the chromosomal conditions, women are offered another test, non-invasive prenatal testing (NIPT), or a diagnostic test. The full screening pathway is shown in <u>Appendix 1.10</u>. Ultrasound scanning is used to look for other **congenital anomalies** between 18 and 21 weeks.

The decision to accept screening for chromosomal and other congenital anomalies raises particular ethical issues for women. Uptake of trisomy or other congenital anomalies screening depends on whether women would wish further investigation or management.

#### 1.4. Delivery of NHSGGC Pregnancy Screening Programmes

Each NHS Board has a statutory requirement to submit data on antenatal activity. In NHSGGC, 10,472 women booked to attend antenatal clinics and overall 91.3% (9,562) managed to book before or equal to 12 weeks and 6 days gestation. The booking details for 37 women were not known but are included in the total number of bookers (10,472). Work continues to encourage all pregnant women to book earlier through the Central Booking Line (**Table 1.1**)

Table 1.1: Number of women booked for their first antenatal appointments in NHSGGC 1 April 2020 to 31 March 2021 by gestation age.

Maternity Unit	<=12Wk s 6Days	13Wks 0Days - 16Wks 6Days	17Wks 0Days - 20Wks 6Days	21Wks 0Days - 24Wks 6Days	25Wks 0Days - 30Wks 6Days	>=31 Wks 0Days	Total	% <=12 Wks 6Days
Princess Royal								
Maternity Hospital	2,438	163	58	32	22	20	2,745	88.8
Queen Elizabeth								
University Hospital	4,925	246	76	35	48	47	5,391	91.4
Royal Alexandra								
Hospital	2,199	50	24	9	21	22	2,336	94.1
Total	9,562	459	158	76	91	89	10,472	91.3

Source: BADGERNET, September 2021

Within NHSGGC, booking for the 1st antenatal appointment varied according to area of residence. 2,297 (86.9%) of pregnant women living in the most deprived areas booked by 12 weeks and 6 days compared to 1,719 (94.8%) 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 2020 to 31 March 2021

SIMD 2016 Quintile	<=12Wk s 6Days	13Wk s 0Days - 16Wk s 6Days	17Wks 0Days - 20Wks 6Days	21Wks 0Days - 24Wks 6Days	25Wks 0Days - 30Wks 6Days	>=31Wk s 0Days	Un known	Total	% <=12Wk s 6Dys
1	2,297	171	78	25	31	25	16	2,643	86.9
2	1,891	113	29	22	20	16	10	2,101	90.0
3	1,866	75	26	9	13	19	6	2,014	92.7
4	1,789	53	13	13	15	14	4	1,901	94.1
5	1,719	47	12	7	12	15	1	1,813	94.8
Total	9,562	459	158	76	91	89	37	10,472	91.3

Source: BADGERNET, September 2021

The majority of pregnant women were aged between 25-34 years (6,416 – 61.2%) and those between 20-24 years (1,267) accounted for 12% of pregnancies. Only 3,332 (3.00%) of pregnant women were under 20 years of age. (**Table 1.3**)

Table 1.3: Age at first antenatal booking appointment by HSCP areas for period 1 April 2020 to 31 March 2021

		HSCP Sector												
Maternal Age At Booking	East Dunbart onshire	East Renfre wshire	Glasgo w City CHP - North East Sector	Glasgo w City CHP - North West Sector	Glasgo w City CHP - South Sector	Inver clyde	Renfre wshire	West Dunb arton shire	Total					
<20	19	17	81	48	82	11	34	30	322					
20-24	54	38	276	207	308	66	212	106	1267					
25-29	145	153	515	467	652	133	477	228	2770					
30-34	334	313	547	644	849	141	598	220	3646					
35+	296	239	318	487	578	95	343	111	2467					
Total	848	760	1737	1853	2469	446	1664	695	10472					

Source: BADGERNET, September 2021

Using OnoMap software, the ethnic origin of pregnant women was identified as follows, Scottish 7,105 (67.8%), Other British 524 (5%), Pakistani 572 (5.5%), Indian 234 (2.2%), African 345 (3.3%), Chinese 99 (0.9%) and 104 (1.0%) of any other ethnic group **(Table 1.4).** 

Table 1.4: Number of NHSGGC residents booked for their first antenatal appointment by ethnic origin during 1 April 2020 to 31 March 2021

appointment by cume origin during 1 April 2020 to 01		<del></del>
Ethnic Category	Total	%
1A. Scottish	7105	67.8
1B. Other British	524	5.0
1C. Irish	84	0.8
1K. Gypsy/ Traveller	4	0.0
1L. Polish	209	2.0
1Z. Any other white ethnic group	564	5.4
2A. Any mixed or multiple ethnic background	80	0.8
3F. Pakistani, Pakistani Scottish or Pakistani British	572	5.5
3G. Indian, Indian Scottish or Indian British	234	2.2
3H. Bangladeshi, Bangladeshi Scottish or Bangladeshi British	17	0.2
3J. Chinese, Chinese Scottish or Chinese British	99	0.9
3Z. Other Asian, Asian Scottish or Asian British	109	1.0
4D. African, African Scottish or African British	345	3.3
4Y. Other African	78	0.7
5C. Caribbean, Caribbean Scottish or Caribbean British	5	0.0
5D. Black, Black Scottish or Black British	18	0.2
5Y. Other Caribbean or Black	4	0.0
6A. Arab, Arab Scottish or Arab British	206	2.0
6Z. Other Ethnic Group	104	1.0
99. Not Known	56	0.5
NULL	55	0.5
Grand Total	10472	

Source: BADGERNET, September 2021

# 1.5. Gestational Diabetes Mellitus (GDM)

Pregnant women are assessed for their diabetes status at the time of booking and the BMI (Body Mass Index) is recorded. There were 47 women with Type 1 diabetes and 30 with Type 2 diabetes. **(Table 1.5)** 

Table 1.5: Number and percentage of women booked for their first antenatal appointments by body mass index and current diabetes status 1 April 2020 to 31 March 2021

		Current	Diabetes		
Body Mass Index Categories	No	Yes Type 1	Yes Type 2	Total	% Diabetic
BMI<18.5	233	0	0	233	0.0
18.5<=BMI<25	4258	23	0	4281	0.5
25<=BMI<30	1689	9	9	1707	1.1
30<=BMI<35	2915	12	10	2937	0.7
35<=BMI<40	700	3	4	707	1.0
40<=BMI<45	277	0	3	280	1.1
BMI>=45	132	0	3	135	2.2
Unknown	191	0	1	192	
Total	10395	47	30	10472	0.7

Source: BADGERNET, September 2021

Women with gestational diabetes are at increased risk of having a large baby, a stillborn baby or a baby who dies shortly after birth. 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. Just over a third of pregnant women 3,768 (36.2%) were recorded as having 'any risk' of GDM and were eligible to be offered an OGTT at 24-28 weeks gestation. (Table 1.6)

Table 1.6: Number of women booked for first antenatal appointments in NHSGGC 1 April 2020 to 31 March 2021 and GDM risk factors excluding current diabetes

	BMI	Previous Macro somic	Family History	Previous	Origin Mother	Any Risk		% Any
Maternity Unit	>=35	Baby	Diabetes	GDM	Risk	*	Total	Risk
Princess Royal								
Maternity								
Hospital (PRM)	348	34	486	248	415	1082	2733	39.6
Queen Elizabeth								
University								
Hospital (QEUH)	479	61	906	461	947	2008	5352	37.5
Royal Alexandra								
Hospital (RAH)	282	22	364	95	103	678	2311	29.3
								36.2
Total	1109	117	1756	804	1465	3768	10396	

Source: BADGERNET, September 2021

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

At the time of their booking appointment, 4,281 (40.9%) of pregnant women had a normal weight, 2,937 (28.0%) were overweight and 1,707 (16.3%) obese. The total number of women who were within the severely obese categories of BMI>=35

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

(35<=BMI >=45) was 1,122 (10.7%). The BMI was not recorded for 192 women (1.8%) **(Table 1.7).** 

Table 1.7: Number and percentage of women booked for their first antenatal appointments by body mass index and by maternity unit from 1 April 2020 to 31 March 2021

BMI Category	Princess Royal Maternity Hospital (PRM)	%	Maternity U Queen Elizabeth University Hospital (QEUH)	%	Royal Alexandra Hospital (RAH)	%	Total	%
Underweight BMI<18.5	51	1.9	139	2.6	43	1.8	233	2.2
Normal	31	1.9	139	2.0	43	1.0	233	2.2
18.5<=BMI<25	1039	37.9	2345	43.5	897	38.4	4281	40.9
Overweight 25<=BMI<30								
	794	28.9	1469	27.2	674	28.9	2937	28.0
Obese 30<=BMI<35	474	17.3	853	15.8	380	16.3	1707	16.3
Severely Obese								
35<=BMI<40	220	8.0	305	5.7	182	7.8	707	6.8
Severely Obese 40<=BMI<45	91	3.3	115	2.1	74	3.2	280	2.7
Severely Obese BMI>=45	40	1.5	64	1.2	31	1.3	135	1.3
Unknown	40	1.5	04	1.2	31	1.3	133	1.3
Olikilowii	36	1.3	101	1.9	55	2.4	192	1.8
Total	2745		5391		2336		10472	

Source: BADGERNET, September 2021

#### 1.7. NHSGGC Antenatal Haemoglobinopathies Screening Programme

#### Haemoglobinopathies

All pregnant women will be offered screening for haemoglobinopathies based on a low prevalence screening model. The haemoglobinopathies are a large group of inherited blood disorders which affect the haemoglobin (oxygen carrying) component of blood. They fall into two main groups – the haemoglobin variants (such as sickle cell disorders) which are associated with the production of abnormal forms of haemoglobin, and the Thalassaemias in which there is an abnormality in the amount of haemoglobin produced.

Sickle cell disorders are caused by a haemoglobin variant HbS - if the child has this in combination with a normal haemoglobin variant, he or she will carry the 'trait' which is likely inherited from a parent/s. However, if he or she has two copies of the HbS and no normal haemoglobin, this may result in severe life threatening

symptoms. Those with beta thalassaemia major require regular blood transfusions to maintain life. 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 Appendix 1.2, Appendix 1.3 and Appendix 1.4.

#### Samples taken for haemoglobinopathies screening

Of the 10,472 women booked for their first antenatal booking, 10,446 (99.7%) were offered haemoglobinopathies screening and 29 refused. The blood is checked for risk of thalassaemia for all women who consented. **(Table 1.8)** 

Table 1.8: NHSGGC Number of women who consented for haemoglobinopathies screening from 1 April 2020 to 31 March 2021

Maternity Unit	Total	HBO offered	HBO Consent Not Known	HBO Refused	HBO Test Performed	FOQ Completed	FOQ Not Completed	% FOQ Completed
Princess Royal Maternity	2745	2742	3	3	2740	2006	734	73.1
Queen Elizabeth University Hospital	5391	5384	7	4	5387	4321	1066	80.2
Royal Alexandra Hospital	2336	2320	16	22	2313	2085	228	89.3
Total	10472	10446	26	29	10440	8412	2028	80.3

Source: BADGERNET, September 2021

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. Across NHSGGC, 8,412 (80.3%) samples had a completed FOQ recorded on BadgerNet and this varied across sites with the Princess Royal Maternity only completing the FOQ for 73.1% of pregnant women. Laboratory staff test samples for haemoglobinopathies and thalassaemia even if the FOQ is missing (Table 1.9). The maternal samples tested for haemoglobinopathies identified 12 fetus at risk and 81 were identified as not at risk. Partner testing was not required in 2 cases and 8 partners should have been offered testing. (Table 1.9)

Table 1.9: NHSGGC haemoglobinopathies screening outcome (HBO performed only) 1 April 2020 to 31 March 2021

	N			
Screening Outcome	Glasgow Princess Royal Maternity	Queen Elizabeth University Hospital	Royal Alexandra Maternity Hospital	Total
01:Fetal At Risk			4	40
	5	6	1	12
02:Fetal Not At Risk	21	55	5	81
03:Positive				
	1	0	0	1
04:Negative	2639	5120	2200	9959
05:Partner Testing Not Required				
·	1	1	0	2
06:Partner Testing Should Be Offered				
	4	2	2	8
Unknown				
	69	203	105	377
Grand Total				
	2740	5387	2313	10440

Source: BADGERNET, September 2021

Table 1.10: KPIs for Pregnancy and Newborn Screening - Haemoglobinopathy 2020-2021

KPI	Performance threshold	NHSGGC 2020-2021
1.1 Coverage	Essential : ≥95% Desirable : ≥ 99%	99.7%
1.3 Completion of FOQ	Essential : ≥ 95%	80.3 %
	Desirable : ≥99%	

#### 1.8. 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 have been offered screening. Some women would not have been offered screening because they have had an early pregnancy loss. A small number of women will transfer out of the health board area.

Uptake across NHSGGC was greater than 99% for all the screening tests. The screening identified 9 women infected with HIV (7 were previously known) and 40 infected with HBV (30 were previously known) and 8 women infected with syphilis (Table 1.11)

Table 1.11: NHSGGC Infectious diseases tests and results 2020/2021

	1 April 2020 - 31 March 2021						sults	
	Total number of samples	No. requesting individual test	No. not requesting individual test	Uptake	Antibody detected <sup>1,2</sup>		antibody not detected	
	(N)	(N)	(N)	%	(N)	%	(N)	%
HIV	10,363	10,362	1	99.9	9 <sup>1</sup>	0.1	10,353	99.9
HBV	10,363	10,360	3	99.9	40 <sup>2</sup>	0.4	10,320	99.6
Syphilis	10,363	10,362	1	99.9	8	0.1	10,354	99.9

Sources: West of Scotland Specialist Virology Centre Oct 2021

Notes:

1. 7 of the 9 HIV infections were previously known about

2. 30 of the 40 HBV infections were previously known about

# 1.9. NHSGGC Trisomy and Other Congenital Anomalies Screening Programme

Trisomies are characterised by an extra copy of a chromosome (trisomy 21, Down's syndrome; trisomy 18, Edwards' syndrome; trisomy 13, Patau's syndrome) and older mothers' are more likely to have a baby with a chromosomal condition, although it can occur in women of any age.

#### 1.10. 1st and 2nd Trimester Trisomy screening

Of the 10,472 women booked at antenatal clinics, 10,085 (96.3%) were tested either for the 1<sup>st</sup> or 2<sup>nd</sup> Trimester during 2020-21 as shown in **Table 1.12** 

Table1.12: 1st and 2nd Trimester Screening for NHSGGC residents

NHS Greater Glasgow and Clyde	2020/2021	2019/2020	2018/2019	2017/2018
First Trimester	7,849	7,801	7,961	8,227
Second Trimester	2,236	2,115	2,393	2,209
Total Screens	10,085	9,916	10,354	10,436
% Second trimester	22.1%	21.3%	23.1%	21.2%

Source: Antenatal Screening Service for Fetal Down's Syndrome Lothian Laboratory and Bolton Lab 2021

The 1<sup>st</sup> Trimester samples are taken during 11 weeks +2 days to 14 weeks +1 day of pregnancy. The samples are sent to Lothian Laboratory and during 2020/2021, 7,849 (77.8%) samples were tested. There were 8 late samples (0.1%) and 579 samples (7.1%) had incomplete request details. The number of increased chance results was 208 (2.7%). **(Table 1.13)** 

Table 1.13: 1st Trimester Trisomy screening samples 2020/2021

2020/2021	Number of Samples	% samples	Late sample	% Late samples	In complete Request details	% In complete Request details	Increased chance results	% Increased chance results
1 <sup>st</sup> Trimester	7,849	77.8%	8	0.1%	579	7.1%	208	2.7%

Source: Antenatal Screening Service for Fetal Down's Syndrome Lothian Laboratory September 2021

The 2<sup>nd</sup> Trimester samples are taken up to 20 weeks+0 days gestation and sent to Bolton Laboratory. During 2020/2021, 2,263 (22.1%) of samples were taken in the 2<sup>nd</sup> Trimester. There were 27 unsuitable samples (0.65%) and 116 high chance results were reported (5.1%). **(Table 1.14)** 

Table 1.14: 2<sup>nd</sup> Trimester Down's syndrome screening samples 2020/2021

2020/2021	Number of samples	% Samples	Number of high chance results	% High chance results	Unsuitable samples	% Unsuitable samples
2 <sup>nd</sup> Trimester	2,263	22.1%	116	5.1%	27	0.65%

Source: Bolton Labs September 2021

# Key Performance Indicators for 1st Trimester Trisomy screening

The following data has been reviewed to provide evidence for the NSS Pregnancy and Newborn Screening Key Performance Indicators (KPIs), for 2019/2020 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	Overall 99.3 % of results were reported within 72 working hours of sample receipt for all Health Boards, fulfilling the desirable target of ≥ 99
KPI 5.3 Completion of laboratory request forms	The proportion of laboratory request forms with complete data, as defined by the KPI list of required fields, is 97.1 %, which fulfils the essential performance criteria.
KPI 5.5 Screen Positive Rate (SPR)	The overall screen positive rate is 2.7 % for NHSGGC
KPI 5.6 Detection Rate (DR)	The Detection Rate for West of Scotland Health Boards was 87.5%

#### **Amniocentesis**

229 amniocentesis samples were analysed by the Cytogenetics Laboratory and 53 abnormalities were detected (23%) and of these 36 had a diagnosis of Trisomy 21 (Down's syndrome) (Table 1.16)

Table 1.16: Amniocentesis Referrals 1 April 2020 to 31 March 2021

	Referral Type					
	Biochemical Screening	Maternal Age	Abnormalities on Scan	NIPT	Other	Total
Number of women (= number of tests)	77	6	82	26	38	229
% total referral reasons	33.6%	2.6%	35.8%	11.3%	16.6%	
Number with normal results	68	6	65	8	29	176
Number with diagnostic trisomy	9	0	10	17	0	36
% number with diagnostic trisomy	11.6%	0	12.1%	65.3%	0	
Number of other non trisomy abnormalities	3	0	13	0	1	17
Total number of abnormalities	12	0	23	17	1	53
% total number of abnormalities	22.6%	0	43.3%	32%	1.8%	

# **Chorionic Villus Biopsies (CVS)**

99 chorionic villus biopsies were analysed by the Cytogenetics Laboratory in 2020/21. 30 abnormalities were detected (30.3%) and 22 of those had a diagnosis of Trisomy 21 (Down's syndrome) **(Table 1.17)** 

Table 1.17: Chorionic Villus Biopsy referrals and outcomes 1 April 2020 to 31 March 2021

		Po	aforral Type			
	Biochemical Screening	Maternal Age	Abnormalities on Scan	NIPT	Other	Total
Number of women (= number of tests)	24	0	59	0	16	99
% total referral reasons	24.2%	0	59.6%	0	16%	
Number with normal results	22	0	34	0	13	
Number with diagnostic trisomy	2	0	19	0	1	22
% total with diagnostic trisomy	8.3%	0	32.2%	0	6.2%	
Number of other non trisomy abnormalities	0	0	6	0	2	8
Total number of abnormalities	2	0	25	0	3	30
% total number of abnormalities	8.3%	0	42.3%	0	18.75%	

#### 1.11. 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 9,390 (89.7 %) of all bookers and 9,322 (99.3%) of scans were performed **(Table 1.18).** 

Table 1.18: Uptake rate for other congenital anomalies (fetal anomaly scan) for the period 31 March 2020 to 1 April 2021

Maternity Unit	Number of bookers	FAS consented	% Consented	Number of fetal anomaly scans performed*	% fetal anomaly scans performed
Princess Royal Maternity			90.0		99.4
Hospital	2745	2470		2455	
Queen Elizabeth University Hospital	5391	4835	89.7	4806	99.4
Royal Alexandra Hospital	2336	2085	89.3	2061	98.8
Total	10472	9390	89.7	9322	99.3

Source: BADGERNET September 2021

Of the 9,322 fetal scans performed, 206 anomalies were suspected. (Table 1.19)

Table 1.19: Outcome of fetal anomaly scans performed for the period 1 April 2020 to 31 March 2021

	Number	Number of	Anomaly		%
	of	Fetal scans	not	Anomaly	Anomaly
Maternity Unit	bookers	performed	suspected	Suspected	Suspected
Princess Royal					
Maternity					
Hospital	2745	2455	2386	69	2.8
Queen Elizabeth					
University					
Hospital	5391	4806	4707	99	2.1
Royal Alexandra					
Hospital	2336	2061	2023	38	1.8
Total					
	10472	9322	9116	206	2.2

Source: BADGERNET September 2021

#### 1.12. Information Systems

The report contains data extracted from BadgerNet, Trakcare and Laboratories.

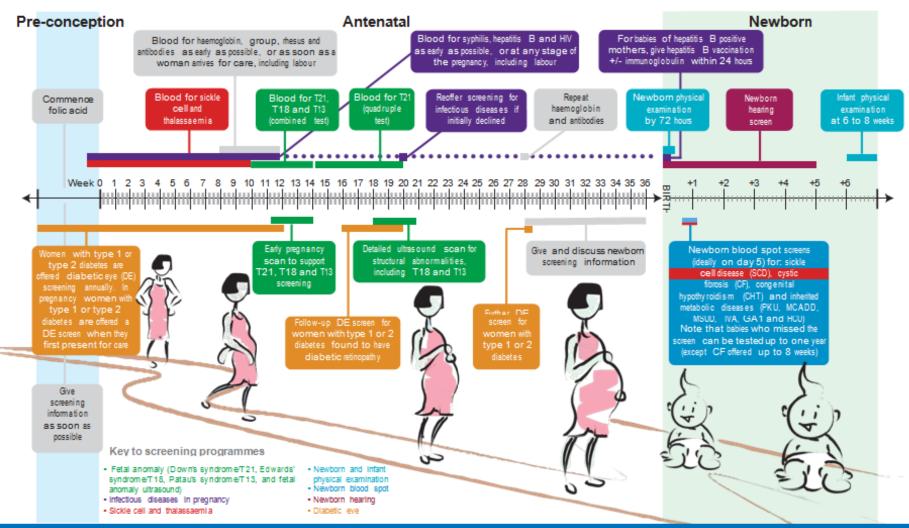
#### 1.13. Challenges and Priorities

- 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 all Pregnancy Screening from Badger Net.

- Setting up reports to capture all Pregnancy Screening Programmes against the NSD Key Performance Indicators
   Implementing changes to meet programme KPIs.

