

**NHS**  
Golden Jubilee

**NHS**  
Greater Glasgow  
and Clyde



Scottish Pulmonary  
Vascular Unit (SPVU)

# Annual Report

2023/24

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## Executive summary

The Scottish Pulmonary Vascular Unit (SPVU) is located in 2 hospitals, the Golden Jubilee University National Hospital(GJUNH) in Clydebank and the Queen Elizabeth University Hospital in Glasgow (NHS

Greater Glasgow and Clyde). This Unit was founded in 1999 for the investigation, management and treatment of all patients with severe pulmonary hypertension in Scotland. The mission is to provide investigation and appropriate treatment for patients who have this life-threatening illness.

Contact:

Dr M K Johnson (Director)  
Scottish Pulmonary Vascular Unit  
Golden Jubilee University National Hospital  
Clydebank  
UK G81 4DY

Tel: [REDACTED]

Website:- <https://hospital.nhsgoldenjubilee.co.uk/a-z-services/scottish-pulmonary-vascular-unit-spvu>

## 1. Service delivery

The Scottish Pulmonary Vascular Unit (SPVU) manages patients with pulmonary hypertension (PH) principally pulmonary arterial hypertension (PAH) and chronic thromboembolic pulmonary hypertension (CTEPH). SPVU is a joint commission between NHS Great Glasgow & Clyde (GG&C) and NHS Golden Jubilee (NHSGJ). The service is delivered over 2 sites: inpatient assessments, treatment initiation and outpatient follow up is delivered at GJUNH and emergency inpatient care is provided at Queen Elizabeth University Hospital (QEUH). Further outpatient care is delivered at outreach clinics in Aberdeen and Edinburgh. The primary aims of the service are to improve quality of life, morbidity and survival by providing accurate diagnosis, ensuring people are offered the appropriate medical and surgical treatment and to monitor long term outcomes.

The service is for adult patients ordinarily resident in Scotland. Pulmonary hypertension is a rare lung disorder. Data on the epidemiology of PH varies between studies and depends upon the population in question and the aetiology of the condition. The UK National Audit on Pulmonary Hypertension 2012 showed the prevalence of PAH in Scotland to be 48.5 cases per million population, which includes a small cohort of patients who also have congenital cardiac disease. The current incidence in Scotland over the last 2 years is 12.1 cases / million / year.

The service is for patients who fall into Groups 1, 4 and 5 of the Nice WSPH 2018 classification,

Group 1 – Pulmonary Arterial Hypertension (PAH)

Group 4 – Chronic Thromboembolic Pulmonary Hypertension (CTEPH)

Group 5 – Miscellaneous causes of pulmonary hypertension

The patient pathway of care is detailed in Figure 1.