Public Health England

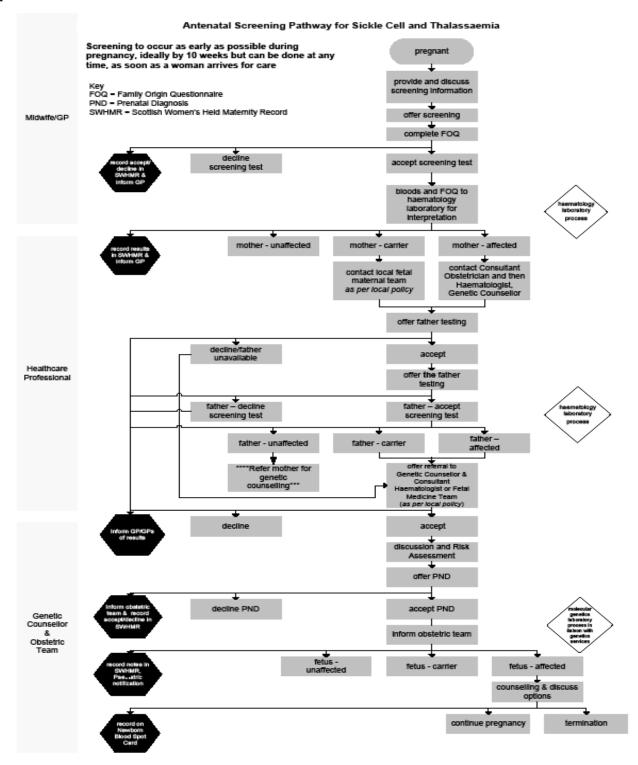




Antenatal and newborn screening timeline – optimum times for testing

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

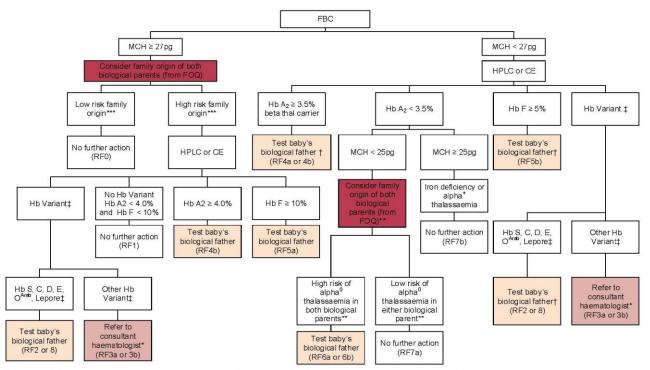


# Screening for Haemoglobinopathies Family Origin Questionnaire (FOQ)

(By Health Care Professional completing the form)

	ame			
II No.				SCOTLAN
timated	Deli	very Date		30012/11
rname	manu.			
rename				
te of Bir	rth			
Idress 1	,101000			
dress 2		S	creening test	declined
stcode			orcoming toot	dodiniod
1	Νh	at are your family origins?		
		ise tick all boxes in ALL sections that apply to the woman an	d the baby's father	
	A.	AFRICAN OR AFRICAN CARIBBEAN (BLACK)	Woman	Baby's fat
	1/	Caribbean Islands		
	2/	Africa (excluding North Africa)		
	3/	Any other African or African-Caribbean family origins (please write in)		
-	В.	SOUTH ASIAN (ASIAN)		_
	1/	India or African-Indian		
	2/	Pakistan		
	3/	Bangladesh		ş <b>——</b>
	C.	SOUTH EAST ASIAN (ASIAN)	<u>v</u> 1999	19 38000
	1/	China including Hong Kong, Taiwan, Singapore	#	#
	2/	Thailand, Indonesia, Burma	#	#
	3/	Malaysia, Vietnam, Philippines, Cambodia, Laos	#	#
	4/	Any other Asian family origins (eg Caribbean-Asian) (please write in)		
	D.	OTHER NON-EUROPEAN (OTHER)		
S.	1/	North Africa, South America etc		
68	2/	Middle East (Saudi Arabia, Iran etc)		
proces	3/	Any other Non-European family origins (please write in)		
screening	E.	SOUTHERN & OTHER EUROPEAN (WHITE)		
e	1/	Sardinia	#	#
<u>a</u>	2/	Greece, Turkey, Cyprus	#	#
2	3/	Italy, Portugal, Spain		
Ele ele	4/	Any other Mediterranean country		
5	5/	Albania, Czech Republic, Poland, Romania, Russia etc		
	F*	UNITED KINGDOM (WHITE) refer to guidance at the back		
L part	1/	England, Scotland, N Ireland, Wales		
A	G*	NORTHERN EUROPEAN (WHITE) refer to guidance at the back		
	1/	Austria, Belgium, Ireland, France, Germany, Netherlands		0 0
2	2/	Scandinavia, Switzerland etc		
п	3/	Any other European family origins, refer to chart (eg Australia, N Am	erica,	
क		S Africa) (please write in)		
5	*Hb	Variant Screening Requested by F and/or G (ie request from low risk gre	oup)	
The completion of this form is an E3	# H	igher risk for alpha zero thalassaemia	<del></del>	
ISIL	H.	DON'T KNOW (incl. pregnancies with donor egg/sperm)		
	I.	DECLINED TO ANSWER		
0	J.	ESTIMATED DELIVERY DATE (please write in if not above)		
9	K.	GESTATION AT TIME OF TEST		
ple	OFF	ER haemoglobin variant screening to all women if they or their bal	by's father have answer	rs in a shaded bo
E (s	Signed	Print Name		
0	en se		20000	
ا ع	ob Ti	tle Contact Tel No	Date	

# Haemoglobinopathy Screening in Low Prevalence Areas



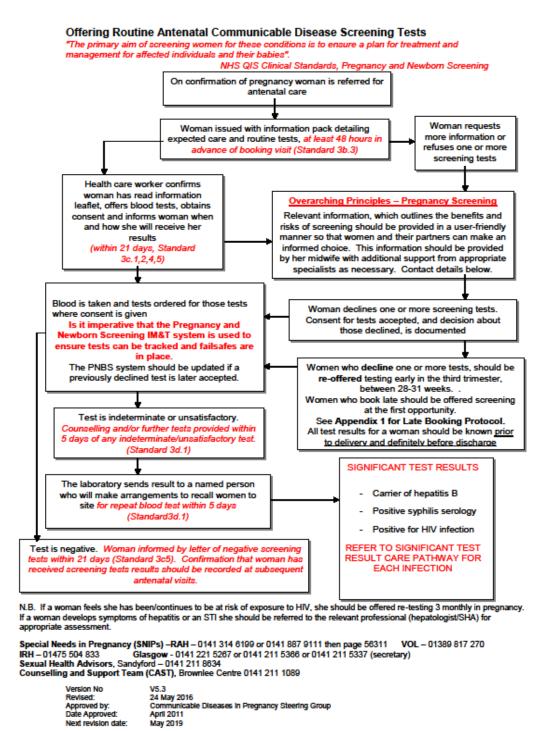
Refer analytical results to consultant for an opinion on the need for a clinical referral or consult the laboratory support service helpline.

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



#### 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</u> delivery:
  - 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/amended%20taxi%20protocol%20-20phase%201\_acute%20services.pdf

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

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

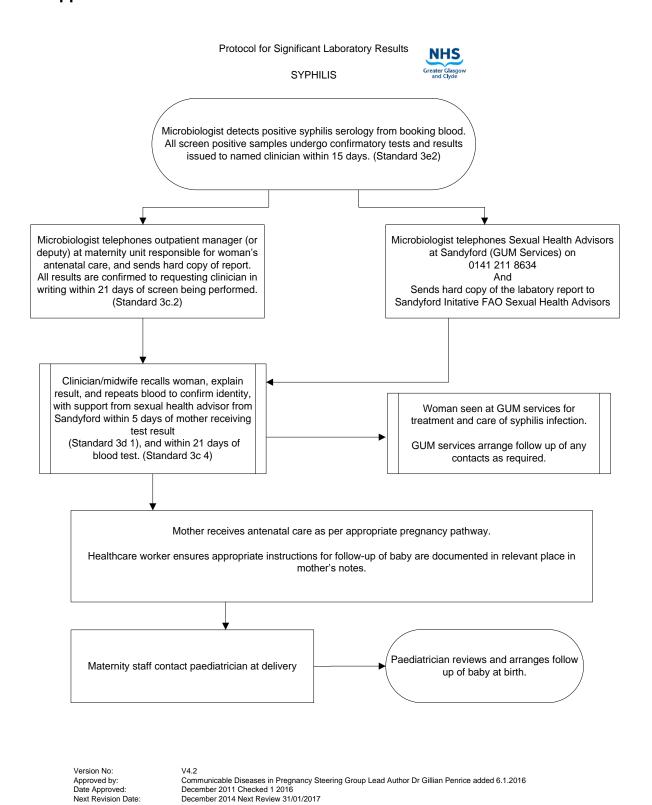
#### 3) The woman presents in labour:

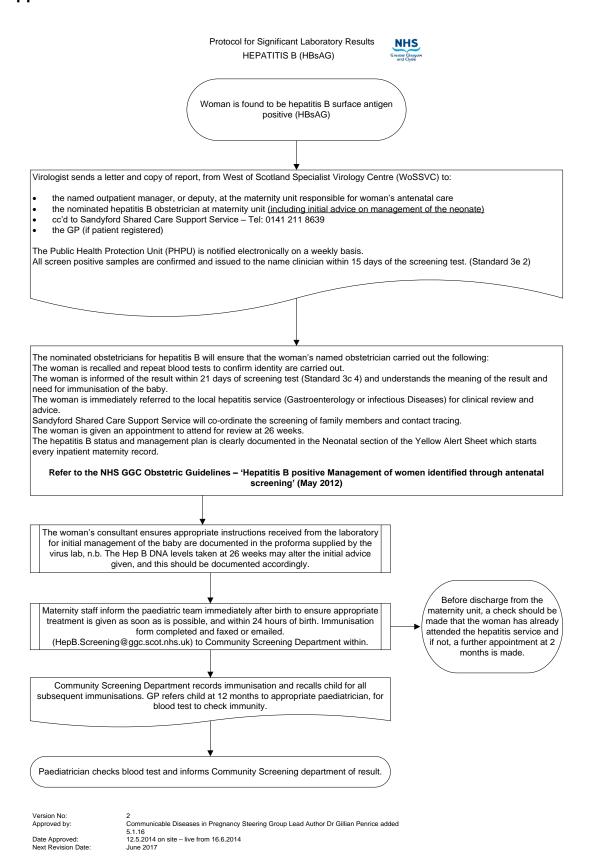
- It is the responsibility of the labour ward staff to ensure that virology screening tests are offered and results received. Even intrapartum diagnosis can significantly, positively modify neonatal outcome therefore it is important to ensure women are offered screening tests no matter how late.
- It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

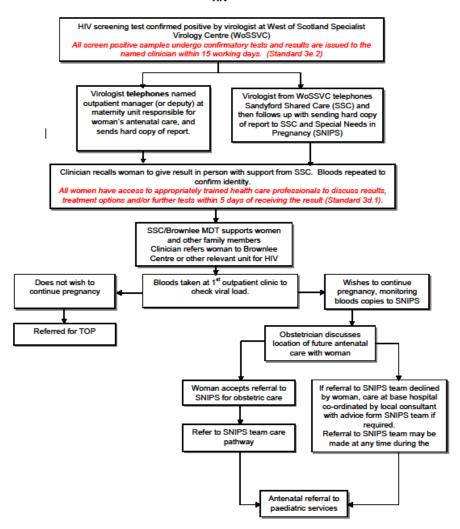
- Communication with paediatricians is essential as their management may be significantly altered by these results however the responsibility for taking and sending these investigations and obtaining these results remains with the midwifery / obstetric team.
- Ensure tests are recorded on PNBS at next opportunity.



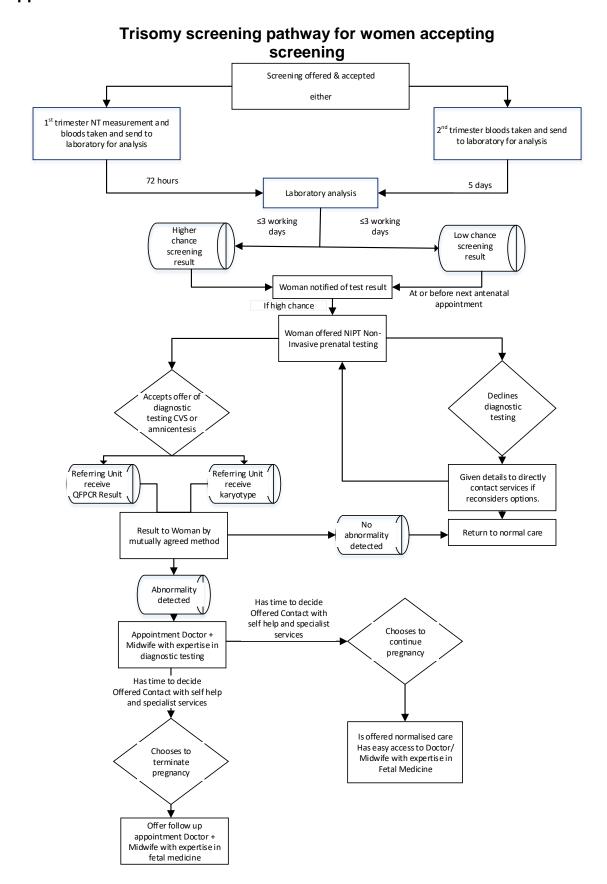




#### **Protocol for Significant Laboratory Results**



V5.1 Communicable Diseases in Pregnancy Steering Group Lead Author - Dr Gillian Penrice added 5.1.2016 On site 12.6.14 Live from 16.6.14



Assessment of Risk to Pregnancy & Newborn Screening Programmes should screening programmes be dialled down /temporarily suspended:

**Reason for continuation:** Pregnancy & Newborn screening is undertaken as part of the routine care provided to pregnant women and new born babies. As screening is completed during regular appointments, the programme should continue to be offered as long as this is possible.

**Considerations:** Guidelines from RCOG have noted that pregnant women do not appear to be more susceptible to the consequences of COVID-19 than the general population and there have been no reported deaths of pregnant women from the virus (<a href="https://www.rcog.org.uk/en/guidelines-research-services/guidelines/coronavirus-pregnancy/covid-19-virus-infection-and-pregnancy/">https://www.rcog.org.uk/en/guidelines-research-services/guidelines/coronavirus-pregnancy/covid-19-virus-infection-and-pregnancy/</a>).

As above, screening is offered during routine care appointments so additional appointments resulting in increased contact would be unlikely to be required for the majority of women. It should be noted that women who receive a higher chance from a screening test may need additional appointments if they decide to have a diagnostic procedure, but this would be very small numbers.

Newborn bloodspot screening is part of routine appointments for babies and if certain conditions are identified early intervention and treatment is required. Specific guidance on the impact of COVID-19 on newborns has not been provided by RCOG, but they do note that there have been no reports of the virus being passed from mother to baby during pregnancy. Assurances have been given by the Scottish Newborn Screening Laboratory that contingency plans have been reviewed and will be enacted if required specifically around laboratory staffing to ensure that samples are received and processed.

Boards will be asked to provide clear contingency plans around resourcing and local resilience plans should they have staff shortages in order that they are able to continue providing pregnancy and newborn screening services.

#### **Risk Assessment:**

Impact Desc Impact on pro	ription: ogramme should screening be suspended
Clinical	Missed screening opportunity for identifying fetal anomalies or conditions identified through the new born blood spot programme resulting in possible diagnosis delay and subsequent delay to possible treatment or medical intervention.  Consideration of  Continuation of services as this is part of routine prenatal and post-natal care pathway and is not an additional appointment  Continuation of pathway for those that have already accepted screening and had samples taken or have received results from

	T
	<ul> <li>initial screening and wish diagnostic testing</li> <li>Possible delay to clinical or medical interventions for serious</li> </ul>
	conditions causing risk to unborn babies or new born babies
Business	Delays will entail need for action plans when programme fully
	resumes
	Consideration:
	Additional laboratory staff to deal with increase of screening or diagnostic samples
	Additional midwife and sonographers required to support
	increase in clinic appointments due to short sample life for testing
Staff	Availability of programme staff to run programme should there be outbreak
	Re-allocation of screening programme staff for essential
	services within Boards, particularly laboratory staff
	Already increased risk around availability of sonographers for
	P&N screening programme
Reputation	Public may query why screening is suspended /delayed
	Communication of any interim arrangements
	Pregnant women may wish to not attend appointments or bring
	new born babies to appointments due to possible risk of contact with COVID-19

**Recommendation:** Based on guidance from RCOG and risk assessment above the recommendation is to continue Pregnancy & Newborn screening as this is part of routine appointments, unless staff resource is not available and this should be addressed at Board level but raised to NSD. Boards have been asked to develop contingency plans around resource and resilience in order to ensure that services are able to continue.

It should be noted that a separate risk and impact assessment is being undertaken regarding the T13, T18, and NIPT implementation to inform a decision around possible delay.

#### Appendix 1.12

# Members of Pregnancy & Newborn Screening Steering Group (At March 2020)

Dr Emilia Crighton

Ms Sally Amor

Dr Catriona Bain

Ms Donna-Maria Bean

Deputy Director of Public Health (Chair)

Health of Health Improvement, NHS Highland

Clinical Director, Obstetrics and Gynaecology

Lead Sonographer (Obstetrics & Gynaecology)

Dr Vicki Brace Consultant Obstetrician
Mr Paul Burton Information Manager
Mrs Lin Calderwood National Portfolio Manager
Ms Kim Campbell Senior Healthcare Scientist
Ms Margaret Cartwright Sector Laboratory Manager
Dr Elizabeth Chalmers Consultant Paediatrician
Ms Barbara Cochrane Metabolic Dietician

Dr Alison Cozens Consultant in Inerted Metabolic Disorders

Dr Rosemarie Davidson Consultant Clinical Geneticist

Dr Anne Devanney Consultant in Paediatric Respiratory Medicine

Dr Catriona Dreghorn Consultant

Mr Ian Fergus Site Technical Manager, Diagnostics Mrs Jaki Lambert Lead Midwife (Argyll and Bute)

Ms Dorothy Finlay Lead Midwife

Ms Marie-Elaine McClair Interim Clinical Service Manager Dr Louisa McIlwaine Consultant Haematologist

Ms Michelle McLauchlan
Ms Barbara McMenemy

Consultant Haematologist
General Manager, Obstetrics
Acute Addiction Manager

Dr Gillian Penrice Consultant in Public Health Medicine
Mrs Uzma Rehman Public Health Programme Manager
Mrs Elizabeth Rennie Screening Programmes Manager
Dr Jim Robins Consultant Obstetrician, Clyde

# Appendix 1.13

#### Members of Communicable Diseases Steering Sub Group (At March 2020)

Dr Gillian Penrice Public Health Protection Unit (Chair)

Dr Tamer Abdelrahman Honorary Virology Registrar

Ms Donna Athanasopoulos Information & Publications Manager

Ms Catrina Bain Clinical Director Obstetrics and Gynaecology

Ms Elizabeth Boyd Clinical Effectiveness Co-ordinator

Mr Paul Burton Information Manager

Mrs Lin Calderwood National Portfolio Programme Manager

Mrs Louise Carroll Programme Manager HIV/STIs
Ms Flora Dick Special Needs (SNIPS) Midwife
Ms Rose Dougan Special Needs (SNIPS) Midwife

Ms Elizabeth Ellis Staff Grade
Ms Dorothy Finlay Lead Midwife

Ms Catherine Frew Data Analyst, Specialist Virology Centre

Ms Claire Glover Clinical Nurse Specialist

Ms Louise Jack Midwife
Mrs Jaki Lambert Lead Midwife

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

Ms Karen McAlpine Lead Midwife

Ms Valerie McAlpine Senior Charge Midwife

Ms Marie-Elaine McClair Interim Clinical Service Manager

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

Ms Jane McOwan Technical Manager, Specialist Virology Centre

Ms Elizabeth Rennie Programme Manager

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

Ms Samantha Shepherd Clinical Scientist

Ms Claire Stewart Clinical Service Manager

Dr Andrew Thomson Consultant Obstetrician & Gynaecologist

# Chapter 2 - Newborn Bloodspot Screening

# Summary

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).

The total number of babies eligible for screening was 10,594 and of these, 10,462 (98.8%) babies were screened. Results were not available for 132 (1.2%) babies.

The uptake of Newborn Bloodspot screening was greater than 98.4% across all HSCP areas and deprivation categories.

The breakdown of the ethnicity groups for babies tested within NHSGGC shows that 7,359 (68.7%) of babies screened were UK White; 825 (7.7%) South Asian; 353 (3.3%) African or African Caribbean; 274 (2.6%) Other non- European; 415 (3.9%) Southern and Other European and 96 (0.9%) North Europe (white). The number from Any Mixed Background was 735 (6.8%) and ethnicity was not stated for 503 (4.7%)

Following screening 6 babies were diagnosed with congenital hypothyroidism (CHT), <5 babies were diagnosed with PKU (phenylketonuria) and 6 tested positive for cystic fibrosis.

The results for Haemoglobinopathy showed that although <5 babies were diagnosed with haemoglobinopathy variants, 79 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.

# **Newborn Bloodspot Screening and COVID 19**

The Scottish Screening Committee provided an assessment of all national screening programmes to the Scottish Government in March 2020 to decide whether to pause or continue with screening.

The Assessment of Risk to Pregnancy & Newborn Screening Programmes concluded that they should be continued. The reason given for the continuation was that Pregnancy & Newborn screening is undertaken as part of the routine care provided to pregnant women and new born babies.

As screening is completed during regular appointments, the programme should continue to be offered as long as this is possible. The full assessment is in <a href="Appendix 2.2">Appendix 2.2</a>

# **Chapter Contents**

2.1.	Newborn Bloodspot Screening	42
	Eligible Population	
	The Screening Test	
	Live births registrations by Health Board and HSCP areas	
	Delivery of NHSGGC Newborn Bloodspot Screening Programmes	
	Ethnicity of babies born in 2020/2021	
	Specimen Tests and Outcomes for 2020/2021	
	Key Performance Indicators for Newborn Bloodspot Screening	
	Information systems	
	. Challenges and Service Improvements	

# 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 are the total number of babies born within the reporting period (2020-2021), 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 births registrations by Health Board and HSCP areas

# 1. By Health Board

2020/21	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Total
NHSGGC	4	17	188	1,701	1,485	1,249	1,364	1,107	851	840	817	927	10,550

#### 2. By Council Areas

HSCP	Number of live births 2020/21
East Renfrewshire	813
East Dunbartonshire	907
Glasgow City	5,960
Renfrewshire	1,533
Inverclyde	591
West Dunbartonshire	746
NHSGGC Total	10,550

#### **Footnotes**

- 1) Data for 2020 and 2021 are provisional.
- 2) The health board areas are based on the boundaries introduced on 1 April 2014.
- 3) During the second half of March 2020 most registration offices closed due to the Covid-19 pandemic and most birth registrations were postpone During late June 2020, registration of births restarted.

The monthly number of registrations shown for 2020 does not reflect the actual number of births in many of those months.

https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/general-publications/weekly-and-monthly-data-on-births-and-deaths/monthly-data-on-births-and-deaths-registered-in-scotland

# 2.5. Delivery of NHSGGC Newborn Bloodspot Screening Programmes

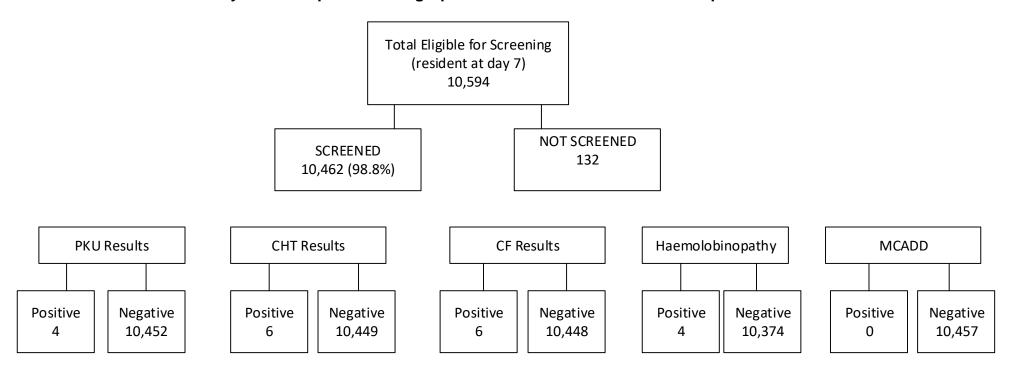
**Figure 2.1** illustrates newborn bloodspot uptake rates and the results of the screening programme from 1 April 2020 to 31 March 2021.