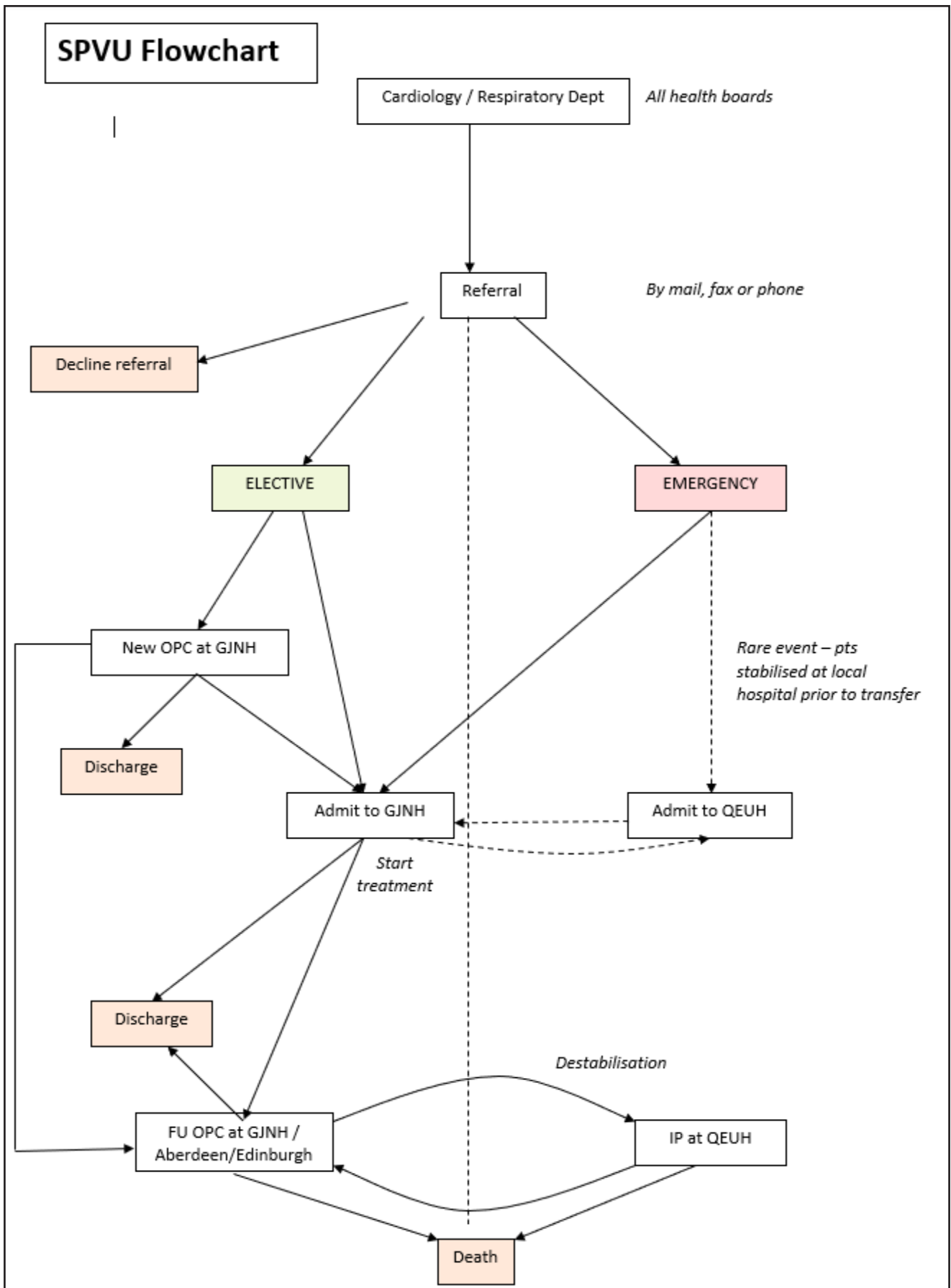


Figure 1: Patient Pathway

The service accepts referrals from consultant Respiratory Physicians, and consultant Cardiologists from NHS Boards in Scotland. The current referral guidelines are shown in Appendix 1. The service also takes on the care of patients transitioning from the Scottish paediatric service which is provided through a shared care arrangement between the national specialist paediatric cardiac service hosted by NHS Greater Glasgow and Clyde, and Great Ormond Street Hospital.

There is no single test to diagnose the precise cause of PH and patients will require a series of tests before a conclusion can be reached. These tests are undertaken to find out whether there are other causes of the symptoms or to assess if there is an underlying condition that may be causing PH.

### **Initial outpatient assessment**

Referrals will be assessed at a Multi Disciplinary Team (MDT) meeting by the clinical team and patients suspected of having PH will be offered either direct admission to GJUNH for further assessment or an appointment at a new outpatient clinic at GJUNH. During the appointment a full medical history and examination is performed and an initial series of tests will be undertaken, which include, chest x ray, ECG and transthoracic echocardiogram. Following this outpatient appointment if PH is still suspected, an inpatient assessment will then be arranged to confirm diagnosis. For those patients where PAH or CTEPH are excluded, a letter explaining the outcomes of the investigations is sent to the referring consultant with recommendations for future management.

### **Emergency referrals**

Emergency referrals account for approximately 10-20% of total referrals. These patients will be directly admitted to the GJUNH for diagnostic testing or occasionally to QEUH for stabilisation prior to investigation.

### **Inpatient assessment**

Patients suspected of suffering from PAH or CTEPH will be admitted to the GJUNH for a 4 day inpatient assessment including:

- Updated chest x-ray
- Transthoracic echocardiogram ± bubble contrast
- Cardiopulmonary exercise testing
- CT Scan
- Right Heart Cardiac Catheterisation ± Pulmonary Angiography ± Vasodilator Studies
- Cardiac MRI,
- Pulmonary function tests
- 6-minute walk test
- Blood tests including NTproBNP.

The principal symptoms of PAH and CTEPH are non-specific, and as such, an accurate diagnosis is made only at the end of the 4 day inpatient assessment.

Following diagnosis patients will be commenced on appropriate drug therapy or will be referred for assessment of suitability for surgery such as pulmonary thromboendarterectomy or lung transplantation. Treatment will usually be initiated in GJUNH but very unwell patients may be referred to QEUH for this process. A staged approach is taken to prescribing. Patients are usually commenced on 2 drugs dependent on severity of condition at diagnosis and treatment response.

### **Pulmonary thromboendarterectomy (PEA)**

Patients with CTEPH will be referred for assessment for surgical intervention to the designated specialist centre in NHS England. This surgery aims to remove abnormal post-thrombotic tissue from the pulmonary arteries of people with CTEPH.