The total number of babies eligible for screening was 10,594 and of these, 10,462 (98.8%) babies were screened. Results were not available for 132 (1.2%) babies.

Following screening, 6 babies were diagnosed with congenital hypothyroidism (CHT), <5 babies were diagnosed with PKU (phenylketonuria) and 6 tested positive for cystic fibrosis. The results for Haemoglobinopathy showed that although <5 babies were diagnosed with haemoglobinopathy variants, 79 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 **NHS Greater Glasgow & Clyde Residents** Summary of Bloodspot Screening Uptake & Results for babies born 1 April 2020 to 31 March 2021



Source: Child Health Date extracted: Oct 2021

Notes:

- 1 Total includes 3 refusals and 4 verifications
- 2 Total includes 2 refusals and 5 verifications
- 3 Total includes 1 late, 2 carriers, 2 refusals and 3 verifications
- 4 Total includes 79 carriers, 2 refusals and 3 verifications
- 5 Total includes 2 Refusals and 3 verifications

The percentage uptake rate of Newborn Bloodspot screening was greater than 98.4% overall across all HSCP areas and deprivation categories. (**Table 2.2**)

Table 2.2: Uptake rate of Newborn Bloodspot screening by HSCP and deprivation Percentage uptake of Bloodspot Screening by HSCP and SIMD, 1 April 2020 to 31 March 2021

	Most De	prived			SIMD 2016	Quintile				Least Deprived		
	1		2		3		4		5		Total	
	No.	%	No.	%	No.	%	No.	%	No.		No.	%
HSCP	Screened	uptake	Screened	uptake	Screened	uptake	Screened	uptake	Screened	% uptake	Screened	uptake
East Dunbartonshire	41	100.0	143	98.6	56	100.0	202	99.5	460	99.3	896	99.3
East Renfrewshire	52	91.8	82	97.6	42	97.6	222	98.2	371	99.2	758	98.6
Glasgow North East	1,145	99.0	225	98.2	205	98.5	194	99.5	40	100.0	1,790	98.9
Glasgow North West	830	99.2	229	98.3	174	100.0	154	98.7	381	98.4	1,749	98.9
Glasgow South	1,049	98.9	564	98.8	305	97.7	351	97.2	203	96.6	2,429	98.3
Inverclyde	289	98.6	81	100.0	66	98.5	54	100.0	77	100.0	562	99.1
Renfrewshire	416	99.5	287	97.6	223	97.8	249	98.8	372	98.9	1,526	98.6
West Dunbartonshire	363	98.9	179	99.4	117	100.0	71	95.8	30	100.0	752	98.9
Grand Total	4,185	99.0	1,790	98.5	1,188	98.6	1,497	98.4	1,934	98.8	10,462	98.8

Source: Child Health (CH2008); Date extracted: October 2021

# 2.6. Ethnicity of babies born in 2020/2021

The breakdown of the recorded ethnicity groups for babies tested within NHSGGC shows that 7,359 (68.7%) of babies screened were UK White; 825 (7.7%) South Asian:

353 (3.3%) African or African Caribbean; 274 (2.6%) Other non- European; 415 (3.9%) Southern and Other European and 96 (0.9%) North Europe (white). The number from Any Mixed Background was 735 (6.8%) and ethnicity was not stated for 503 (4.7%) (Table 2.3).

Table 2.3: NHSGGC Newborn Bloodspot screening – ethnicity of babies tested 1 April 2020 to 31 March 2021

African or African- Carib bean	South Asian (Asian)	South East Asian (Asian)	Other non- European (other)	Southern & other European (White)	United Kingdom (White)	North Europe (White)	Any Mixed Back ground	Not Stated
353	825	143	274	415	7,359	96	735	503
3.3%	7.7%	1.3%	2.6%	3.9%	68.7%	0.9%	6.8%	4.7%

Source: Scottish Newborn Screening Laboratory - Newborn Bloodspot Screening 2020/21

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

# 2.7. Specimen Tests and Outcomes for 2020/2021

During 2020/2021, the Scottish Newborn Screening Laboratory received 11,291 newborn bloodspot cards from NHSGGC. The number and reason for repeat tests due to avoidable problems is detailed in **Table 2.4.** 

Table 2.4: Number and reason for repeat samples

Reason	Number	Percentage
Insufficient sample	196	1.74
Sample taken <96 hours	41	0.36
Incorrect blood application	67	0.59
Compressed /damaged sample	54	0.48
Blood quality of sample	17	0.15
Missing CHI	68	0.6
Expired card used	16	0.14
>14 days in transit	7	0.06
Total	466	3.99%

Source: SNSL Report 2020-2

# 2.8. Key Performance Indicators for Newborn Bloodspot Screening

Table 2.5 below shows the Newborn Bloodspot Screening against Key Performance Indicators for NHSGGC during 2020-2021. (**Table 2.5**)

Table 2.5: NBBS KPIs and performance during 2020-21 for NHSGGC

NBBS KPI	Performance threshold	2020/2021
8.1 Coverage  Information not available for KPI 8.1	95-99%	98.8%
8.2 Movers in	95-99%	137 children offered and 1 refused (100%)
8.3 Avoidable repeats	<1.0 to <2.0 %	3.99 %
8.4 Null or incomplete result on CHIS	Essential – regular checks to identify babies	Checks carried out on daily basis for overdue NBBS result.
8.5 CHI number recorded on bloodspot card	98-100%	99.4% had valid CHI
8.6 Timely sample collection	95-99%	41 samples were taken at less than 4 days. (0.36%)
8.7 Timely receipt of sample in the lab	95-99%	7 samples were too old in transit and too old for analysis (0.06%)
8.8 Timely second sample for CF screening	95% taken on day 21-24	3 out of 4 samples taken within timescale (75%)
8.9 Timely second sample for borderline CHT screening	95 – 99%	12 out of 17 samples (70.5%)
8.10 Timely second sample for CHT for preterm infant	95 – 99%	39 out of 59 samples (66.1%)
8.11 Timely processing CHD & IMD	Clinical referral within 3 days – 100%	All referred by 3 days
8.12 Timely entry into clinical care (data for Scotland)	IMDs appt by 14 days – 100%	89%
	CHT referral on 1 <sup>st</sup> sample	94%
	CHT referral on 2 <sup>nd</sup> sample	88%
	CF appt by 28 days – 80- 100%	95%
	CF appt by 35 days – 80-100%	86%
	SCD appt by 90 days	100%

# 2.9. Information systems

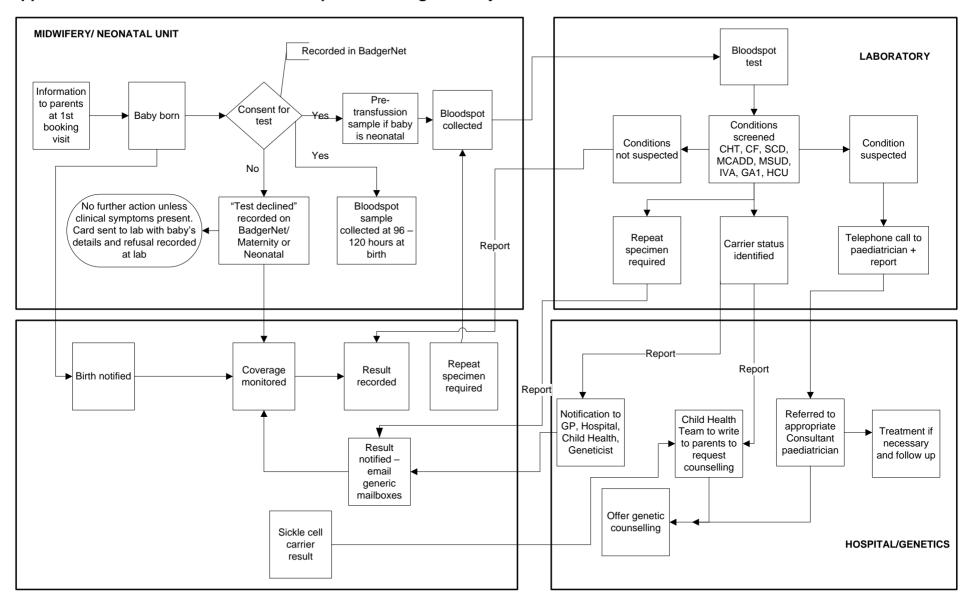
Pregnancy and Newborn Bloodspot screening tests results are provided by the National Laboratory's Information Management System and data are reported on the old former NHS Greater Glasgow and NHS Argyll and Clyde basis.

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.

# 2.10. Challenges and Service Improvements

- 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 StaffNet and the BadgerNet App.
- Ensure that services meet KPIs for Newborn Bloodspot Screening

Appendix 2.1: NHSGGC Newborn Bloodspot Screening Pathway



## Appendix 2.2

Assessment of Risk to Pregnancy & Newborn Screening Programmes should screening programmes be dialled down / temporarily suspended:

**Reason for continuation:** Pregnancy & Newborn screening is undertaken as part of the routine care provided to pregnant women and new born babies. As screening is completed during regular appointments, the programme should continue to be offered as long as this is possible.

Considerations: Guidelines from RCOG have noted that pregnant women do not appear to be more susceptible to the consequences of COVID-19 than the general population and there have been no reported deaths of pregnant women from the virus (<a href="https://www.rcog.org.uk/en/guidelines-research-services/guidelines/coronavirus-pregnancy/covid-19-virus-infection-and-pregnancy/">https://www.rcog.org.uk/en/guidelines-research-services/guidelines/coronavirus-pregnancy/covid-19-virus-infection-and-pregnancy/</a>). As above, screening is offered during routine care appointments so additional appointments resulting in increased contact would be unlikely to be required for the majority of women. It should be noted that women who receive a higher chance from a screening test may need additional appointments if they decide to have a diagnostic procedure, but this would be very small numbers.

Newborn bloodspot screening is part of routine appointments for babies and if certain conditions are identified, early intervention and treatment are required. Specific guidance on the impact of COVID-19 on newborns has not been provided by RCOG, but they do note that there have been no reports of the virus being passed from mother to baby during pregnancy. Assurances have been given by the Scottish Newborn Screening Laboratory that contingency plans have been reviewed and will be enacted if required specifically around laboratory staffing to ensure that samples are received and processed.

Boards will be asked to provide clear contingency plans around resourcing and local resilience plans should they have staff shortages so that they are able to continue providing pregnancy and newborn screening services.

#### Risk Assessment:

Impact Description:						
Impact on programme should screening be suspended						
Clinical	Missed screening opportunity for identifying fetal anomalies or conditions identified through the new born blood spot programme resulting in possible diagnosis delay and subsequent delay to possible treatment or medical intervention.  Consideration of  Continuation of services as this is part of routine prenatal and post-natal care pathway and is not an additional appointment  Continuation of pathway for those that have already accepted screening and had samples taken or have received results from initial screening and wish diagnostic testing  Possible delay to clinical or medical interventions for serious conditions causing risk to unborn babies or new born babies					

Business	Delays will entail need for action plans when programme fully resumes Consideration:  • Additional laboratory staff to deal with increase of screening or diagnostic samples
	<ul> <li>Additional midwife and sonographers required to support increase in clinic appointments due to short sample life for testing</li> </ul>
Staff	<ul> <li>Availability of programme staff to run programme should there be outbreak</li> </ul>
	<ul> <li>Re-allocation of screening programme staff for essential services within Boards, particularly laboratory staff</li> <li>Already increased risk around availability of sonographers for</li> </ul>
Domitation	P&N screening programme
Reputation	Public may query why screening is suspended /delayed
	Communication of any interim arrangements
	<ul> <li>Pregnant women may wish to not attend appointments or bring new born babies to appointments due to possible risk of contact with COVID-19</li> </ul>

**Recommendation:** Based on guidance from RCOG and risk assessment above, the recommendation is to continue Pregnancy & Newborn screening as this is part of routine appointments, unless staff resource is not available and this should be addressed at Board level but raised to NSD. Boards have been asked to develop contingency plans around resource and resilience in order to ensure that services are able to continue.

It should be noted that a separate risk and impact assessment is being undertaken regarding the T13, T18, and NIPT implementation to inform a decision around possible delay.

# Appendix 2.3

# Members of Pregnancy & Newborn Screening Steering Group (At March 2020)

Dr Emilia Crighton

Ms Sally Amor

Dr Catriona Bain

Ms Donna-Maria Bean

Deputy Director of Public Health (Chair)

Health of Health Improvement, NHS Highland

Clinical Director, Obstetrics and Gynaecology

Lead Sonographer (Obstetrics & Gynaecology)

Dr Vicki Brace Consultant Obstetrician
Mr Paul Burton Information Manager
Mrs Lin Calderwood National Portfolio Manager
Ms Kim Campbell Senior Healthcare Scientist
Ms Margaret Cartwright Sector Laboratory Manager
Dr Elizabeth Chalmers Consultant Paediatrician
Ms Barbara Cochrane Metabolic Dietician

Dr Alison Cozens Consultant in Inerted Metabolic Disorders

Dr Rosemarie Davidson Consultant Clinical Geneticist

Dr Anne Devanney Consultant in Paediatric Respiratory Medicine

Dr Catriona Dreghorn Consultant

Mr Ian Fergus Site Technical Manager, Diagnostics

Mrs Jaki Lambert Lead Midwife (Argyll and Bute)

Ms Dorothy Finlay Lead Midwife

Ms Marie-Elaine McClair Interim Clinical Service Manager

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

Dr Gillian Penrice Consultant in Public Health Medicine
Mrs Uzma Rehman Public Health Programme Manager
Mrs Elizabeth Rennie Screening Programmes Manager
Dr Jim Robins Consultant Obstetrician, Clyde

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

# Summary

Universal Newborn Hearing screening can detect early permanent congenital hearing impairment in babies as mild and unilateral losses. Of the 10,574 eligible babies, 10,474 were screened for hearing loss, giving an uptake of 99.0%.

1,395 (13%) babies required a second stage follow up and of these, 191 (2.0%) babies were referred to audiology. 45 babies were confirmed with a hearing loss (0.4 % of the screened population). 26 had confirmed bilateral hearing loss and 19 babies had confirmed unilateral hearing loss.

100 (1.0%) babies did not complete the screening programme, of these 6 parents declined or withdrew consent. The rest included babies who did not attend for screening (94), are deceased (3) or babies were unsettled (5) during the screening process.

## Coronavirus Pandemic - Changes to UNHS

Following a national risk assessment the screening pathway was amended during 2020 due to the Covid-19 pandemic:

- From 16/03/2020 outpatient screening was stopped and babies were only screened whilst an inpatient.
- If a baby did not have a screening test result before discharge they were listed for deferred screening follow up.
- If a baby had a unilateral refer result on AABR1 and it was not possible to carry out AABR2 before discharge they were listed for deferred screening follow up.
- If a baby had a bilateral refer result on AABR1 and it was not possible to carry out AABR2 before discharge they were referred directly for immediate diagnostic audiology assessment.
- If a baby had a bilateral refer on AABR2 they were referred for immediate diagnostic audiology assessment.
- If a baby had a unilateral refer on AABR2 they were listed for deferred diagnostic audiology assessment.
- Deferred screening follow up was commenced on 25/05/2020 and transition to standard protocols with routine outpatient screening started after this.
- Deferred diagnostic audiology assessments were commenced on 18/05/2020 and transition to standard protocols started after this.

The effect of these changes to the KPI figures noted in Section 3.6 is in increased timescales to complete screening (KPI 7.1) and time to diagnostic audiology assessment (KPI 7.6 and KPI 7.7). Additionally there was a proportion of parents who opted to delay attendance at diagnostic audiology assessment due to the pandemic and this had an impact on KPI 7.7.

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	Challenges and Future Priorities	

# 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 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 <a href="Appendix 3.1">Appendix 3.1</a>.

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

The uptake of Newborn Hearing Screening is high across all areas and ranged from 99.1% in West Dunbartonshire to 99.8% in East Dunbartonshire (**Table 3.1**).

Table 3.1: NHSGGC Residents Universal Newborn Hearing – Annual Uptake by HSCP, 1 April 2020 to 31 March 2021

HSCP	Not Screened	Screened	Total	% Uptake
East Dunbartonshire	2	877	879	99.8
East Renfrewshire	2	761	763	99.7
Glasgow North East	13	1,790	1,803	99.3
Glasgow North West	13	1,744	1,757	99.3
Glasgow South	17	2,437	2,454	99.3
Inverclyde	3	563	566	99.5
Renfrewshire	6	1,542	1,548	99.6
West Dunbartonshire	7	755	762	99.1
Total	63	10,469	10,532	99.4

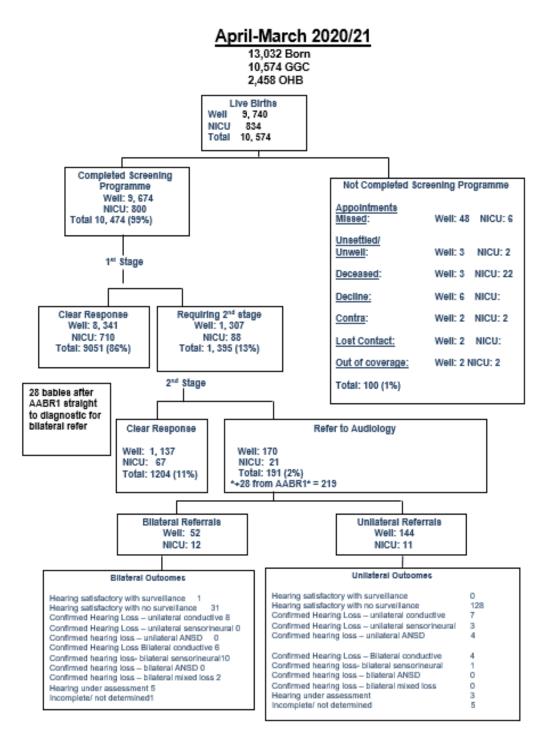
Source: Scottish Birth Record (SBR) Extracted: October 2021

Data provided by the Hearing and Screening service is presented in **Figure 3.1.** Universal Newborn Hearing screening can detect early permanent congenital hearing impairment in babies' as well mild and unilateral losses. Of the 10,574 eligible babies, 10,474 were screened for hearing loss, giving an uptake of 99.0%.

1,395 (13%) babies required a second stage follow up and of these, 191 (2.0%) babies were referred to audiology. 45 babies were confirmed with a hearing loss (0.4 % of the screened population). 26 had confirmed bilateral hearing loss and 19 babies had confirmed unilateral hearing loss.

100 (1.0%) babies did not complete the screening programme, of these 6 parents declined or withdrew consent. The rest included babies who did not attend for screening (94), are deceased (3) or babies were unsettled (5) during the screening process. **(Figure 3.1).** 

Figure 3.1 Summary of NHSGGC Residents Universal Newborn Hearing Screening activity for period 1 April 2020 to 31 March 2021



#### Definitions

1st Stage – is first AABR for Greater Glasgow and the first OAE for Clyde

2<sup>nd</sup> Stage – is the second AABR for Greater Glasgow and the second OAE and first AABR for Clyde

**Results pending** – includes all those babies who we are still trying to complete the screen

Incomplete/not completed – are all those babies we cannot complete a screen or diagnostic assessment for i.e. DNAs, deceased, transferred out or moved away etc. Clear Response – is a pass (though some are followed up due to risk factors)

Hearing Under assessment – all babies who have referred from the screen and their diagnostic assessment is ongoing.

# 3.6. Universal Newborn Hearing Screening KPIs 2020-21

7.1 The proportion of babies eligible for UNHS for whom the screening process is complete by 4 weeks corrected age 7.4 The proportion of well babies tested using the AABR protocol who do not show a clear response in both ears at AABR1	10,469 completed screening i.e. 99.4% 1,395 required 2 <sup>nd</sup> stage	UNHS: Coverage Essential ≥ 98% Desirable ≥99.5%  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  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	191 referred to Audiology 2.0%	UNHS: Test Performance - (4) Referral rate to diagnostic audiology assessment Essential ≤3% Desirable ≤2% 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 an appointment within the required timescale. The required timescale is either 4 weeks of scan completion or by 44 weeks gestational age.	86.5%	UNHS: Time from screening outcome to attendance at an audiology assessment appointment Essential ≥90% Desirable ≥95%

# 3.7. Information Systems

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

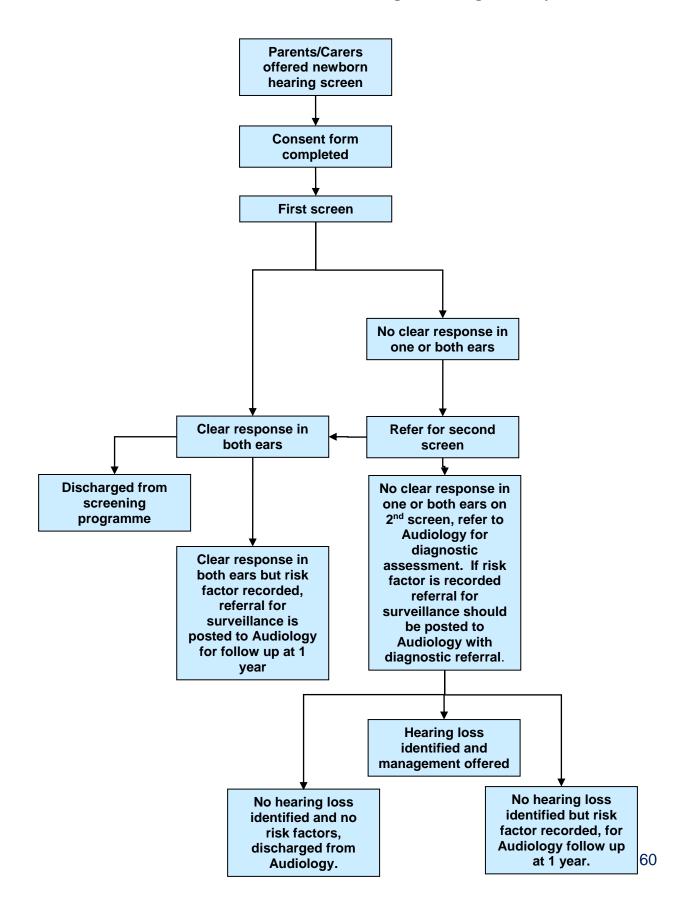
The Child Health Surveillance Programme Pre-School system (CHSP-PS) holds screening outcomes and is used as a failsafe to ensure all babies are offered hearing screening.

# 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.

Appendix 3.1

# **NHSGGC Universal Newborn Hearing Screening Pathway**



# Appendix 3.2

# Universal Newborn Hearing Screening Programme Steering Group (At March 2020)

Dr Emilia Crighton Deputy Director of Public Health (Chair)
Ms Isobel Cook Midwife/Screener, Argyll and Bute

Mrs Dorothy Finlay Lead Midwife

Patricia Friel Lead Nurse, Neonatal Mr James Harrigan Head of Audiology

Ms Fiona Jarvis Specialist Speech and Language Therapist

Ms Ainsley Keenan Screening Manager

Alison McGrory Health Improvement Principal Dr Juan Mora Consultant Audio logical Physician

Mrs Julie Mullin Assistant Programme Manager, Screening Dept

Dr Andrew Powls Consultant Neonatologist

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

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.

# **COVID Pandemic and impact on Pre School Vision Screening**

During March 2020, all nurseries were closed due to the lockdown imposed as a response to the COVID Pandemic. This resulted in planned screening within nurseries being cancelled.

Children who do not attend nursery or school, whose nursery is unknown or who miss their appointment within the nursery, are invited to a hospital Orthoptic clinic to have their vision screened during the summer holidays. This was not possible within the lockdown period in 2020 and had an impact on screening those that had missed out on vision screening.

The number of Pre-School children who missed out on screening in 2019/2020 was 4,961 and a process was established to appoint them at mop-up clinics. The children were screened and the process completed by September 2021.

At the time of writing this report it was estimated that the screening for the 2020/2021 cohort will be completed by March 2022. This chapter will be updated once all the data is available for children screened in any nursery, or mop up clinic and in Primary 1.

Parents received a letter advising them to take their child to an Optometrist if they had concerns about their vision if they were still waiting to be screened.

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

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

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.

# **COVID Pandemic and impact on Pre School Vision Screening**

The Primary 7 cohort of children who were due to be screened during the 2020-21 school year missed out on screening due to school closures. The steering group with support from Managers in NHSGGC Children & Families Teams decided to train Health Care Support Workers, Dental Health Support Workers and Nursery Nurses to undertake screening in as many schools as possible during June 2021. The data for this cohort was not available at the time of writing this report.

This chapter will be updated once all data for both Nursery and Primary 7 vision screening is available for the 2020-21 cohort of children

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	P7 Child Health Screening Information Systems	

#### **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.

Amblyopia 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 2016 and 28 February 2017 were downloaded from CHI and matched against the lists received from nurseries.

Pre-school vision screening clinics take place in the nursery setting. Children who do not attend nursery or school, whose nursery is unknown or who 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 initially. The assessment appointment involves a full eye examination and allows clinicians 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.

# **Primary 7 School Vision Screening Programme**

# 4.6. P7 Eligible Population

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

#### 4.7. P7 Vision Test

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

#### 4.8. 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:

- 1. 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.
- 2. Children who have specific visual abnormalities leading to visual impairment, if not already known are also referred to a community paediatrician.
- 3. 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.

# 4.9 P7 Child Health Screening Information Systems

Child Health Surveillance System—Pre-school (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.

# Appendix 4.1

# Members of Child Vision Screening Steering Group (At March 2020)

Dr Emilia Crighton Deputy Director of Public Health (Chair)

Ms Nikki Meek Optometrist

Mr Paul Burton Information Manager

Mrs Sandra Simpson Assistant Screening Programme Manager

Mrs Carolyn MacLellan Lead Orthoptist
Mr Eddie McVey Optometric Adviser

Mr Gordon Simpson AOC Rep

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

Mrs Uzma Rehman Programme Manager, Public Health

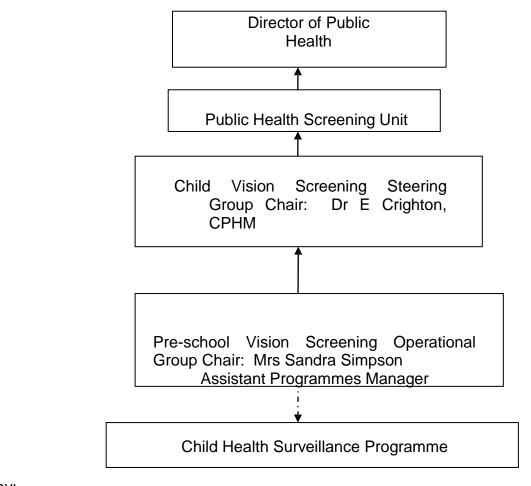
Mrs Diane Russell Lead Orthoptist
Ms Rose O'Hare Team Lead

Ms Elaine Salina Principal Optometrist Dr Nicola Schinaia Argyll & Bute HSCP

Dr Kathy Spowart Paediatrician, Community Child Health

Mrs Claudine Wallace Lecturer in Orthoptics, GCU

# Appendix 4.2 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 asymptomatic 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.

During the period 2020-2021, the total number of eligible men was 6,648 and 5,754 (86.6%) were invited. The essential threshold for screening uptake (70%) for those invited was met across all deprivation quintiles. Overall, men who resided in the most deprived areas had uptake rates 13% lower than men residing in the least deprived areas (72% vs. 85% respectively).

The majority (95.3%) of men invited were of white ethnic origin. Uptake of AAA screening differs between ethnic groups and due to low numbers in some ethnic groups, it is not possible to directly compare programme uptake across ethnic subgroups.

Following screening, 31 men (1.2%) had an enlarged aorta (≥3cm). Of these, 27 men (0.7%) had an aorta measuring between 3cm to 5.49cm, requiring surveillance scans and less than 5 men (0.08%) had a large aneurysm measuring 5.5 cm or more, requiring surgical assessment and intervention.

# **COVID-19 Pandemic**

## Impact of COVID-19 pandemic on the AAA screening programme

On 30 March 2020 the Scottish Government, on the advice of the Scottish Screening Committee, decided to temporarily pause the AAA screening programme as a result of the COVID pandemic. Following an assessment, the recommendation was to:

- Pause all screening as soon as possible and agree that the treatment pathway for men with large AAAs are decided by the local vascular departments.
- Cancel all scheduled clinics and stop the issuing of any new invitations within 18/24 hours of a decision to pause screening.

This followed work with local programmes who in the preceding weeks were already taking safety precautions by cancelling AAA screening clinics and deferring participants to be called up at a later stage. The last AAA screening clinics before the pause were on 20 March 2020.

The impact of stopping screening and cancellation of clinics will have affected the uptake rate and referrals and treatment within Vascular Services. The full assessment is provided in Appendix 5.3.

For the annual data for the year ending 31 March 2020, the effect on the key performance indicators is limited, as much of the screening activity for the period reported had already occurred before the pandemic caused disruption.

The first AAA screening programme clinics resumed at the end of July 2020 and by September 2020 all local NHS Board programmes were having regular clinics. Results for the year ending 31 March 2021 will be published in the next annual report published in March 2022.

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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 clinic to assess willingness and fitness for either surgery or for referral to

<sup>&</sup>lt;sup>1</sup>https://www.healthcareimprovementscotland.org/our work/standards and guidelines/stnds/aaa scre ening standards.aspx June 2021

<sup>&</sup>lt;sup>2</sup> http://www.isdscotland.org/Health-Topics/Public-Health/AAA-Screening/2018-03-06-AAA-KPI-Definitions.pdf (accessed Nov 2021)

interventional radiological services for assessment for endovascular aneurysm repair (EVAR). There is multidisciplinary team decision making for aneurysm patients (both screened and unscreened). Some patients will not go on to have an intervention, mainly due to fitness for surgery or a preference for no intervention after consultation and assessment.

Sometimes an image cannot be achieved if, for example, an individual has a high BMI, large abdominal girth, bowel gas or previous surgery, which can cause issues with visualisation of the aorta thus 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

Due to the pause in screening during 2020, the number of invitations for AAA was reduced. **Table 5.1** shows the difference in activity for the two years, 2019/20 and 2020/21

Table 5.1: AAA activity summary 1st April 2019 to 31st March 2021

	1 <sup>st</sup> April 2019 to 31 <sup>st</sup> March 2020	1st April 2020 to 31st March 2021
Appointed	7,266	4,049
Attended	5,294	2,970
Not Attended	1,972	1,079
Discharge	4,672	2,519
3 Months	155	144
12 Months	263	225
Refer to Vascular	15	16

Source: AAA metric reports

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.

During the period 2020-2021, the total number of eligible men was 6,648 and 5,754 (86.6%) were invited. The essential threshold for screening uptake (70%) for those invited was met across all deprivation quintiles. Overall, men who resided in the most deprived areas had uptake rates 13% lower than men residing in the least deprived areas (72% vs. 85% respectively). **(Table 5.2)** 

Table 5.2: Uptake of AAA screening among eligible population by SIMD quintile for NHSGGC, 2020-2021

SIMD Quintile 2020	Total	Invited	% Invited	Not Screened	Screened	% Screened
1 (Most Deprived)	2,182	1,885	86.4	527	1,358	72.0
2	1,122	968	86.3	214	754	77.9
3	814	695	85.4	134	561	80.7
4	1,060	928	87.5	141	787	84.8
5 (Least Deprived)	1,470	1,278	86.9	192	1,086	85.0
Total	6,648	5,754	86.6	1,208	4,546	79.0

Source: AAA Application, OnoMap, September 2021

The majority (95.3%) of men invited were of white ethnic origin. **(Table 5.3)** Uptake of AAA screening differs between ethnic groups, with uptake variable across groups. However, due to low numbers in some ethnic groups it is not possible to directly compare programme uptake across ethnic subgroups.

Table 5.3: Uptake of AAA screening by ethnicity for NHSGGC, 2020-2021

2001 Census				Not		%
Ethnic Group	Total	Invited	%Invited	Screened	Screened	Screened
A) WHITE - BRITISH	5,469	4,723	86.4	952	3,771	79.8
B) WHITE - IRISH	748	643	86.0	122	521	81.0
C) WHITE - ANY OTHER WHITE BACKGROUND	134	123	91.8	47	76	61.8
H) ASIAN OR ASIAN BRITISH - INDIAN	50	44	88.0	12	32	72.7
J) ASIAN OR ASIAN BRITISH - PAKISTANI	127	118	92.9	37	81	68.6
K) ASIAN OR ASIAN BRITISH - BANGLADESHI	≥5	≤5	100.0	≤5	≥5	66.7
L) ASIAN OR ASIAN BRITISH - ANY OTHER ASIAN BACKGROUND	≤5	≤5	100.0	≤5	0	0.0
N) BLACK OR BLACK BRITISH - AFRICAN	9	8	88.9	≤5	≤5	50.0

R) OTHER ETHNIC GROUPS - CHINESE	32	26	81.3	8	18	69.2
S) OTHER ETHNIC GROUPS - ANY OTHER ETHNIC GROUP	55	46	83.6	16	30	65.2
Y) UNCLASSIFIED	17	16	94.1	7	9	56.3
Total	6,648	5,754	86.6	1,208	4,546	79.0

Source: AAA Application, OnoMap, September 2021

Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

The essential threshold for screening uptake (70%) was met in all HSCPs, with a highest uptake rate of 88.5% in East Dunbartonshire HSCP and the lowest uptake rates of 71.7% in Renfrewshire (**Table 5.4**)

Table 5.4: Uptake of AAA screening among eligible population by Health & Social Care Partnership in NHSGGC, 2020-2021

	Total	Invited	%Invited	Not	Screened	% Screened
HSCP				Screened		
East	707	689	97.5	79	610	88.5
Dunbartonshire						
HSCP						
East Renfrewshire HSCP	562	523	93.1	86	437	83.6
Glasgow North East Sector	965	941	97.5	191	750	79.7
Glasgow North West Sector	1,023	863	84.4	222	641	74.3
Glasgow South Sector	1,272	1,259	99.0	249	1,010	80.2
Glasgow City	3,260	3,063	94.0	662	2,401	78.4
Inverclyde HSCP	493	163	33.1	33	130	79.8
Renfrewshire HSCP	1,028	835	81.2	241	594	71.1
West	598	481	80.4	107	374	77.8
Dunbartonshire HSCP						
Total	6,648	5,754	86.6	1,208	4,546	79.0

Source: AAA Application, September 2021

#### 5.5. Abdominal Aneurysm Screening Results

**Table 5.5** shows that 31 men (1.2%) had an enlarged aorta (≥3cm). Of these, 27 men (0.7%) had an aorta measuring between 3cm to 5.49cm, requiring surveillance scans and 4 men (0.08%) had a large aneurysm measuring 5.5 cm or more, requiring surgical assessment and intervention.

Table 5.5: Abdominal Aneurysm screening results for NHSGGC, 2020-2021

Result Type	<3	3 - 5.49	>=5.5	Not Known	Total
Negative	4,461	0	0	0	4461
Non	0	0	0	53	53
Visualisation					
Positive	0	27	4	0	31
Technical Fail	0	0	0	1	1
Total	4,461	27	4	54	4,546

Source: AAA Application, September 2021

#### **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. 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. The KPIs report was not available at the time of writing this report. The report will be added after September 2022 (Appendix 5.2)

#### 5.8 Quality Improvement

Healthcare Improvement Scotland's 2017 external quality assurance review of the AAA programme in Scotland<sup>3</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.

<sup>3</sup>http://www.healthcareimprovementscotland.org/our\_work/cardiovascular\_disease/screening\_for\_aaa\_/aaa\_screening\_review.aspx (Accessed 26th October 2018)

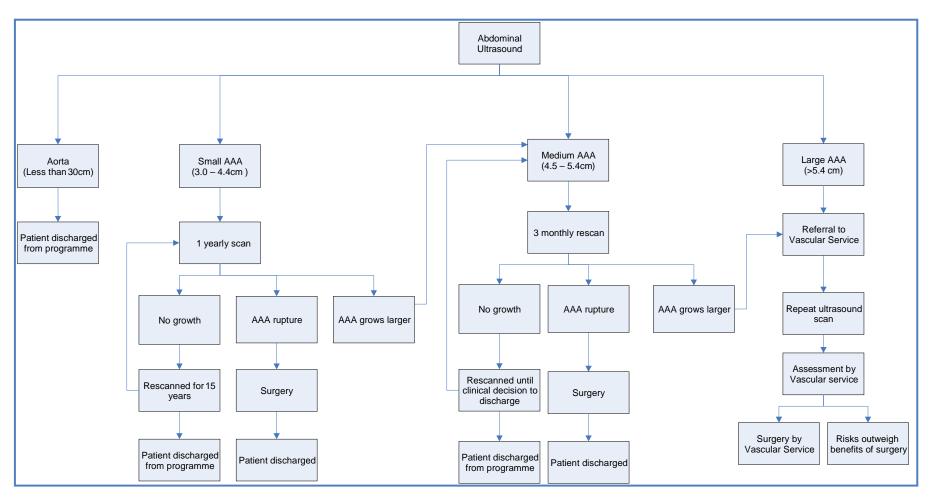
## 5.9 Challenges and Future Priorities

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 to enable a more coordinated approach to reducing inequalities in uptake through targeted intervention plans.

Appendix 5.1: Positive Abdominal Aortic Aneurysm Screening Pathway



Appendix 5.2: Abdominal Aortic Aneurysm Key Performance Indicators, NHS Greater Glasgow & Clyde (2015–2020)

Please note that KPI data cannot be fully assessed for year ending March 2021 and will be available in Sept 2022.

KPI	Description	Essential Threshold	Desirable Threshold	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	Year ending 31 <sup>st</sup> March 2020	Year ending March 2021.
Invita	ation and attendance				•				
1.1	Percentage of eligible population who are sent an initial offer to screening before age 66	≥ 90%	100%	99.0%	100%	99.9%	100%	99.9%	This information is not yet available
1.2	Percentage of men offered screening who are tested before age 66 and 3 months	≥ 70%	≥ 85%	80.1%	80.5%	80.1%	81.2%	80.5%	This information is not yet available
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%	72.7%	73.1%	73.6%	75.4%	75.1%	This information is not yet available

1.4a	Percentage of annual surveillance appointments due where men are tested within 6 weeks of due date	≥ 90%	100%	93.0%	94.0%	92.5%	95.3%	92.5%	This information is yet not available
1.4b	Percentage of quarterly surveillance appointments due where men are tested within 4 weeks of due date	≥ 90%	100%	98.6%	92.1%	87.4%	91.7%	92.9%	This information is not yet available
	ty of screening			1					
2.1a	Percentage of screening encounters where aorta could not be visualised	< 3%	< 1%	2.4%	2.8%	3.3%	2.5%	2.4%	This information is not yet available
2.1b	Percentage of men screened where aorta could not be visualised	< 3%	< 1%	2.1%	2.3%	2.6%	2.1%	2.1%	This information is not yet available
2.2	Percentage of screened images that failed the quality assurance audit and required immediate recall	< 4%	< 1%	1.4%	1.0%	1.1%	0.9%	0.7%	This information is not yet available
	ral, clinical intervention and			1					
3.1	Percentage of men with	≥ 75%	≥ 95%	100%	100.0	91.7%	100%	92.9%	

	AAA≥5.5cm seen by vascular specialist within two weeks of screening				%				This information is not yet available
3.2	Percentage of men with AAA≥5.5cm deemed appropriate for intervention/ operated on by vascular specialist within eight weeks of screening	≥ 60%	≥ 80%	53.8%	62.5%	57.1%	60.0%	75.0%	This information is not yet available

Scottish Abdominal Aortic Aneurysm (AAA) screening programme statistics - Year ending 31 March 2020 - Scottish Abdominal Aortic Aneurysm (AAA) screening programme statistics - Publications - Public Health Scotland September 2020.

#### Appendix 5.3

Assessment of Risk to Abdominal Aortic Aneurysm (AAA) Screening Programme should screening programme be dialled down /temporarily paused:

AAA screening is a screening programme for men aged 65 - a one off scan for most men ( $\pm 98\%$ ) besides those with an AAA (<1.5%) who are put on a surveillance cycle or referred on for treatment.

### Reasons why screening programme may need to be paused:

- Risk for either participants or staff picking up the virus
- Re-allocation of screening programme staff to support other essential services within Boards
- Minimising the impact on essential NHS services by cutting down on referrals
- Availability of service staff to screen /operate the programme should there be outbreak
- Participants may not travel/wish to attend routine screening appointments at this time

#### **Considerations:**

- A 18/24 hour notice period to cancel clinics Invitations are issued for routine screening 3 weeks in advance of appointment dates
- Communications with population /key stakeholders as to halt to service
- Timing and lead in time for re-instatement of programme and action plans given delay to service

#### Risks:

#### Risks of continuing screening:

- Participants picking up coronavirus due to this screening age group (<65)
  they more at risk having complications from the virus compared to the under
  65 age group</li>
- Screening staff picking up coronavirus
- Local vascular departments not being able to take on any new referrals from the AAA screening programme. A man needing treatment might need to be in a ITU and this resource might be need by Boards for patients with coronavirus
- Not being able to clean the screening equipment sufficiently between episodes and thus the potential to be exposed to the coronavirus
- Resultant increased anxiety of men diagnosed with an aneurysm that don't get appropriate follow up care timeously.
- Risk of cancelation of clinics being cancelled on GP/independent premises as GP practices/independent venues may not agree to screening clinics going ahead
- Inefficient usage of resources there could be a spike in DNAs (as men invited to screening might deem it a greater risk attending than not) and that would mean clinical staff not being used to the full capacity
- Limited staffing available to operate screening service (already a known shortfall of key clinical staff e.g. sonography)

## Risks of pausing screening:

Possible delay to diagnosis of an AAA

- Possible rupture of an AAA for not having AAA identified in the next 3 months. [There is ±15 large AAAs identified a year (±4 in a 3-month period) out of a screening population of ±26000 and the risk is for one of these to rupture. The likelihood of this happening is statistically very small. In contrast, this is set against the risk of an individual picking up the coronavirus by attending a screening clinic and increased risk of community infection thereafter as well as endangering the individual.]
- Reputation of the screening programme(s)/health service
- Not meeting the programmes KPIs

## Recommendation:

Pause all screening as soon as possible and agree that the treatment pathway for men with large AAAs are decided by the local vascular departments.

This would involve cancelling all the scheduled clinics and stop the issuing of any new invitations.

This can be done within 18/24 hours of a decision to pause screening. Given that there is an 8 week treatment time target for men with large aneurysm we recommend that a decision is made as early next week as possible for the AAA programme.

This assessment and recommendation agreed in consultation with the AAA Programme Board and key stakeholders from the AAA screening programme including the Clinical Lead Mr Douglas Orr

#### Appendix 5.4

# Members of Abdominal Aortic Aneurysm Screening Steering Group (At March 2020)

Dr Emilia Crighton Deputy Director of Public Health (Chair)

Mrs Karen Bell Clinical Services Manager, Surgery & Anaesthetics

Mr Paul Burton Information Manager

Mrs Lin Calderwood HI&T Service Delivery Manager

Mrs Mairi Devine Lead Sonographer
Miss Mary Fingland Glasgow LMC

Mrs Irene Fyfe Health Records Services Manager

Mrs Antonella Grimon AAA Data Administrator

Mrs Elaine Hagen Screening Programme Support Officer, Screening Dr Oliver Harding Consultant in Public Health Medicine, NHS Forth

Valley

Dr Ram Kasthuri Consultant Interventional Radiologist

Mr Calum McGillivray Programme Support Officer, Screening Department

Ms Heather McLeod Sonographer, NHS Forth Valley
Mrs Uzma Rehman Public Health Programme Manager

Mrs Elizabeth Rennie Programme Manager, Screening Department

Mrs Lynn Ross General Manager, Diagnostics

Mr Kevin Daly 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 2019. Ninety three percent of bowel cancers detected are among people aged over 50 years of age.

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.

Between 2019 and 2021, 292,420 NHSGGC residents were invited for bowel screening. Over half (59.6%) of those invited returned the screening test, of which 5,147 tested positive (3.0%). Of those individuals who had a positive result, 4,652 (90.3%) accepted a nurse pre-assessment and over three quarters 3,674 (78.9%) had a colonoscopy performed. Subsequently, 165 cancers and 1,734 adenomas were detected.

Women were more likely to return a bowel screening test than men (62.1% vs. 57.2% respectively). Uptake was lowest among those aged 50-54 years, at 53.2% and increased to 66.7% between 70 and 74 years, a difference of 13.5%.

Uptake of bowel screening programme increased with decreasing levels of deprivation. It was lowest in people living in the most deprived Board areas (50.6%) and highest in the least deprived areas (69.6%). Ethnic groups also have lower uptake than White British.

Overall, 3.0% (5,147 of 292,420) of completed screening test were reported positive, meriting further investigation. Women have a lower positivity than men (2.4% vs.

3.6 %, respectively); older people have higher positivity than younger people (4.2% aged 70-74 vs. 2.3% aged 50-54); and those living in our most deprived communities have higher positivity than the least deprived (4.2% vs. 2.2%, respectively).

#### Impact of COVID pandemic on Bowel Screening Programme

The Scottish Government announced a temporary pause to screening programmes including the Bowel Screening Programme on the 30 March 2020. There were a number of factors behind this decision, primarily to reduce the risk of participants becoming infected with the virus, to facilitate social distancing and to minimise the impact on essential NHS services as they respond to COVID-19. No further screening kits were issued to participants and those already returned to the laboratory were processed and letters issued. The full assessment is in Appendix 6.2

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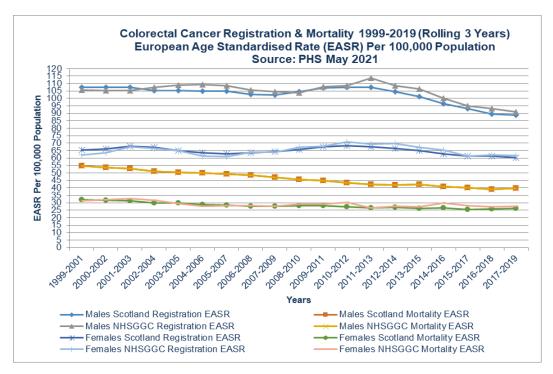
#### 6.1. Background

Colorectal (Bowel) Cancer is the third most common cancer in Scotland for both men and women accounting for 12% of all cancers <sup>4</sup>. There were 4,166 people diagnosed with colorectal cancer in Scotland in 2019. This is an increase on previous years (4,108 diagnosed in 2018 and 3,816 in 2017/18). Ninety three percent of bowel cancers detected are among people aged over 50 years of age<sup>5</sup>.

In 2019, 812 people residing in the NHSGGC area were diagnosed with bowel cancer. This gives an age-standardised incidence rate of 89.6 per 100,000 of the population for men, lower than the Scotland rate of 90.6 per 100,000. For women the age-standardised incidence rate is 66.6 per 100,000 of the population, higher than the Scotland rate of 65.5 per 100,000. In the same year, in NHSGGC an age-standardised mortality rate of 41.1 per 100,000 population for men and 28.3 per 100,000 population for women was recorded.

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 1999-2019 (Rolling 3 Years) European Age Standardised Rate (EASR) Per 100,000 Population



Source: Registration Source: PHS May 2020, Mortality Source: PHS October 2020

<sup>&</sup>lt;sup>4</sup> https://publichealthscotland.scot/media/7753/2021-05-11-cancer-incidence-report.pdf (Accessed December 2021)

<sup>&</sup>lt;sup>5</sup> https://publichealthscotland.scot/publications/cancer-mortality/cancer-mortality-in-scotland-2019/ (Accessed December 2021)

In the 10 year period between 2009 and 2019, the age-standardised incidence rate of bowel cancer in Scotland decreased in both men (107.4 to 90.8 per 100,000) and women (67.6 to 62.9 per 100,000). Mortality rates of bowel cancer in Scotland decreased in men (from 42.4 to 40.6 per 100,000), however there was a slight increase in mortality rates in women (26.6 to 28.6 per 100,000).

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>6</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>7</sup> and National Bowel Screening Standards<sup>8</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

<sup>&</sup>lt;sup>6</sup> https://www.isdscotland.org/Health-Topics/Cancer/Publications/2019-04-30/Cancer in Scotland summary m.pdf (Accessed November 2021)

<sup>&</sup>lt;sup>7</sup> Scottish bowel screening programme statistics - For the two-year period of invitations between May 2018 and March 2020 - Scottish bowel screening programme statistics - Publications - Public Health Scotland (Accessed December 2021)

<sup>&</sup>lt;sup>8</sup>http://www.healthcareimprovementscotland.org/our work/cancer care improvement/programme reso urces/bowel screening standards.aspx (Accessed December 2021)

for population-wide colorectal cancer screening by the European Guidelines for Quality Assurance in Colorectal Cancer Screening<sup>9</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 this gives it higher user acceptability. FIT is more accurate at detecting cancers and also better at determining patients who are unlikely to have cancer.

Figure 6.2 provides an overview of the bowel screening pathway.

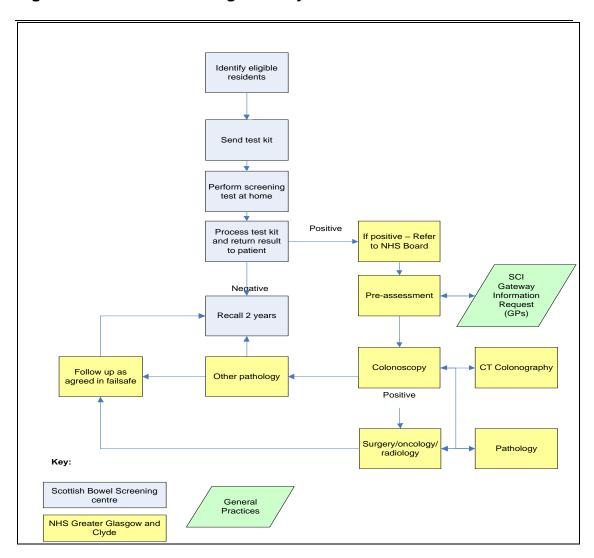


Figure 6.2: Bowel Screening Pathway

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

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<sup>&</sup>lt;sup>9</sup> https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4482205/ (accessed November 2021)

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. 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.

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.

## 6.5. Overall 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.

Public Health Scotland publish Scottish Bowel Screening Programme Statistics annually in February, relating to previous 2 year screening round. <a href="Appendix 6.1">Appendix 6.1</a> summarises reported the most recent published KPIs for NHSGGC and Scotland for time period **1st March 2018 to 30 April 2020**.

Figure 6.3 summarises bowel screening activity and outcomes for the screening round 1<sup>st</sup> April 2019 to 31<sup>st</sup> March 2021 from local analysis, which is based on NHSGGC resident population only.

During this time period, 292,420 NHSGGC residents were invited for bowel screening. Over half (59.6%) of those invited returned the screening test, of which 5,147 tested positive (3.0%). Of those individuals who had a positive result, 4,652 (90.3%) accepted a nurse pre-assessment and over three quarters 3,674 (78.9%) had a colonoscopy performed. Subsequently, 165 cancers and 1,734 adenomas were detected.

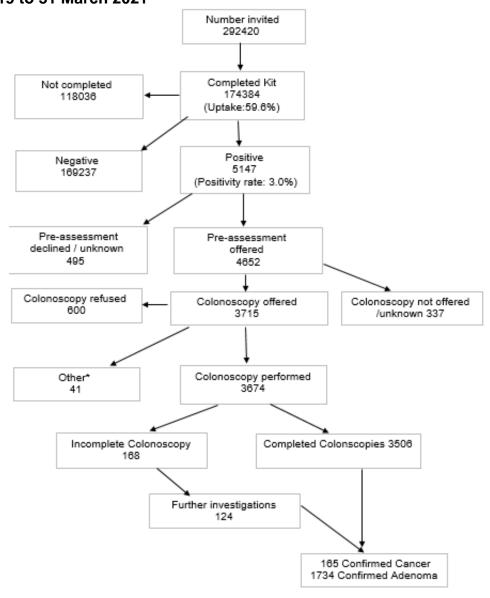


Figure 6.3: NHSGGC Eligible Residents Bowel Screening Activity 1 April 2019 to 31 March 2021

Source: NHS Greater Glasgow and Clyde Bowel Screening IT System, Pathology, Cancer Audit (Extracted: November 2021)

#### 6.6. Uptake of Screening

Local analysis was undertaken to explore variations in uptake by sex, age, deprivation, ethnicity and by Health and Social Care Partnership (HSCP) area.

Overall, uptake of bowel screening was 59.6%, less than national standard of 60%. Women were more likely to return a bowel screening test than men (62.1% vs. 57.2% respectively). (Table 6.1). However, uptake continues to increase following the implementation of FIT in 2017. This increase is

<sup>\*</sup> Clinical decision, DNA, deceased, no reason given

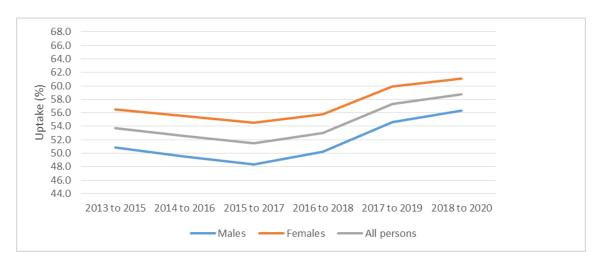
observed in both men and women, though uptake remains lower in men (Figure 6.4).

Table 6.1: Uptake of bowel screening by sex in NHSGGC, 2019-2021

Sex	Not Screened	Screened	Total	% Screened
Female	55,957	91,503	147,460	62.1
Male	62,079	82,881	144,960	57.2
Total	118,036	174,384	292,420	59.6

Source: Bowel Screening IT system (November 2021)

Figure 6.4: Uptake of Bowel Screening in NHSGGC 2013-2020 by sex



Source: Public Health Scotland Bowel Screening Annual Programme Statistics (February editions)

There was progressively greater uptake of bowel screening with increasing age **(Table 6.2).** Uptake was lowest among those aged 50-54 years, at 53.2% and increased to 66.7% between 70 and 74 years, a difference of 13.5%.

Table 6.2 Uptake of bowel screening by age in NHGGC, 2019-2021

Age Group	Not Screened	Screened	Total	% Screened
50-54	39,835	45,237	85,072	53.2
(50-52)	15,933	17,978	33,911	53.0
55-59	23,517	30,398	53,915	56.4
60-64	25,908	40,580	66,488	61.0
65-69	14,582	29,757	44,339	67.1
70-74	14,194	28,412	42,606	66.7
Total	118,036	174,384	292,420	59.6

Source: Bowel Screening IT system (November 2021)

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 (50.6%) and highest in the least deprived areas (69.6%).

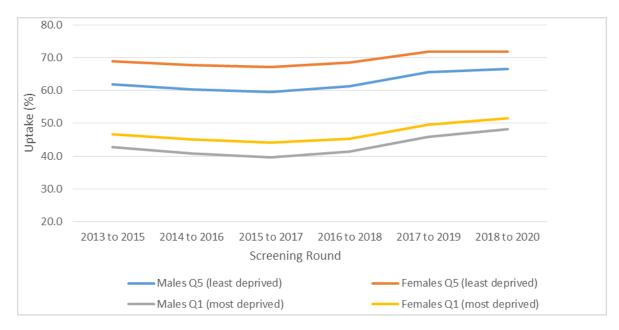
Table 6.3: Uptake of bowel screening by SIMD in NHS Greater Glasgow and Clyde, 1 April 2019 to 31 March 2021

SIMD Quintile 2016	Not Screened	Screened	Total	% Screened
1 (Most Deprived)	47,740	48,968	96,708	50.6
2	21,926	29,567	51,493	57.4
3	14,073	22,535	36,608	61.6
4	14,722	28,569	43,291	66.0
5 (Least Deprived)	19,575	44,745	64,320	69.6
Total	118,036	174,384	292,420	59.6

Source: Bowel Screening IT system (November 20

Following the implementation of FIT, there has also been an increase in uptake across all SIMD deprivation quintiles, though lowest uptake continues to be observed in the most deprived areas (Figure 6.5).

Figure 6.5: Uptake of bowel screening in NHSGGC 2013-2020 by most and least deprived SIMD quintile



Source: Public Health Scotland Bowel Screening Annual Programme Statistics (February editions)

Uptake of screening target 60% was achieved in the White British groups 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, 1 April 2019 to 31 March 2021

	Not			%
2001 Census Ethnic Group	Screened	Screened	Total	Screened
White - British	94,014	148,614	242,628	61.3
White - Irish	10,953	15,784	26,737	59.0
White – Any Other Background	4,081	3,541	7,622	46.5
Asian or Asian British – Indian	1,398	1,033	2,431	42.5
Asian or Asian British – Pakistani	3,193	2,016	5,209	38.7
Asian or Asian British –				
Bangladeshi	152	109	261	41.8
Asian or Asian British – Any other				
Asian	95	56	151	37.1
Black of Black British	≤5	≤5	8	37.5
Black or Black British – African	548	401	949	42.3
Other Ethnic Groups - Chinese	984	1,062	2,046	51.9
Other Ethnic Groups – Any Other				
Ethnic Group	1,916	1,348	3,264	41.3
Unclassified	697	417	1,114	37.4
Total	118,036	174,384	292,420	59.6

Source: Bowel Screening IT system (November 2021); OnoMap Numbers ≤5 redacted as per ISD statistical disclosure control protocol

Variations in bowel screening uptake across HSCPs persist **(Table 6.5).** They range from 54.0% in Glasgow City North East Sector to 68.8% in East Dunbartonshire HSCP. Only four 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 57.3% to 62.1%). 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 2019-21 screening round.

Table 6.5: Indirectly Standardised Uptake of Bowel screening by HSCP in NHS Greater Glasgow and Clyde, 2019-21

	Not	_				SUR	SUR
	Screene	Screene		%	SUR	%	%
HSCP	d	d	Total	Screened	%	LCI	UCI
East Dunbartonshire	9,533	21,050	30,583	68.8	61.9	61.1	62.7
East Renfrewshire	7,996	16,770	24,766	67.7	61.0	60.0	61.9
Glasgow North East	19,714	23,108	42,822	54.0	57.3	56.6	58.1
Glasgow North West	20,237	24,923	45,160	55.2	56.8	56.1	57.5
Glasgow South	24,539	29,688	54,227	54.7	57.9	57.2	58.5
(Glasgow City)	64,490	77,719	142,209	54.7	57.4	57.0	57.8
Inverclyde	8,426	13,796	22,222	62.1	62.1	61.1	63.1
Renfrewshire	17,820	29,972	47,792	62.7	60.6	60.0	61.3
West							
Dunbartonshire	9,771	15,077	24,848	60.7	61.8	60.9	62.8
Total	118,036	174,384	292,420	59.6			

Source: Bowel Screening IT system (November 2021)

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

### 6.7. Screening Test Positivity

Overall 3.0% (5,147 of 292,420) of completed screening test were reported positive, meriting further investigation in period 2019-2021. Women have a lower positivity than men (2.4% vs. 3.6 %, respectively); older people have higher positivity than younger people (4.2% aged 70-74 vs. 2.3% aged 50-54) and those living in our most deprived communities have higher positivity than the least deprived (4.2% vs. 2.3%, respectively) **(Tables 6.6 and 6.7).** 

Table 6.6: Uptake for Bowel screening and positivity rate by age and sex for NHS Greater Glasgow and Clyde, 1 April 2019 to 31 March 2021

		% Screened	% Positive				
Age Group	Male	Female	Total	Male	Female	Total	
50-54	49.8	56.8	53.2	2.7	2.1	2.3	
55-59	53.3	59.4	56.4	3.0	2.0	2.5	
60-64	58.8	63.2	61.0	3.4	2.3	2.8	
65-69	65.9	68.3	67.1	4.3	2.4	3.3	
70-74	66.5	66.9	66.7	5.2	3.3	4.2	
Total	57.2	62.1	59.6	3.6	2.4	3.0	

Source: Bowel Screening IT system (November 2021)

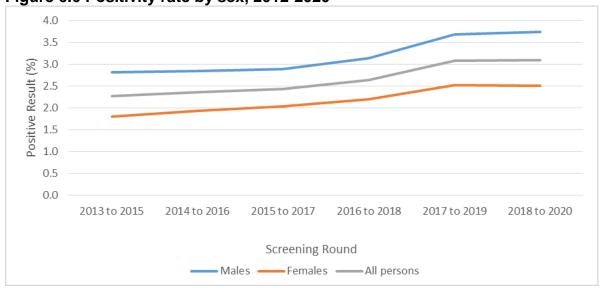
Table 6.7: Bowel screening positivity rate by SIMD for NHS Greater Glasgow and Clyde, 1 April 2019 to 31 March 2021

SIMD Quintile 2016	Negative	Positive	Total	% Screened
1 (Most Deprived)	46,998	1,970	48,968	4.0
2	28,628	939	29,567	3.2
3	21,903	632	22,535	2.8
4	27,852	717	28,569	2.5
5 (Least Deprived)	43,856	889	44,745	2.0
Total	169,237	5,147	174,384	3.0

Source: Bowel Screening IT system (November 2020)

The increased sensitivity of the new FIT test in 2017 consequently led to an increase in the percentage of people with a positive test result (Figure 6.6).

increase in the percentage of people with a positive test result (Figure 6.6). Figure 6.6 Positivity rate by sex, 2012-2020



Source: Public Health Scotland Bowel Screening Annual Programme Statistics (February editions)

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.

#### 6.8. Adenoma and Polyp Detection

Of the 6,916 people who had a positive screening test, 3,684 people underwent a colonoscopy. Of these, 2,151 people (58.4%) had a polyp detected, 1,734 people (47.4%) had a confirmed adenoma detected and 165 (4.5%) people had a confirmed colorectal cancer diagnosis (**Table 6.8**).

Table 6.8: Adenoma and polyp detection rate by age and gender in NHSGGC, 2017-2019 (M=Male; F=Female)

	Patients having investigations* performed		tions* % Polyps Detected			% Adenomas Detected			% Cancer Detected			
Age Group	М	F	Total	М	F	Total	М	F	Total	М	F	Total
50-54					13			10				
	430	345	775	245	9	384	199	9	308	11	6	17
55-59					10							
	314	246	560	200	3	303	161	74	235	12	≤5	16
60-64					18			14				
	485	363	848	319	5	504	263	7	410	24	22	46
65-69					13			10				
	430	265	695	300	9	439	245	1	346	26	17	43
70-74					17			14				
	478	328	806	348	3	521	291	4	435	30	13	43
Total		1,54	3,68		73		1,15	57	1,73	10		
	2,137	7	4	1,412	9	2,151	9	5	4	3	62	165

Source: Bowel Screening IT system (November 2021)

Numbers ≤5 redacted as per ISD statistical disclosure control protocol

**Table 6.9** shows the proportion of polyps identified at colonoscopy and the adenoma pathology diagnosis. 66.1% of men and 47.8% of women who underwent colonoscopies had polyps detected. Adenomas were diagnosed in 54.2% of men and 37.2% of women, 4.8% of men and 4.0% of women had a confirmed cancer diagnosis.

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 6.9: Polyp, Adenoma and Cancer detection rate by SIMD and gender in NHSGGC, 2019-2021 (M=Male; F=Female)

	Patients having investigations* performed			Poly	% % % % Polyps Detected Adenomas Detected Cancer Detected									etected
SIMD Quintile 2016	М	F	Total	М	F	Total	М	F	Total	M	F	Total		
1 (Most Deprive d														
	798	573	1371	70.3	49.4	61.6	57.0	39.4	49.7	3.9	3.1	3.6		
2	383	291	674	66.6	47.8	58.5	55.1	36.4	47.0	3.9	4.1	4.0		
3	250	196	446	64.4	49.5	57.8	54.8	38.8	47.8	6.8	4.6	5.8		
4	320	217	537	63.1	44.2	55.5	50.3	32.7	43.2	5.3	4.6	5.0		
5 (Least Deprive d	386	270	656	60.4	45.9	54.4	50.5	35.6	44.4	6.0	4.8	5.5		
Total	2137	1547	3684	66.1	47.8	58.4	54.2	37.2	47.1	4.8	4.0	4.5		

Source: Bowel Screening IT system (November 2021) \* Colonoscopy or other investigation

Data presented in **Table 6.10** shows the Dukes staging of the 165 people who had a confirmed colorectal cancer diagnosis.

Table 6.10: Dukes stage of colorectal cancel for NHSGGC, 2019-21

<b>DUKES Staging</b>	Number	%
Α	55	33.3
В	38	23.0
C1	20	12.1
C2	≤5	1.8
D	≤5	2.4
Unknown	45	27.3
Total	165	

Source: Local Cancer Audit, November 2021

Numbers ≤5 redacted as per ISD statistical disclosure control protocol

#### 6.9. Quality Improvement in Colonoscopy

The Public Health Screening Unit leads a programme of bowel screening audit, focusing 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 also being audited.

#### 6.10. 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 2019/2021. A significant amount of work was undertaken to increase screening colonoscopy capacity, reducing waiting times now less than 21 days in 2019. However due to the pause in screening due to COVID 19 and associated restrictions, there is significant pressure on the service for both pre-assessment and colonoscopy procedures.

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

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

Appendix 6.1

Key Performance Indicators: November 2020 data submission Invitations between 1 May 2018 to 30 April 2020

KPI	Key Performance: Indicator Description	Target	Scotland %	NHSGCC %								
Scree	Screening Uptake											
1.	Overall uptake of screening - percentage of people with a final outright screening test result, out of those invited.	60%	63.2%	58.7%								
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) quintile 1 (Q1 most deprived) to quintile 5 (Q5 least deprived)	60%	Q1 51.1% Q2 58.6% Q3 64.5% Q4 68.4%	Q1 49.8% Q2 56.8% Q3 61.1% Q4 65.8%								
3.	Percentage of people with a positive test result, out of those with a final outright screening test result.	N/A	71.8% 2.83%	69.3% 3.1%								
Refer	ral, 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	28.3% 28.0% 43.6%	14.2% 16.9% 69.0%								
5.	Percentage of people with a positive screening test result going on to have a colonoscopy performed.	N/A	73.0%	69.0%								
6.	Percentage of people having a completed colonoscopy, out of those who had a colonoscopy performed.	90%	94.9%	96.1%								
7.	Percentage of people requiring admission for complications arising directly from the colonoscopy, out of those who had a colonoscopy performed.	N/A	0.29%	0.13%								
8.	Percentage of people with colorectal cancer, out of those with a final outright screening test result.	N/A	0.114%	0.121%								
9-14.	Percentage of people with colorectal cancer staged:  9. Dukes' A. 10. Dukes' B.	N/A	36.7% 22.6% 26.5%	35.4% 24.3% 26.2%								

	11*. Dukes' C (includes 12 – previously C2) 13. Dukes' D. 14. Dukes' Not known.		7.0% 7.2%	9.5% 4.6%
45				
15 <b>–</b> 16.	Percentage of people with colorectal cancer 15. Where the stage has not yet been supplied. 16. That has a recorded stage.	N/A	0% 100%	0% 100%
17.	Percentage of people with polyp cancer out of those with a final outright screening test result.	N/A	0.020%	0.004%
18.	Percentage of people with polyp cancer, out of those with colorectal cancer.	N/A	17.3%	3.0%
19.	Percentage of people with adenoma as the most serious diagnosis, out of those with a final outright screening test result.	N/A	0.947%	0.970%
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	0.150%	0.142%
21.	Positive Predictive Value of current screening test for colorectal cancer.	N/A	5.4%	5.2%
22.	Positive Predictive Value of current screening test for adenoma as the most serious diagnosis.	N/A	45.5%	45.3%
23.	Positive Predictive Value of current screening test for high risk adenoma as the most serious diagnosis.	N/A	7.2%	6.6%
24.	Positive Predictive Value of current screening test for high risk adenoma as the most serious diagnosis or colorectal cancer.	N/A	12.6%	11.8%
25.	Positive Predictive Value of current screening test for adenoma as the most serious diagnosis or colorectal cancer.	N/A	50.9%	50.5%
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	68.9% 3.4% 27.5%	70.3% -% 29.7%

Source: <a href="https://beta.isdscotland.org/find-publications-and-data/conditions-and-diseases/cancer/scottish-bowel-screening-programme-statistics/">https://beta.isdscotland.org/find-publications-and-data/conditions-and-diseases/cancer/scottish-bowel-screening-programme-statistics/</a> (Accessed November 2021)

#### Appendix 6.2

#### **Scottish Bowel Screening Programme**

The Scottish Bowel Screening Programme issues bowel screening kits to all eligible men and women aged 50 to 74 years of age across Scotland and for those over 75 years who self-refer into the programme. The kits are completed at home and returned to a central laboratory for testing.

## Reasons why screening programme may need to be paused:

- Royal Mail decision made to stop circulation of mail (incoming/outgoing).
- Re-allocation of screening programme staff (26) to support other essential services within Boards e.g. laboratory staff assist in higher priority laboratories.
- Availability of service staff to operate the programme should there be outbreak, may lead to significant delays to testing therefore more feasible to pause programme to allow restart/retest.
- Colonoscopy services may not be fully available should Boards reduce/pause elective procedures.

#### **Considerations:**

- Kits issued timing /return timescales
  - For kits already in participant's homes, the participant has the expiry time of the actual tube to respond. This is an approximately 2 years.
- Processing of returned kits how long sample last?
  - The samples are stable for <14 days at room temperature and 120 days at 4°C and longer than that frozen. The Bowel Screening Laboratory does not have the storage capacity to store more than a few days of samples so long-term storage i.e. more than a week is not feasible.
- Continuation of processing kits within the system.
- Onward clinical referral and care pathways agreed to minimise impact on essential services.
- Additional Helpline measures to implement to update participants contacting the service
- 3rd party suppliers of services e.g. Mailing / IT system impacted resulting in reduced support for programme.
- Required communications with screening population /Board Coordinators/key stakeholders as to halt to service and impact.
- Timing and lead in time for re-instatement of programme and action plans given delay to service. Start-up procedures/impact to be considered after short term or long term pause to programme.
- Change to participants recall date on BOSS (IT System).

#### Risks:

#### Risks for continuing

- Risk of diagnosed patients not being able to access colonoscopy services (which already have workload pressures) if elective procedures are paused by the host NHS Boards (this is already happening in some Boards) (High Risk)
- Increased anxiety in diagnosed patients if significant increased delay to colonoscopy services.
- Possible contamination of kits. Highest risk of infection are those that have faecal

- material inside the envelope and / or on the outside of the tube. These are segregated from the routine workload.
- Aerosol risk as sample tubes are pierced on the top of the tube. To minimise the
  risk of air borne particles, tubes are being carefully tipped into bags after testing
  and tubes are being left for approx 10 minutes after coming off analysers to allow
  settling and minimise risk. Low risk.

#### Risks for pausing

- Delay to 24month screening cycle. Risk that participant will miss their last screening round.
- Potential delay to diagnosis of bowel cancer or significant bowel disease.
- Financial risk.
- Reputational risk.

#### Recommendation:

- Proceed to pause the Screening Programme immediately in order to reduce pressure on colonoscopy services and prevention of raised anxiety in diagnosed patients.
- This will allow laboratory staff to be redeployed by NHS Tayside on critical COVID 19 work as appropriate whilst completing the current workload in the system.

#### Appendix 6.3

#### Members of Bowel Screening Steering Group (At March 2020)

Dr Emilia Crighton Deputy Director of Public Health (Chair)

Dr Stuart Ballantyne Lead Clinician for Radiology

Ms Carol Beckwith CRUK

Mr Paul Burton Information Manager

Mrs Lin Calderwood H&IT Service Delivery Manager

Ms Claire Donaghy CRUK

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

Ms Ailsa Forsyth Lead Nurse, GGH

Dr Rachel Green Chief of Medicine, Diagnostics

Dr Graeme Marshall Clinical Director, Glasgow HSCP, NE Sector

Dr David Mansouri Clinical Lecturer, Glasgow University

Mrs Susan McFadyen Interim General Manager
Ms Joyce McFadyen Health Records Site Manager

Mr Calum McGillivray Programme Support Officer, Screening Dept

Mrs Tricia McKenna Colorectal Nurse Endoscopist Natalie McMillan Clinical Service Manager

Ms Gill Mitan Administration Manager, North Sector

Mr John Mooney CPHM, NHS Highland

Dr John Morris Consultant Physician and Gastroenterologist

Mrs Uzma Rehman Public Health Programme Manager Mr Michael Reilly Business Analyst Project Lead

Mrs Elizabeth Rennie Programme Manager, Screening Dept

Dr Andrew Renwick Consultant, RAH

Ms Heather Richardson Clinical Service Manager Nicola Schinaia Consultant, Highland

Mr Greig Thomson CRUK

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

Mr Paul Witherspoon Consultant Surgeon

## **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 2019, 1,047 new breast cancers were registered among women residing in NHSGGC. This gives an age-standardised incidence rate of 175.4 per 100,000 per population, as compared with the Scotland rate of 167.1 per 100,000. In 2019, 205 women with a diagnosis of breast cancer died in NHSGGC, giving a standardised mortality rate of 34.1 per 100,000 population, comparable with the Scotland rate of 33.0 per 100,000<sup>10</sup>.

During 2015-2016, the Scottish Breast Screening Programme implemented a new Scottish Breast Screening System (SBSS) IT system. Public Health Scotland publishes annual programme statistics 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 were screened on client request until the breast screening pause during COVID. To date this has not been reinstated nationally.

The percentage of women eligible for breast screening and uptake for the period 2016/17 and 2018/19 was 66.7%, this is lower than the national uptake of 72.3% and acceptable and achievable standard of 70%. From August 2020 to June 2021, 44,632 women were invited and 32,637 attended which is 73%.

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 Officers 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 recommendations from the Scottish Government's review of the Scottish Breast Screening Programme during 2019/2020 will be available in 2021.

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<sup>&</sup>lt;sup>10</sup> https://publichealthscotland.scot/publications/scottish-breast-screening-programme-statistics/scottish-breast-screening-programme-statistics-annual-update-to-31-march-2019/

## **COVID Pandemic and impact on Breast Screening**

In response to COVID-19, risks assessments were drawn up for each of the national screening programmes outlining points of consideration and the risks associated with both continuing screening and ceasing screening. The Scottish Government announced on the 30<sup>th</sup> March 2020 a temporary pause to a number of screening programmes including the Breast Screening Programme. The assessment is in Appendix 7.1

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### 7.1. Background

Breast cancer is the most common cancer in women in Scotland, accounting for 28.1% of all new cancers diagnosed in women.

In 2019, 1,047 new breast cancers were registered among women residing in NHSGGC. This gives an age-standardised incidence rate of 175.4 per 100,000 per population, as compared with the Scotland rate of 167.1 per 100,000. In 2019, 205 women with a diagnosis of breast cancer died in NHSGGC, giving a standardised mortality rate of 34.1 per 100,000 population, comparable with the Scotland rate of 33.0 per 100,000<sup>11</sup> (**Figure 7.1**).

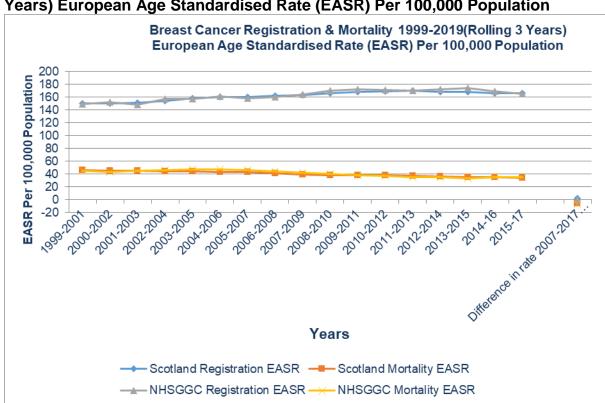


Figure 7.1: Breast Cancer Registration & Mortality 1999-2019 (Rolling 3 Years) European Age Standardised Rate (EASR) Per 100,000 Population

### 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

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<sup>&</sup>lt;sup>11</sup> https://publichealthscotland.scot/publications/scottish-breast-screening-programme-statistics/scottish-breast-screening-programme-statistics-annual-update-to-31-march-2020/

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 about whom the screening programme is made aware, 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 2019/2020. A final report will be published in late 2021.

### 7.3. Programme Monitoring

The Scottish Breast Screening Programme (SBSP) delivery and quality is monitored against key programme statistics<sup>12</sup> and (new) National Breast Screening Service Standards<sup>13</sup>.

The latest report for Scotland is presented below in **Table 7.1**; this data was not available by Health Board level.

<sup>&</sup>lt;sup>12</sup> https://publichealthscotland.scot/publications/scottish-breast-screening-programme-statistics/scottish-breast-screening-programme-statistics-annual-update-to-31-march-2019/

<sup>&</sup>lt;sup>13</sup> https://publichealthscotland.scot/publications/scottish-breast-screening-programme-statistics/scottish-breast-screening-programme-statistics-annual-update-to-31-march-2019/

Table 7.1: Scotland: Health Improvement Scotland Breast Screening Standards 2019-20. This data was not available by NHS Board.

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Standard	Appointment type <sup>3</sup>	Age group	Acceptable Standard	Achievable Standard	Results 2019/20
Attendance rate (percentage of women invited)	All routine appointments	50-70 years	>= 70%	>=80%	72%*
Invasive cancer detection rate (per	Routine- Initial screen (Prevalent) in response to first invitation	50-52 years	>= 2.7	>= 3.6	6.6*
1000 women screened)	Routine- Subsequent screen (Incident) (previous screen within 5 years)	53-70 years	>= 3.1	>= 4.2	6.5*
Small (<15mm) invasive cancer detection rate (per	Routine- Initial screen (Prevalent) in response to first invitation	50-52 years	>= 1.5	>= 2.0	2.7*
1000 women screened)	Routine- Subsequent screen (Incident) (previous screen within 5 years)		>= 1.7	>= 2.3	3.5*
Non-invasive cancer detection rate (per	Routine- Initial screen (Prevalent) in response to first invitation	50-52 years	>= 0.5	-	1.5*
1000 women screened)	Routine- Subsequent screen (Incident) (previous screen within 5 years)	53-70 years	>= 0.6	-	0.9*
Standardised Detection Ratio (SDR) (observed invasive cancers detected divided by the number expected given the age distribution of the population)	Routine-All initial screens (Prevalent) and Subsequent screen (Incident) (previous screen within 5 years)	50-70 years	>= 1.0	>= 1.4	1.47*
Recalled for assessment rate	Routine- Initial screen (Prevalent) in response to first invitation	50-52 years	<10%	<7%	7.1%*
(percentage of women screened)	Routine- Subsequent screen (Incident) (previous screen within 5 years)	53-70 years	<7%	<5%	2.9%*
Benign biopsy rate (per 1000 women	Routine- Initial screen (Prevalent) in response to first invitation	50-52 years	< 1.5	< 1.0	1.8*
screened)	Routine- Subsequent screen (Incident) (previous screen within 5 years)	53-70 years	< 1.0	< 0.75	0.4*

<sup>&</sup>lt;sup>1</sup> Health Improvement Scotland Breast Screening Standards 2019.

Source: <a href="https://publichealthscotland.scot/publications/scottish-breast-screening-programme-statistics/scottish-breast-screening-programme-statistics-annual-update-to-31-march-2019/">https://publichealthscotland.scot/publications/scottish-breast-screening-programme-statistics/scottish-breast-screening-programme-statistics-annual-update-to-31-march-2019/</a>

<sup>&</sup>lt;sup>2</sup> Breast Screening year runs from 1st April to 31st March.

<sup>&</sup>lt;sup>3</sup> Routine appointments exclude self/GP referral appointments.

<sup>\*</sup> Met acceptable standard

### 7.4. The Screening Test and Pathway

The screening method used consists of two mammographic views of each breast. The test is a straightforward procedure involving two images being taken of each breast using an X-ray machine (also known as a mammogram). Adaptations and/or extra views are captured for augmented breasts including breast implants and implantable devices.

The WoSBSS screens NHSGGC residents in either the static facility in Nelson Mandela Place or, in the majority of cases, in one of the 7 mobile units that visit pre-established sites across the NHSGGC area to ensure ease of local access for women. 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 2020/21 screening round, the service has been active in NHSGGC areas detailed in **Table 7.2**.

Table 7.2: 2020/2021 screening locations for NHSGGC residents

HSCP	Mobile Unit	Static (Nelson Mandela Place)
East Dunbartonshire	Bishopbriggs, Kirkintilloch	N/A
East Renfrewshire	Barrhead	Newton Mearns, Clarkston, Crookfur
Glasgow City	Govan, Toryglen	Clarkston, Shawlands, Toryglen, Towhead, Thornwood, Charing Cross, Pollokshields ,Hyndland, Finnieston, Dowanhill, Charing Cross, Kelvingrove, Pollokshaws, Scotstoun, Partick, Yoker, Anniesland, Knightswood, Kinning Park, Maryhill
Inverclyde	Johnstone, Linwood, Bishopton	N/A
Renfrewshire	Renfrew, Paisley	N/A
West Dunbartonshire	Alexandria	N/A

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.

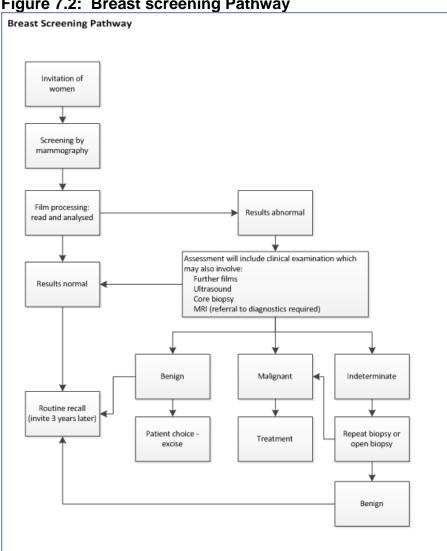


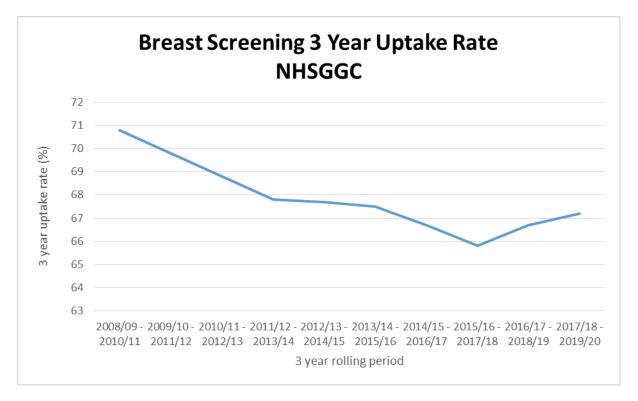
Figure 7.2: Breast screening Pathway

#### 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 2015/2016. Public Health Scotland published annual programme statistics in April 2021 for the year 2019-2020, relating to breast screening uptake and outcomes<sup>14</sup>. Uptake of breast screening has increased in the last two periods as illustrated below. (Figure 7.3).

<sup>14</sup> https://publichealthscotland.scot/publications/scottish-breast-screening-programmestatistics/scottish-breast-screening-programme-statistics-annual-update-to-31-march-2019/

Figure 7.3: Breast screening uptake by NHS Board of Residence 1st April 2008 to 31st March 2020 (females aged 50-70 years)



Source: <a href="https://publichealthscotland.scot/publications/scottish-breast-screening-programme-statistics/scottish-breast-screening-programme-statistics-annual-update-to-31-march-2019/">https://publichealthscotland.scot/publications/scottish-breast-screening-programme-statistics-annual-update-to-31-march-2019/</a>

The national SBSP statistics published in April 2021, in **Figure 7.4** shows that women from more deprived areas are less likely to attend for breast screening, with 56.6% of women from the most deprived areas going for screening compared with 77.5% of women living in the least deprived areas in NHSGGC<sup>15</sup>.

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<sup>&</sup>lt;sup>15</sup> https://publichealthscotland.scot/publications/scottish-breast-screening-programme-statistics/scottish-breast-screening-programme-statistics-annual-update-to-31-march-2019/

Breast screening percentage uptake by deprivation quintile, Scotland and NHSGGC: 2017/18 - 2019/20 90 80 70 € 60 uptake rate 50 40 30 20 10 0 SIMD 1 SIMD 2 SIMD 3 SIMD 4 SIMD 5

н.

NHSGGC

Figure 7.4: Breast Screening Uptake by Deprivation: Scotland and NHSGGC 2017/2018 to 2019/20 combined

<u>Source:</u> https://publichealthscotland.scot/publications/scottish-breast-screening-programme-statistics/scottish-breast-screening-programme-statistics-annual-update-to-31-march-2019/

Scotland

### COVID 19 - Pause in screening and uptake

Breast screening was paused from April to July 2020 due to COVID restrictions, and resumed from August 2020. **Table 7.3** shows that uptake increased between August 2018/June 2019 and Aug 2020/June 2021 from 67% to 73%.

The West of Scotland Breast Screening Service revised administration and appointment processes with the aim of improving uptake. Patients were encouraged to contact the centre and this allowed staff to discuss pandemic related changes. A courtesy call from the service 14 prior to the appointment allowed staff to encourage and engage with those who may have been reluctant to attend.

More women were also invited to attend breast screening at Nelson Mandela Place instead of mobile units within local areas of Glasgow City (outlined in Table 7.4). The service also had to deal with additional factors such as PPE and social distancing during the screening process and longer appointment times.

Table 7.3 Comparison of update pre-COVID and after restart of screening in August 2020

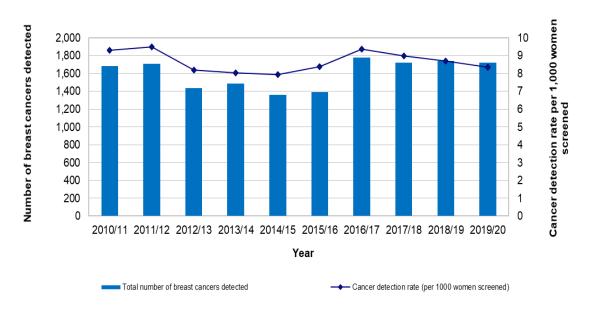
	Aug 2018/June 2019	Aug 2020/June 2021
Invites issued	60,248	44,632
Attendance	40,122	32,637
% attended	67%	73%

Source: RO70 report Aug 2021

### 7.6. Breast Screening Outcomes

The national SBSP statistics published in April 2020 noted the number of screen-detected breast cancers in women of all ages in Scotland in 2019/2020 was 1,724, a rate of 8.4 per 1,000 women screened<sup>16</sup>. This represents a slight decrease in numbers and rates compared to 2018-2019. **(Figure 7.5).** 

Figure 7.5: Trends in the number of breast cancers detected, and cancer detection rates per 1,000 women screened: Scotland, 2010/2011 to 2019/2020(All appointment types)



<sup>&</sup>lt;sup>16</sup> https://publichealthscotland.scot/publications/scottish-breast-screening-programme-statistics/scottish-breast-screening-programme-statistics-annual-update-to-31-march-2019/

### 7.7. Challenges and Future Priorities

Following difficulties faced by WoSBSS in securing accessible locations capable of accommodating the mobile units due to the pandemic, work is ongoing with NHSGGC Estates and local communities to secure future sites.

WoSBSS continue to actively monitor slippage in the system, overbooking appointments, and being sensitive to local uptake rates, the available screening appointments were optimised in 2020/21, the rate of uptake increased to 73% compared to 67% for 2018/19. The staff spoke to and encouraged more women to attend when they called to confirm/cancel their appointment.

WoSBSS has secured approval to implement new telephony within the Service which will enable SMS and telephone reminders. This will be implemented during 2021. 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 2019/2020.

### Appendix 7.1

### **Scottish Breast Screening Programme**

**Eligible Population:** Women from 50 to 71<sup>st</sup> birthday are sent a letter of invitation for breast screening every 36 months for an appointment on a mobile unit or at a screening centre

### Reasons why screening programme may need to be paused:

- Minimise the impact on essential NHS services
- Availability of service staff to screen women / operate the programme should there be outbreak
- Women may not travel/wish to attend routine screening appointments at this time
- Re-allocation of screening programme (approximately 130 clinical and 85 admin) staff to support other essential services within Boards, if they remain well
- Participants/staff travelling to centre and mobile units e.g. use of public transport
- Mobile unit locations: access to toilet facilities for staff not available as leisure facilities etc., closed given outbreak

### Considerations:

- Invitations are issued for routine screening 3 weeks in advance of appointment dates
- Invitations for further assessment are issued 1-2 weeks from resulting for an appointment
- Continuation of reading and processing of results within the system should the service be paused. This could take approximately further 2- 3 weeks.
- Continuation/triage of assessment appointments to ensure women are appropriately managed and avoid delay to diagnosis.
- Onward clinical referral and care pathways would need agreed to minimise impact on symptomatic breast service/hospital services should Boards decide to reduce / pause elective work
- Communications with population / key stakeholders as to pause to service.
- Any technical issues for SBSS IT system. Safeguard process would identify those who have not been offered screening if system paused.
- Delays will entail need for action plans / lead in times when service fully resumes.
- Additional staff / appointments / clinics may be needed when the programme resumes.

### Risks for continuing

- Onward transmission of Covid-19 to staff and otherwise well screening population by continuing to screen
- Limited staffing available to operate screening service (already staff in self isolation in addition to a known shortfall of key clinical staff e.g. radiology)
- New sites for mobile units require to be found given closure of toilet facilities on current / planned sites

### Risks for pausing

- Delay to 36 month offer of invitation
- Possible delay to diagnosis of breast cancer. It is estimated that by suspending screening for a three month period, there would be a delay in diagnosing around 368 cases of breast cancer. Even if screening continued however, significant pressures on Acute Services would delay any surgical treatment for these women.
- Limited capacity to provide additional screening when programme reinstated
- Potentially IT risks in pausing and resuming SBSS processes (yet to be assessed).

#### Recommendation:

Immediately proceed to pause invitations and cancel all issued routine breast screening appointments within 48 hours of paused decision.

Continue to result caseload within the system and review women referred for further screening assessment with onward referral/management as appropriate within Board.

The NSD Breast Review will proceed as long as staff are available within NSD, however, a reduction in available resource may cause a pause to the review. This will be kept under consideration.

### Appendix 7.2

### **Members of Breast Screening Steering Group (At March 2020)**

Dr Emilia Crighton Deputy Director of Public Health (Chair)
Celia Briffa-Watt Public Health Specialist, NHS Lanarkshire

Paul Burton Information Manager

Lin Calderwood National Portfolio Programme Manager, National

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Dr Aileen Holliday Clinical Effectiveness Coordinator, NHS Forth Valley

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

### **Summary**

Cervical cancer was the eleventh most common cancer in females in 2019 in Scotland but also the most common cancer in women under the age of 35 years. In 2019, 92 new cervical cancers were registered among NHSGGC residents. This gives an age-standardised incidence rate of 14.8 per 100,000 population, comparable to the Scotland rate of 12.7 per 100,000. In the same year, 18 women who had a diagnosis of cervical cancer died in NHSGGC, giving a standardised mortality rate of 3.0 per 100,000 population lower than the Scotland rate of 3.5 per 100,000.

Cervical screening is offered to anyone with a cervix aged between 25 and 64 years. HPV testing replaced cervical cytology as the primary test in April 2020. Cytology-based tests will be used if high-risk HPV is found in the sample. A person's pathway and subsequent follow-up will differ according to the test results. If no high-risk HPV is found, the person has a very low risk of developing cervical cancer within 5 years. They are therefore invited for their next routine cervical screening appointment in 5 years' time, regardless of their age.

Uptake in NHSGGC for 2020/21 was 64.5% against a target of 80%, a total of 221,805 women being adequately screened within the specified period. Uptake is poorest among women aged between 25 and 29 (48.2%), and among women from ethnic minorities (for Chinese women it was 24.4%). Uptake for women living in the least deprived areas was 70.5% compared with 62.1% 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 2020/21processed 87,738 cervical screening tests and 20,820 cytology tests.

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 2020, 20 of 52 (38.4%) women diagnosed with invasive cervical cancer had a complete smear history compared to 26 (50%) women who had incomplete smear histories. The smear history for the remaining 6 cases (12%) was 'not applicable' or 'not known'.

### **COVID Pandemic and impact on Cervical Screening**

In response to COVID-19, risks assessments were drawn up for each of the national screening programmes including Cervical Screening and the implementation of HPV testing. (Appendix 8.3 and Appendix 8.4)

On the 30<sup>th</sup> March 2020, The Scottish Government announced a temporary pause for Cervical Screening. There were a number of factors behind this

decision, primarily to reduce the risk of participants becoming infected with the virus, to facilitate social distancing and to minimise the impact on essential NHS services as they respond to COVID-19.

For cervical screening no more prompts and reminders were sent to participants and both primary care and other clinics stopped taking samples. Results for those participants who had been screened before the pause continued to be processed. NHS Boards managed Colposcopy referrals appropriately.

HPV Primary Testing was implemented as planned on the 30<sup>th</sup> March 2020 and samples taken after restart were tested for HPV.

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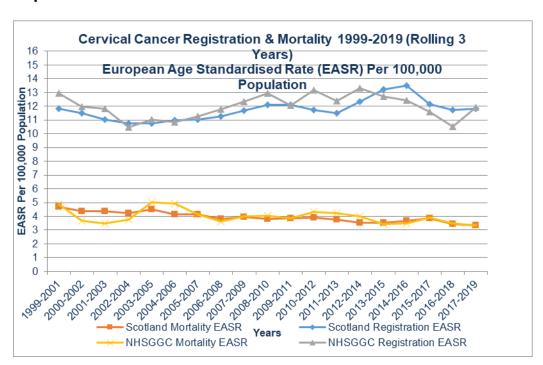
### 8.1. Background

Cervical cancer was the eleventh most common cancer in females in 2019 in Scotland and most common cancer in women under the age of 35 years<sup>17</sup>. In 2019, the most recent year for which completed data is available<sup>18</sup>, 355 women were diagnosed with cervical cancers (cancer of the cervix uteri) in Scotland, giving an age standardise rate of 12.7 per 100,000. This is an increase on previous years.

In 2019, 92 new cervical cancers were registered among NHSGGC residents. This gives an age-standardised incidence rate of 14.8 per 100,000 population. In the same year, 18 women with a diagnosis of cervical cancer died.

Standardised incidence and mortality rates over rolling 3 year periods for cervical cancer for NHSGGC and Scotland are illustrated in **Figure 8.1**.

Figure 8.1: Cervical Cancer Registration & Mortality 1999-2019 (Rolling 3 Years) European Age Standardised Rate (EASR) Per 100,000 Population



Source: Registration Source: PHS May 2020, Mortality Source: PHS October 2020

<sup>&</sup>lt;sup>17</sup> Cancer Incidence and Prevalence in Scotland (to December 2019) (publichealthscotland.scot) (accessed December 2021)

<sup>&</sup>lt;sup>18</sup>https://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Female-Genital-Organ/#cervix data extracted March 2019 (accessed August 2021)

### 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 usually occur over a period of 10 to 20 years through HPV infection 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. Cervical Screening Programme and Eligible Population

Cervical screening is offered to anyone with a cervix aged between 25 and 64 years. HPV testing replaced cervical cytology as the primary test in April 2020. Cytology-based tests will be used if high-risk HPV is found in the sample. A person's pathway and subsequent follow-up will differ according to the test results. If no high-risk HPV is found, the person has a very low risk of developing cervical cancer within 5 years. They are therefore invited for their next routine cervical screening appointment in 5 years' time, regardless of their age.

### 8.4. Programme Monitoring

The national cervical screening programme delivery and quality is monitored against key programme statistics<sup>19</sup> and National Cervical Screening Standards<sup>20</sup>. The uptake of cervical screening is monitored using two different methods to define the eligible population:

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

<sup>&</sup>lt;sup>19</sup> https://www.isdscotland.org/Health-Topics/Cancer/Publications/2019-09-03/2019-09-03-Cervical-Screening-Report.pdf (accessed August 2021)

<sup>&</sup>lt;sup>20</sup>Cervical screening standards (healthcareimprovementscotland.org)

### 8.5. The HPV Screening Test and Pathway

Appendix 8.1 provides a summary of the HPV screening pathway. 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.

HPV testing is performed on the liquid-based cytology (LBC) sample that is taken when a woman attends for cervical screening. The HPV test is the initial test performed on all cervical screening samples. Those testing HPV negative will require no further testing. Samples testing positive for HPV will be forwarded for LBC processing to produce a cytology slide.

Cytology slides undergo a full cytological examination as well as internal quality control by rapid preview or rapid review. Samples considered potentially abnormal will be examined by checkers and forwarded to a Cytopathologist for reporting as necessary. Cytology results must be reported together with the HPV test results in a combined screening report from the cytology laboratory.

The Scottish Cervical Call Recall System (SCCRS) provides a complete ehealth record detailing smear history which professionals involved with the screening programme access. Results are automatically available for the smear takers to view in SCCRS and patients are sent notification directly from Scottish Cervical Call Recall System.

The system also produces individual, and practice performance automated reports. The National Colposcopy Clinical Information Audit System (NCCIAS) is used by colposcopy staff for the clinical management and audit of all colposcopy referrals.

### 8.6. HPV Vaccination

Since 2008, all girls aged 11 to 13 years in their second year of secondary school are routinely offered vaccinations to protect them against the Human Papilloma Virus (HPV). The purpose of the HPV immunisation programme is to protect girls from the two types of HPV that cause around 75% of cases of cervical cancer. The HPV vaccine does not protect against all cervical cancers, so regular cervical screening is still important.

In 2020/21, 67.1% of women aged 24-29 years had a full HPV immunisation record compared to 64.8% with an incomplete immunisation status. 26.7% had no HPV immunisation. **Table 8.1** 

Table 8.1: Cervical Screening by Health Board and HPV Immunisation status: 1 April 2020 to 31 March 2021. Percentage uptake of females who had a record of a previous screening test taken within the last 3.5 years by age

	HPV Immunisation status (Full¹)  Age						HPV Immunisation status (Incomplete <sup>1</sup> )  Age							
NHS Board of Residence	24	25	26	27	28	29	24-29	24	25	26	27	28	29	24-29
Scotland	40.9	61.7	68.9	72.0	73.3	76.1	68.2	34.4	45.7	57.8	66.7	67.4	71.0	65.3
Greater Glasgow & Clyde	40.2	60.7	67.2	71.2	72.2	75.0	67.1	27.5	39.7	60.7	66.8	68.1	68.3	64.8

Source: Scottish

- 1. The Immunisation Status of FULL is where the individual has been Fully Immunised, i.e. had all HPV doses.
- 2. Incomplete is where the individual has had at least one of the Immunisations but not all of them.
- 3. Based on SCCRS population denominator (excluding medically ineligible women) ages 23-28.

### 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 2016/2017 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;
- The performance of screening tests on women who have agreed to participate in the Programme;
- Arranging for women to be informed of the results of the test; and
- Ensuring the test results are followed up appropriately.

'Additional Services' remains part of the new contract 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.

During 2020/2021 contract year, there were 367,011women aged 25 to 64 years residing in NHSGGC area and registered with an NHSGGC GP practice. A total of 116,398 (31.7%) had a GMS exclusion applied (**Table 8.2**).

Table 8.2: Exclusions from cervical screening among eligible population for NHS Greater Glasgow and Clyde, 2020-2021

Exclusion	Frequency	%
Anatomically Impossible	10	0.01
CHI Exclusion	9,839	<i>8.4</i> 5
Co Morbidity	7	0.01
Defaulter	89,520	76.91
No Cervix	13,261	11.39
No Further Recall	321	0.28
Not Clinically Appropriate	372	0.32
Opted Out	2,634	2.26
Pregnant	426	0.37
Terminally III	8	0.01
Total	116,398	

Source SCCRS August 2021

Of the remaining eligible population (250,613), a total of 208,504 women (83.2%) were screened in the previous 5.5 years (**Table 8.3**), the GMS cervical screening target of 80% was met in all age groups apart from 25-29 and 30-34 years groups.

Table 8.3: GMS Uptake of cervical screening among eligible population by age for NHS Greater Glasgow and Clyde, 2020-2021 in previous 5.5 years

Age Group	Not Screened	Screened	Total	% Uptake
25-29	14,156	25,418	39,574	64.2
30-34	8,492	30,071	38,563	78.0
35-39	6,366	29,366	35,732	82.2
40-44	4,839	26,531	31,370	84.6
45-49	3,234	20,329	23,563	86.3
50-54	2,910	27,663	30,573	90.5
55-59	1,214	27,289	28,503	95.7
60-64	898	21,837	22,735	96.1
Total	42,109	208,504	250,613	83.2

Source: SCCRS August 2021

### 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. <u>Appendix 8.2</u> provides a summary of NHSGGC activity against these national statistics for the time period 1st April 2019 and 31st March 2020.

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 years for women aged 25-49 years or 5.5 years for women aged 50 – 64 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 for a screening test taken within the last 5.5 years. **(Table 8.4)** 

Table 8.4: Uptake for Cervical Screening by NHS Board and Age: Percentage uptake of females aged 25-64. Uptake is age appropriate based on being screened within the specific period (within 3.5 or 5.5 years)

Age Group	NHSGGC	Scotland
25-64 years	65.4%	69.3%
25-49 years	61.4%	66.3%
50-64 years	73.1%	74.4%

Source Scottish cervical screening programme statistics - Annual update to 31 March 2021 - Scottish cervical screening programme statistics - Publications - Public Health Scotland

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 8.5).

Among women aged 25 to 29, the uptake rate was 48.2% compared to women aged over 40, whose overall uptake rate ranged from 64.2% to 72.3%. No age group achieves the 80% target uptake.

Table 8.5: Uptake of cervical screening among eligible population by age for NHS Greater Glasgow and Clyde, 2020-21 in previous 5.5 years

Age Group	Not Screened	Screened	Total	% Uptake
25-29	29,648	27,561	57,209	48.2
30-34	19,913	32,687	52,600	62.1
35-39	15,289	31,667	46,956	67.4
40-44	11,712	28,383	40,095	70.8
45-49	8,311	21,668	29,979	72.3
50-54	11,621	29,568	41,189	71.8
55-59	13,159	27,958	41,117	68.0
60-64	12,453	22,313	34,766	64.2
Total	122,106	221,805	343,911	64.5

Source: SCCRS (August 2021)

Uptake was higher in areas of lower deprivation. Uptake for women aged 25 to 64 in the least deprived areas was 70.5% compared with 62.1% in the most deprived areas. The target of 80% was not met in any deprivation quintile **(Table 8.6).** 

Table 8.6: Uptake of cervical screening among eligible population by SIMD for NHS Greater Glasgow and Clyde, 2020-21 in previous 5.5 years

SIMD Quintile 2016	Not Screened	Screened	Total	% Uptake
1 (Most Deprived)	47,075	77,214	124,289	62.1
2	20,445	37,472	57,917	64.7
3	18,551	30,438	48,989	62.1
4	17,362	32,072	49,434	64.9
5 (Least Deprived)	18,673	44,609	63,282	70.5
Total	122,106	221,805	343,911	64.5

Source: SCCRS (August 2021)

There was a large variation in uptake across the different ethnic groups **(Table 8.7)**. The target of 80% was not met by any ethnic group. The highest uptake was among White – Irish and British ethnic categories at 67.8% and 66.0% respectively, and the lowest uptake of 24.4% was among Chinese women.

Table 8.7: Uptake of cervical screening among eligible population by ethnicity for NHS Greater Glasgow and Clyde, 2020-21 in previous 5.5 years

2001 Census Ethnic	Not			%
Group (OnoMap)	Screened	Screened	Total	Uptake
A) WHITE - BRITISH	75,077	179,103	254,180	70.5
B) WHITE - IRISH	6,907	14,575	21,482	67.8
C) WHITE - ANY OTHER WHITE BACKGROUND	13,125	10,113	23,238	43.5
H) ASIAN OR ASIAN BRITISH - INDIAN	3,369	2,775	6,144	45.2
J) ASIAN OR ASIAN BRITISH - PAKISTANI	4,631	5,090	9,721	52.4
K) ASIAN OR ASIAN BRITISH -	454	315	769	
BANGLADESHI				41.0
L) ASIAN OR ASIAN BRITISH - ANY OTHER	357	166	523	
ASIAN BACKGROUND				31.7
M) BLACK OR BLACK BRITISH - CARIBBEAN	15	18	33	54.5
N) BLACK OR BLACK BRITISH - AFRICAN	1,797	1,466	3,263	44.9
R) OTHER ETHNIC GROUPS - CHINESE	7,900	2,554	10,454	24.4
S) OTHER ETHNIC GROUPS - ANY OTHER	5,018	3,855	8,873	
ETHNIC GROUP				43.4
Y) UNCLASSIFIED	3,456	1,775	5,231	33.9
Total	122,106	221,805	343,911	64.5

Source: SCCRS (August 2021)

Variations in cervical screening uptake across HSCPs persist (**Table 8.8**). They range from 52.1% in Glasgow City North West Sector to 76.0% in East Dunbartonshire HSCP and no HSCPs met the minimum target of 80%. However, when the known effects of age, sex, deprivation and ethnicity are taken into account by standardisation (SUR), differences in uptake persist that are not explained by population demographics.

Table 8.8: Indirectly Standardised Uptake of Cervical Screening by HSCP in NHS Greater Glasgow and Clyde, 2020-21

	Not			%		SUR %	SUR %
HSCP	Screened	Screened	Total	Screened	SUR %	LCI	UCI
East Dunbartonshire HSCP	6,884	21,778	28,662	76.0	69.0	68.0	69.9
East Renfrewshire HSCP	6,253	18,307	24,560	74.5	68.4	67.4	69.4
Glasgow North East Sector	21,958	34,429	56,387	61.1	63.8	63.1	64.5
Glasgow North West Sector	34,227	37,222	71,449	52.1	56.7	56.2	57.3
Glasgow South Sector	25,557	43,863	69,420	63.2	64.7	64.1	65.3
Glasgow City	81,742	11,5514	197,256	58.6	61.6	61.3	62.0
Inverclyde HSCP	6,215	14,262	20,477	69.6	66.1	65.1	67.2
Renfrewshire HSCP	13,911	34,730	48,641	71.4	67.7	67.0	68.4
West Dunbartonshire HSCP	7,101	17,214	24,315	70.8	68.0	67.0	69.0
Total	122,106	221,805	343,911	64.5	·		

Source: SCCRS (August 2021)

# 8.9. Cervical Screening Activity: Pause in screening due to COVID and number of samples taken from August 2020 to 31st March 2021

The pause in screening resulted in no smears being taken on a routine basis from April 2020 to July 2020. The programme restarted in August and **Table 8.9** shows the number of smears taken within Colposcopy Clinics, GP practices and Smear Taking Clinics on a monthly basis. This information has been provided by the national team

Table 8.9: Numbers of smears taken from August 2020 to March 2021

Month	Colposcopy Clinic	GP Practice	Smear Taking Clinic	Total
Aug 2020	126	3,371	208	3,705
Sep 2020	34	1,952	161	2,147
Oct 2020	60	3,799	187	4,046
Nov 2020	48	4,090	145	4,283
Dec 2020	56	3,614	172	3,842
Jan 2021	67	3,269	150	3,486
Feb 2021	47	3,920	148	4,115
Mar 2021	5	1,210	59	1,274
				26,898

### 8.10 NHSGGC Cytopathology Laboratories

The introduction of High risk HPV screening in April 2020 impacted on the workload of the NHSGGC Cytopathology laboratories. The Glasgow laboratory is one of the two laboratories that delivers the new HPV pathway across Scotland.

**Table 8.10** provides an overview of the number of cervical screening tests and cervical cytology tests processed across Scotland at the NHSGGC and Lanarkshire laboratories for the period 1st April 2020 to 31st March 2021.

Test	Scotland	Glasgow	Lanarkshire
Number of cervical tests processed	174,299	87,738	86,561
Number off cytology tests Processed	40,666	20,820	19,846

Source Scottish cervical screening programme statistics - Annual update to 31 March 2021 - Scottish cervical screening programme statistics - Publications - Public Health Scotland

The total number of cervical tests processed in NHSGGC laboratory in 2020/21 was 87,738. An essential criterion of the NHS HIS standards requires the laboratories to process a minimum of 15,000 cervical screening samples annually and this has been achieved. These included repeat samples and those taken at colposcopy as one woman can have more than one cervical screening sample.

The number of cervical tests processed at the Glasgow Laboratory was 87,738 followed by a further 20,820 cervical cytology tests.

### 8.11 Colposcopy

**Table 8.11** shows the activity data across NHSGGC colposcopy services. In 2019/2020, there were 3,629 new and 911 return appointments. New outpatient episodes include all patients attending colposcopy services; return episodes will include treatment visits following the diagnosis of cervical intraepithelial neoplasia (CIN) in addition to standard follow up visits for colposcopy based indications.

Table 8.11: NHSGGC Colposcopy Services Workload 1 April 2020 to 31 March 2021

### **Out Patients**

Appointment t Status	NEW OP	RETURN OP	Grand Total
Attend	2,529	459	2,988
DNA	240	101	341
Cancelled by Clinic	345	202	547
Cancelled by Patient	317	20	337
Cancelled Unspecified		≤ 5	≤ 5
COVID 19 Cancel by Patient		≤ 5	≤ 5
COVID 19 Cancellation	174	119	293
Patient Cancelled Day of Clinic	24		24
Deceased		6	6
Grand Total	3,629	911	4,540

Source: National Colposcopy Clinical Audit System (Extracted Dec 2021)
Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

**Table 8.12** shows the performance against benchmarking standards for NHS GGC clinics.

The Vale of Leven and the New Victoria hospital met the 90% target for cytoversion rates at 4-12 months after treatment if a smear was taken and all site met the target of  $\leq$  5% confirmed treatment failure at 12 months.

The majority of colposcopy units met the target of 97% for adequacy of a cervix biopsy for histology.

The proportion of new referrals for high grade dyskariosis having a biopsy at first visit ranged from 80.1% at Royal Alexandra Hospital to 97.1% at the New Victoria Hospital.

The percentage of women recommended for treatment under general anaesthetic was below the 20% target across all sites.

Table 8.12: NHS Greater Glasgow & Clyde: COLPOSCOPY BENCHMARKING STANDARDS

	Total New Outpatient Attendances	New Outpatient Attendances Abnormal Screening Smear	Cyto- reversion rates at 4 - 12 months after treatment if a smear is taken	Confirmed histological treatment failures at 12 months	Adequacy of cervix biopsy for histology	Proportion of women, referred with abnormal cytology, where SCJ is visualised, treated at 1st visit with CIN on histology	New referral for high grade dyskaryosis having biopsy	% Recommended for treatment as Inpatient
TARGET	None	>= 50 (per annum)	> 90%	<= 5%	> 97%	>= 90%	> 90%	< 20%
SCOTLAND	12,835	8,672	87.3	3.7	98.2	82.2	91.7	10.3
Greater Glasgow & Clyde	4,040	2,299	86.6	2.1	97.7	82.0	90.6	9.6
Royal Alexandra Hospital	539	420	87.5	0.5	97.4	83.8	80.1	12.2
Inverclyde Royal Hospital	220	82	75.9	2.5	97.1	44.4	87.2	6.9
Vale of Leven District General Hospital	67	56	90.0	0.0	98.1	100.0	86.4	8.3
Western Infirmary	0	0	0.0	0.0	0.0	0.0	0.0	0.0
New Victoria Hospital	1,316	673	94.1	0.9	99.2	78.9	97.1	10.6
Glasgow Royal Infirmary	8	≤ 5	0.0	0.0	100.0	0.0	0.0	0.0
Stobhill Hospital	1,711	1,028	83.3	3.2	96.9	86.0	92.9	8.5
Sandyford Initiative	179	37	87.5	5.0	98.9	100.0	93.3	5.0

Source: National Colposcopy Clinical Information & Audit System (Extracted December 2021)

#### 8.12. 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 2020, we reviewed the notes of 52 women who developed invasive cervical cancer and had a pathology diagnosis made in NHS Greater Glasgow and Clyde laboratories.

**Table 8.12** shows numbers and the distribution of women's age at diagnosis for years 2010 to 2020. The largest number of cervical cancers occurred in women aged between 30 and 39 years.

Table 8.12: Number of NHSGGC residents with invasive cervical cancers by age at diagnosis and year of diagnosis

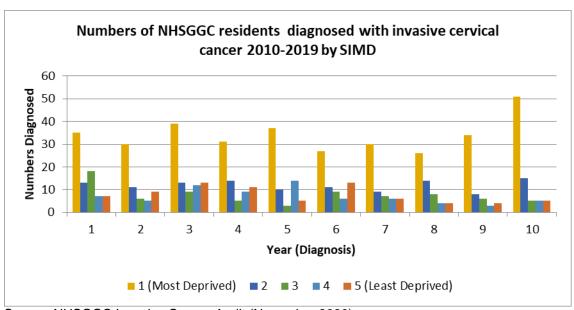
			Year	(Diagn								
Age Group	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	Total
20-29	10	7	12	6	9	8	16	7	7	6	≤5	89
30-39	23	16	27	23	21	18	9	20	14	22	15	208
40-49	22	10	17	17	14	16	10	13	13	18	10	160
50-59	7	10	9	10	11	9	10	6	13	17	10	112
60-69	5	7	11	≤5	6	10	8	≤5	5	13	11	83
70-79	10	8	7	7	5	≤4	≤3	5	≤3	≤3	≤5	59
<b>80</b> +	≤5	≤5	<b>≤</b> 5	≤5	≤5	≤5	≤5	≤5	0	≤5	<b>≤</b> 5	23
Total	80	61	86	70	69	66	58	56	55	81	52	734

Source: NHSGGC Invasive Cancer Audit (November 2021)

Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

**Figure 8.3** shows numbers of women diagnosed for years 2010 to 2019 by SIMD. Women from the most deprived quintile are more likely to be diagnosed for cervical cancer

Figure 8.3: Numbers of NHSGGC residents diagnosed with invasive cervical cancer 2010-2019



Source: NHSGGC Invasive Cancer Audit (November 2020)

**Table 8.13** shows the distribution of clinical stage at diagnosis over an eleven year period from 2010 to 2020.

Table 8.13: 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	2019	2020	Total
Not Known	21	12	20	19	14	11	19	13	17	27	≤5	175
1a1 (less than 3mm deep and >=7mm wide)	0	≤5	≤5	≤5	0	≤5	≤5	≤5	≤5	≤5	10	21
1a2 (3-5mm deep and <7mm wide)	14	14	24	19	26	21	10	15	16	12	≤5	172
1b (confined to cervix)	39	33	38	30	29	33	26	27	20	41	8	324
2 or Greater (spread outwith cervix)	≤5	≤5	≤5	0	0	0	0	0	0	≤5	31	42
Total	80	61	86	70	69	66	58	56	55	81	52	734

Source: NHSGGC Invasive Cancer Audit (November 2021)

Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

**Table 8.14** shows that in 2020, 10 of the cases were screen detected. The majority of the cases (40) were presented to the service were symptomatic.

Table 8.14: Number of women with invasive cancers split by modality of presentation by year of diagnosis

Presentation	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	Total
Not Known	24	20	0	0	≤5	0	≤5	0	0	0	2	50
Smear detected	29	20	39	31	33	28	27	20	22	0	10	259
Symptomatic	27	21	46	38	34	36	26	35	33	31	40	367
Incidental Finding	0	0	≤5	≤5	≤5	≤5	≤5	≤5	0	50	0	58
Total	80	61	86	70	69	66	58	56	55	81	52	734

Source: NHSGGC Invasive Cancer Audit (November 2021)

Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

In 2020, 20 of 52 (38.4%) women diagnosed with invasive cervical cancer had a complete smear history compared to 26 (50%) women who had incomplete smear histories. The smear history for the remaining 6 cases (12%) was 'not applicable' or 'not known'. **(Table 8.15)**. Over the eleven years audited, 75 (10.2%) women out of the 734 that developed cancer had never had a smear; 255 (34.7%) had complete smear histories and 394 (53.6%) of women had incomplete smear histories.

Table 8.15: Smear histories of women with invasive cervical cancer 2010-2020

Smear History	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	Total
Adequate	25	25	34	24	28	21	23	17	13	25	20	255
Incomplete	42	22	40	36	36	39	30	34	39	50	26	394
Not Applicable	12	14	11	10	≤5	≤5	≤5	≤5	≤5	6	≤5	75
Not Known	≤5	0	≤5	0	0	≤5	≤5	≤5	≤5	0	≤5	10
Total	80	61	86	70	69	66	58	56	55	81	52	734

Source: NHSGGC Invasive Cancer Audit (November 2021)

Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

**Table 8.16** 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 8.16: Follow up status of women with invasive cervical cancer

	Year (Diagnosis)											
Current Status	201 0	2011	201 2	201 3	201 4	2015	201 6	201 7	2018	2019	2020	Total
Lost to colposcopy service	≤5	0	≤5	≤5	≤5	≤5	0	0	0	0	0	6
On follow up at colposcopy	21	8	24	18	13	11	15	10	9	23	8	160
On follow up at Oncology/ Beatson	47	38	46	46	52	48	31	16	11	47	35	417
Early recall	0	0	≤5	0	0	0	≤5	0	0	0	≤5	5
Death	7	9	11	≤5	0	≤5	0	≤5	≤5	≤5	5	51
No further recall	0	≤5	0	0	0	≤5	8	24	28	7	0	70
Unknown	≤5	≤5	≤5	≤5	≤5	0	≤5	≤5	≤5	0	≤5	24
Total	80	61	86	70	69	66	58	56	55	81	52	734

Source: NHSGGC Invasive Cancer Audit (November 2021)

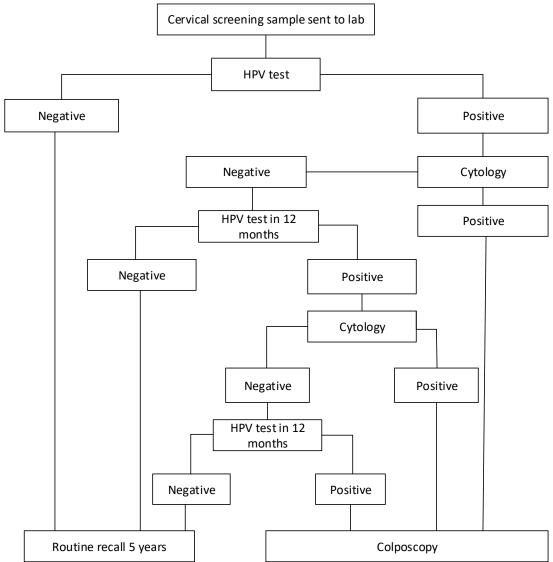
Numbers ≤5 redacted as per ISD Statistical Disclosure Control Protocol

### 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 continue monitoring and influencing uptake of cervical screening within Primary Care.
- To continue to work in partnership with 3<sup>rd</sup> sector and HSCP staff to raise awareness of cervical screening.

## Appendix 8.1

## Cervical Screening Pathway



Source: www.healthscotland.scot/cervical screening

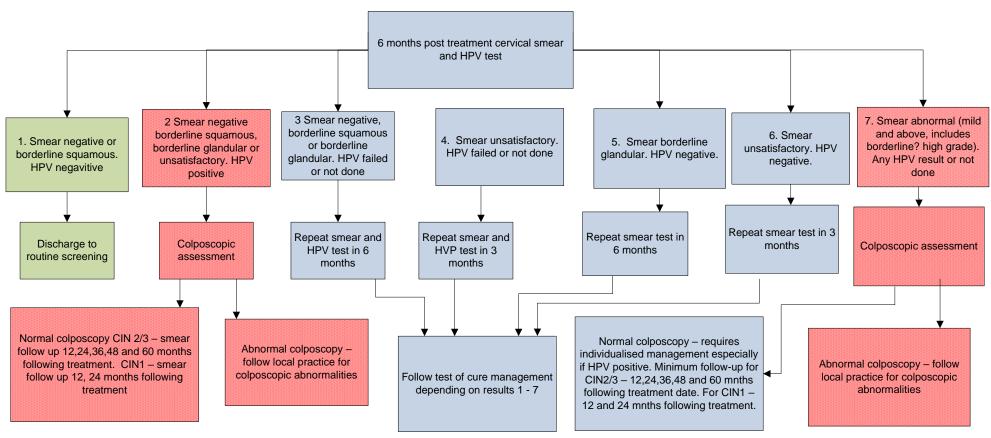
### Management and follow up for cytology results: Post Total Hysterectomy

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

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



#### **National Performance Standards 2020/21**

Source: Scottish Cervical Screening Programme Statistics. Public Health Scotland Uptake for Cervical Screening; Scotland & NHSGGC 1 April 2020 to 31 March 2021

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	69.3	65.4			
Percentage uptake by deprivation quintile						
SIMD 1 (most deprived)		73.7	68.5			
SIMD 2		73.6	69.6			
SIMD 3	80	69.6	63.9			
SIMD 4		67.1	65.7			
SIMD 5 (least deprived)		63.2	62.5			
Uptake by Age Group						
25-49 years		66.3	61.4			
50-64 years		74.4	73.1			
25-64 years		69.3	65.4			

# Uptake for Cervical Screening by HPV vaccinated: Scotland & NHSGGC 1 April 2020 to 31 March 2021

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

	Age						
<b>HPV</b> vaccination status	24	25	26	27	28	29	24-29
HPV Immunisation status (Full <sup>1</sup> )							
Scotland	49.0	61.7	68.9	72.0	73.3	76.1	68.2
Greater Glasgow & Clyde	40.2	60.7	67.2	71.2	72.2	75.0	67.1
Н	HPV Immunisation status (Incomplete <sup>1</sup> )						
Scotland	34.4	45.7	57.8	66.7	67.4	71.0	65.3
Greater Glasgow & Clyde	27.5	39.7	60.7	66.8	68.1	68.3	64.8
No HPV Immunisation status							
Scotland	6.4	17.4	26.6	35.4	39.4	45.2	32.2
Greater Glasgow & Clyde	40.2	60.7	67.2	71.2	72.2	75.0	67.1

<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.

<sup>2.</sup> Based on SCCRS population denominator (excluding medically ineligible women) ages 24-29.

# Cervical screening tests processed<sup>1</sup>: Scotland & NHSGGC laboratories, 1 April 2020 to 31 March 2021

Year/ quarter	Scotland	Greater Glasgow & Clyde
Q4	72,975	36,791
Q3	66,811	33,590
Q2	31,776	15,598
Q1	2,737	1,759
Total	17.299	87,738

<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, 1 April 2020 to 31 March 2021

Year/ quarter	Scotland	Greater Glasgow & Clyde
Q4	39	34
Q3	43	32
Q2	30	36
Q1	14	14

<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, 1 April 2029 to 31 March 2021 (Mean number of days by quarter)

Year/ quarter	Scotland	Greater Glasgow & Clyde
Q4	9	10
Q3	9	8
Q2	9	11
Q1	5	5

# Assessment of Risk to the implementation of HPV into the Cervical Screening Programme should this be delayed:

HPV Primary Testing is scheduled to be implemented into the Cervical Screening Programme on 30 March 2020.

### The reasons why implementation may be delayed:

- Staff shortages availability of staff to implement the change (NHS and external suppliers)
- The decision is made to pause the Cervical Screening Programme (although it may be able to continue with implementation if there was the staff to do so)

#### **Considerations:**

- New implementation date would be required to be agreed
- What test do we resume with?
- Resuming the Cervical Screening Programme using hr-HPV would see less pressure on the laboratories (in which there will only be 2 come 30 March 2020)
- Would not meet the Ministerial commitment for implementation in 2019/2020
- Communication to the public and NHS Boards / Heath Care Professionals

#### Risks:

Delay in implementing the new test

#### **Recommendation:**

 Implementation to go ahead, if possible, regardless of whether the Cervical Screening Programme is paused

# Assessment of risk to Cervical Screening Programme should screening programme be paused:

Cervical screening is a 3 yearly screening programme for women aged 25 - 49 and 5 yearly for women aged 50 - 64. Women on non-routine screening will be invited up to age 70. This is a programme for well women and as such would not be deemed an essential service.

### The reasons why a screening programme may need to be paused:

- Staff shortages availability of service staff to run programme should there be outbreak
- Re-allocation of screening programme staff for essential services within Boards (laboratory and sample takers in particular – sample takers are more often than not practice nurses)
- Colposcopy service not available if NHS Boards decide to reduce / pause elective work
- Women may not wish to attend at this time
- GPs may not wish for women to come to the Practices

### **Considerations:**

- Continuation/triage of cases referred to colposcopy (if NHS Boards have not decided to reduce / pause elective work)
- Continuation of resulting samples already taken
- Cancellation of appointments already issued at GP practices and colposcopy (these could be weeks in advance and not centrally known)
- Suspension of further prompts / reminders
- Raise awareness of symptomatic referral pathways
- Delay in testing samples in the laboratory / may need to retest (vials can be stored at room temp for 30 days and in a fridge for 105 days. If in a HPV tube another 60 days can be added)
- Delays will entail need for action plans when service fully resumes
- Additional staff / appointments / clinics may be needed when the programme resumes
- Prompts / reminders sent to women new safeguarding to ensure none are missed when resuming the programme
- Phased commencement to ensure GP practices can cope with demand
- Communication to the public and NHS Boards / Heath Care Professionals
- Any technical issues for SCCRS

#### Risks:

#### Risks for continuing

 Onward transition of Covid-19 to staff and otherwise well screening population by continuing to screen

### Risks for pausing

- Delay to screening with possible delayed diagnosis of pre-cancerous cells / cervical cancer
- Potentially significant IT risks in pausing and resuming SCCRS processes (yet to

be assessed)

#### Recommendation:

Within 48 hours of decision to pause, the issue of new prompts and reminders and request that GP Practices offer no further appointments for samples to be taken. However laboratories will result samples already taken (for as long as feasibly possible). Any existing cervical screening appointments to be managed locally by GP Practices. Colposcopy referrals to be managed as appropriate within NHS Boards.

Clinical Lead and Scientific Manager (NHS Lanarkshire Lab Lead) within the cervical screening programme have been consulted and provided input to the recommendations.

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# **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 2019 reports that in Scotland, there were 312,390 people with known diabetes recorded on local diabetes registers in 2019, representing 5.7% of the population. In the same year in Greater Glasgow and Clyde, there were 66,332 people with known diabetes (5.6% of the population), compared to 48,602 people in 2007 (4.1% of the population). The crude incidence rate for all ages (cases per 100,000 per year) has risen from 311 in 2011 to 336 in 2019.

Of the 63,424 diabetics aged over 12 years and eligible for DRS screening only 25,168 (39.7%) were screened during 2020/21. This was due to pause in screening from March 2020. The service then had to deal with the backlog of patients who were 'not invited' during that period. The COVID 19 restrictions led to lack of available clinical space within acute and community sites. In addition, social distancing, staffing and the reduction in the numbers of patients that could be safely screened within clinics resulted in fewer appointments. High risk groups like newly diagnosed Diabetics, pregnant women, those with a 6 monthly review and Ophthalmology failsafes are being added to the screening programme and prioritised for appointments.

Through policy and service changes, it is anticipated that the back log will be cleared by March 2022.

#### **DRS Screening and COVID Pandemic**

The Scottish Government, on the advice of the Scottish Screening Committee, decided to temporarily pause the DRS screening programme as a result of the COVID pandemic. An assessment (<u>Appendix 9.1</u>) was undertaken and the recommendation was to:

- Pause all screening and agree that the secondary care pathway for patients in ophthalmology should be decided by the local ophthalmology departments.
- Cancel all the scheduled clinics and stop the issuing of any new invitations.

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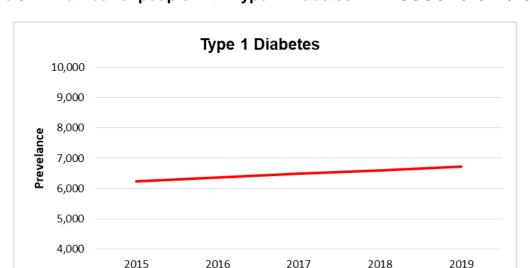
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# 9.1. Background

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 latest Scottish Diabetes Survey 2019<sup>21</sup> reports that in Scotland, there were 312,390 people with known diabetes recorded on local diabetes registers in 2018, representing 5.7% of the population of all ages. 89.1% (274,346) of all people registered in Scotland with diabetes were recorded as having type 2 diabetes and 10.9% (33,427) of all registered people were recorded as having type 1 diabetes. In the same year in Greater Glasgow and Clyde, there were 66,332 people with known diabetes in 2019, (5.6% of the population) compared to 48,602 people in 2007 (4.1% of the population).

**Figures 9.1 and 9.2** 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 6,724 in 2019, an increase of 7.6%. Similarly for type 2 diabetes, there 54,515 people in 2015 when compared to 58,641 in 2019, representing an increase of 7.6%.



Year

Figure 9.1: Number of people with Type 1 Diabetes in NHSGGC 2015- 2019

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<sup>&</sup>lt;sup>21</sup>https://www.diabetesinscotland.org.uk/wp-content/uploads/2020/10/Diabetes-Scottish-Diabetes-Survey-2019.pdf accessed November 2021

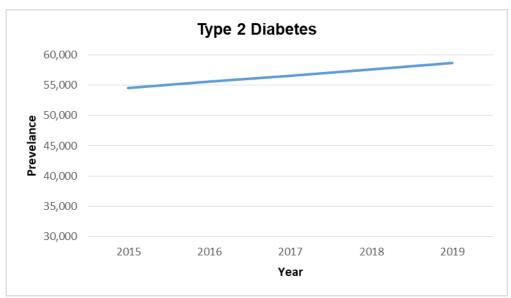


Figure 9.2: Number of people with Type 2 Diabetes in NHSGGC 2015- 2019

Source: Diabetes in Scotland reports 2015-2019

Diabetic Retinopathy is a complication of diabetes affecting blood vessels of the retina and is the biggest single cause of blindness and visual impairment amongst working age people in Scotland. Retinopathy is symptom-free until its late stages, and programmes of retinal screening can reduce the risk of blindness in 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 NHSGGC 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.

The Diabetic Eye Screening programme differs from other screening programmes in that it is an important part of the patient's care pathway rather than screening for a particular condition.

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>22</sup> and Key Performance Indicators<sup>23</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. OPTIMIZE 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.

#### 9.5. Screening Pathway

Figure 9.3 illustrates the pathway to reduce diabetes related blindness in the general population by identifying and treating sight threatening diabetic retinopathy.

<sup>&</sup>lt;sup>22</sup>http://www.healthcareimprovementscotland.org/our\_work/long\_term\_conditions/programme\_resources/diabetic <u>retinopathy screening.aspx</u> (Accessed November 2021)

23 <u>http://www.ndrs-wp.scot.nhs.uk/?page\_id=122</u> (Accessed November 2021)

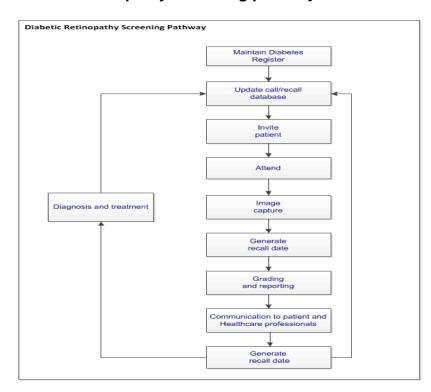


Figure 9.3: Diabetic Retinopathy screening pathway

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

The VECTOR system, introduced in March 2017, was used to produce the National KPI data for reports. The OPTIMIZE system replaced VECTOR in 2020 and the KPIs are **not yet available** for reporting.

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 2020 to 31<sup>st</sup> March 2021. This data has been obtained from SCIDIABETES rather than OPTIMIZE.

Of the 60,897 diabetics aged over 12 years and eligible for DRS screening only 25,168 (39.7%) were screened during 2020/21 compared to an uptake of 73.5% during 2019/2020.

The drop in screening was due to a 'pause' in screening from March 2020. The service then had to deal with the backlog of patients who were 'not invited' during that period. The COVID 19 restrictions led to lack of available clinical space within acute and community sites. In addition, social distancing, staffing and the reduction in the numbers of patients that could be safely screened within clinics resulted in fewer appointments.

High risk groups like newly diagnosed Diabetics, pregnant women, those with a 6 monthly review and Ophthalmology failsafes are being added to the screening programme and prioritised for appointments.

**Table 9.1** shows that more than half (55.5%) of the eligible resident population screened were male. Within NHSGGC the overall uptake was 39.7%. Males accounted for 40.5% of people screened. 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 2020-2021

				%
Sex	Not Screened	Screened	Total	Screened
Female	17,215	10,859	28,074	38.7
Male	21,041	14,309	35,350	40.5
TOTAL	38,256	25,168	63,424	39.7

Source: SCIDIABETES NOVEMBER 2021

**Table 9.2** shows that 47.7% of 0-14 year's old were screened, and just over 40% of those aged 55 to 74 years old. Only 36.3% aged 15 to 24 were screened.

Table 9.2: Uptake of DRS screening by age in NHSGGC, by Board of Residence 2020-2021

٨٥٥		_		%
Age	Not Screened	Screened	Total	Screened
0 to 14	101	92	193	47.7
15 to 24	610	348	958	36.3
25 to 34	1,161	723	1,884	38.4
35 to 44	2,553	1,529	4,082	37.5
45 to 54	5,380	3,442	8,822	39.0
55 to 64	9,868	6,639	16,507	40.2
65 to 74	9,925	6,829	16,754	40.8
75 to 84	6,425	4,209	10,634	39.6
85+	2,233	1,357	3,590	37.8
TOTAL	38,256	25,168	63,424	39.7

Source: SCIDIABETES NOVEMBER 2021

38.5% of those screened resided in the most deprived Board areas compared to 40.8% from the most affluent areas. The uptake target of 80% was not met in any deprivation quintile.

Table 9.3: Uptake of DRS screening by deprivation in NHSGGC, by Board of Residence 2020-2021

SIMD	Not Screened	Screened	Total	% Screened
1 (most deprived)	15,823	9,922	25,745	38.5
2	7,567	5,126	12,693	40.4
3	4,593	3,020	7,613	39.7
4	4,752	3,290	8,042	40.9
5 (least deprived)	5,521	3,810	9,331	40.8
TOTAL	38,256	25,168	63,424	39.7

Source: SCIDIABETES NOVEMBER 2021

There are variations in those screened across HSCPs (**Table 9.5**). They range from 35.7% in West Dunbartonshire to 65.3% in Inverclyde. No HSCP met the 80% target for screening.

Table 9.5: Uptake of diabetic retinopathy screening by HSCP in NHGGC, 2020-2021

	Not			%
HSCP	Screened	Screened	Total	Screened
East Dunbartonshire	3,200	1,953	5,153	37.9
East Renfrewshire	2,765	1,755	4,520	38.8
Glasgow North East	6,504	3,657	10,161	36.0
Glasgow North West	6,124	3,571	9,695	36.8
Glasgow South	8,398	5,295	13,693	38.7
Inverclyde	1,607	3,023	4,630	65.3
Renfrewshire	6,141	3,963	10,104	39.2
West Dunbartonshire	3,517	1,951	5,468	35.7
Total	38,256	25,168	63,424	39.7

Source: SCIDIABETES NOVEMBER 2021

#### 9.7. Challenges and Future Developments

The national DRS database VECTOR implemented in 2017, was replaced by the OPTIMIZE 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 January 2021 the service implemented 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 with maculopathy from DRS to ophthalmology.

In addition, a visual acuity threshold for patients with maculopathy was introduced in line with the SMC recommendations for treatment, in order to reduce the burden on both the OCT clinics and on secondary care. This new, modified approach is in keeping with the ethos of "Realistic Medicine".

By changing the screening interval for patients at low risk of sight loss from one year to two years it was predicted that there would be a reduction in demand for DRS screening appointments and this will be offset by an increase in new DRS OCT appointments. However due to the COVID 19 pause in screening and issues in inviting patients within restrictions like availability of clinical space, social distancing and PPE the backlog in appointments will take time resolve, estimated to be March 2022. The Senior Management Team is aware of this and estimation of time and clinics required to deal with the backlog is work in progress.

NHSGGC 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, the screening department has progressed virtual printing via Royal Mail for patient screening invites which will release staff capacity.

# Assessment of Risk to Diabetic Retinopathy Screening (DRS) Programme should screening programme be dialled down /temporarily paused:

DRS screening is a screening programme for all patients over the age of 12 who have been identified with Diabetes – it is an annual and 6 monthly screening programme with less than 4% of patients sent on for further investigations/treatment.

# Summary for DRS business as usual screening

#### Reasons why screening programme may need to be paused:

- Risk for either participants or staff picking up the virus
- Re-allocation of screening programme staff to support other essential services within Boards
- Minimising the impact on essential NHS services by cutting down on referrals
- Availability of service staff to screen /operate the programme should there be outbreak
- Participants may not travel/wish to attend routine screening appointments at this time

#### Considerations:

- A 18/24 hour notice period to cancel clinics Invitations are issued for routine screening 3 weeks in advance of appointment dates
- Communications with population /key stakeholders as to halt to service
- Timing and lead in time for re-instatement of programme and action plans given delay to service

#### Risks:

#### Risks of continuing screening:

- Participants picking up coronavirus due to this screening group all have diabetes they more at risk having complications from the virus compared to the general population
- Screening staff picking up coronavirus
- Not being able to clean the screening equipment sufficiently between episodes and thus the potential to be exposed the coronavirus
- Ophthalmology departments not being able to take on any new referrals from the DRS programme.
- Risk of cancelation of clinics being cancelled on GP/independent premises as GP practices/independent venues may not agree to screening clinics going ahead
- Inefficient usage of resources there could be a spike in DNAs (as men invited to screening might deem it a greater risk attending than not) and that would mean clinical staff not being used to the full capacity
- Limited staffing available to operate screening service

### Risks of pausing screening:

- Possible delay to diagnosis of retinopathy or sight loss. The likelihood of sight loss happening is statistically very small. In contrast, this is set against the risk of an individual picking up the coronavirus by attending a screening clinic.]
- Reputation of the screening programme(s)/health service
- Not meeting the programmes KPIs

#### **Recommendation:**

Pause all screening and agree that the secondary care pathway for patients in ophthalmology should be decided by the local ophthalmology departments.

This would involve cancelling all the scheduled clinics and stop the issuing of any new invitations.

This assessment and recommendation agreed in consultation with key stakeholders from the DRS programme including some Clinical Leads of the local programmes

## Summary for DRS Development work: DRS Optimze/RIS&OCT project

#### Reasons to continue DRS Optimze/RIS&OCT project:

- Minimal risks of clinical risk for staff picking up the virus as they work could be done remotely
- Identified staff for the project already agreed and disruption would be minimal
- Supplier has not reported any issues to-date

#### Considerations:

- If DRS is suspended the project plan might need to be revaluated.
- The project could be monitored on a weekly basis and contingency arrangements made as and when issues arise
- There are contractual (milestone) issue that would need to be reconsidered in any suspension of the project

#### Risks:

Risks of continuing the project: none identified

### Risks of suspending the project:

- Projects targets/deadlines not met
- There are contractual (milestone) issue that would need to be reconsidered in any suspension of the project
- Delay to moving to a new platform and introducing revised interval screening and OCT surveillance
- Reputation of the screening programme(s)/health service
- Not meeting the programmes KPIs. The project is deemed necessary in order to reduce the workload for the DRS programme and ensure the risk of clinical risks in not meeting the KPIs are reduced

## Recommendation:

Ask the DRS Optimize Project Board to revaluate the timescales for the project and ensure it is continued as per the current objectives agreed for the project.

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