## Heart and lung transplantation

Lung or heart / lung transplantation may be required for some patients if other therapies have proven to be ineffective. Patients requiring transplant are referred to the designated cardiothoracic transplantation service at the Newcastle Upon Tyne Hospitals NHS Foundation Trust, Freeman Hospital, for transplant assessment. Consultants from Freeman Hospital provide an outreach transplant clinic in Glasgow depending on the demand (on average every 3 months).

### Outpatient follow-up

There is communication at an early stage with the GPs and referring clinicians and other appropriate professionals to support the long term care of the patient following diagnosis. Patients are initially seen after 3-6 months by the service at outpatient clinics.

Once stable follow up will be on a 6 or 12 monthly basis dependent on patient need. Patients receive lifelong follow up by the service. This will take place either at GJUNH (~60 clinics per year), Aberdeen (4 clinics per year) or Edinburgh (12 clinics per year). If a patient's PH condition deteriorates, inpatient care may be provided at the QEUH.

### Interdependencies with other services

Provision of a streamlined SPVU pathway requires effective joint working relationships between the GJUNH and QEUH. Both hospitals are interdependent for matters relating to patient flow, clinical governance and efficiency. GJUNH has facilities and imaging infrastructure to support cardiopulmonary diagnostic investigations. QEUH has access to an acute care infrastructure including coronary care unit and high dependency unit for patients who require emergency respiratory care if their condition becomes unstable.

### Workforce

The staff members in the Unit currently are as follows;

Dr Martin Johnson, Director	
Dr Colin Church, Consultant Physician	
Dr Melanie Brewis, Consultant Physician	
Dr Michael Sproule, Consultant Radiologist	
Dr Simon Sheridan, Consultant Radiologist	
Dr Christopher Rush, Consultant Cardiologist	
Dr William Kerrigan, Pulmonary Vascular Fellow	
Dr Stephanie Lua, Pulmonary Vascular Fellow	
Dr Jamie Ingram, Pulmonary Vascular Fellow	
[REDACTED], Clinical Nurse Specialist	[REDACTED], Clinical Pharmacist (secondment)
[REDACTED], Clinical Nurse Specialist	[REDACTED], Clinical Psychologist
[REDACTED], Clinical Nurse Specialist	[REDACTED], Data Manager
[REDACTED], Clinical Nurse Specialist	[REDACTED], Secretary
[REDACTED], Clinical Nurse Specialist	[REDACTED], Secretary
[REDACTED], Clinical Pharmacist	[REDACTED], Admin Assistant
	[REDACTED], Research Nurse
	[REDACTED], Research Nurse
	[REDACTED], Research Nurse
	[REDACTED], Research Nurse
	[REDACTED], CSM GJUNH
	[REDACTED], Assistant CSM GJUNH
	[REDACTED], CSM QEUH

## 2. Activity Levels

	SLA	2023-24	2022-23	2021/22	2020/21
Referrals (Total)		496	441	365	225
Referrals (Accepted for assessment)	240	256	254	219	161
Referrals (Declined at consultant triage of referral)		240	187	146	64
Inpatient OBDs	1800	2488	1766	1652	1346
New outpatients <sup>1</sup> (face to face)	180	183	168	147	95
Return outpatients <sup>2</sup>					
• Face to face		699	651	558	206
• Virtual (telephone/video)	1000	258	284	489	935
Day patients	110	148	85	116	45
Patients on disease-targeted therapy	400	518	483	461	447

Table 1

<sup>1</sup> New outpatients assessed, this excludes DNAs. Other new patients arrive as direct inpatient admissions.

<sup>2</sup> Return patients (GJUNH/Aberdeen/Edinburgh) assessed; this excludes DNAs.

	2023-24	2022-23	2021/22	2020/21
Number of new outpatient slots (GJUNH clinics)	Approx 240	Approx 240	Approx 240	Approx 240
Number of new outpatient DNAs/late cancellations (GJUNH clinics)	41	16	22	12
Number of patients discharged <sup>1</sup>	84	99	95	83
Inpatient Occupied Bed Days (OBD) (Inpatient assessment - GJUNH)	547	551	485	328
Number of right heart catheterisations (RHC)*	176	184	167	121
Number of return patient slots (GJUNH/Aberdeen/Edinburgh clinics)	Approx 1145	Approx 1130	Approx 1168	Approx 1192
Number of return outpatient DNAs/late cancellations (GJUNH/Aberdeen/Edinburgh clinics)	195	202	182	69
Number of late cancellations (New or Return)		80		
Inpatient Occupied Bed Days (OBD) (Review of treatment QEUH)	1941	1215	1168	1018
Incidence of PAH <sup>2</sup>	69	63	60	36
Deaths	115	90	94	76
Number of patients in service:				
a) Number active <sup>3</sup> for at least 1 day during the period (i.e. period prevalence)	885	842	800 <sup>6</sup>	758 <sup>6</sup>
b) Snapshot of number active <sup>3</sup> at the end of the period (i.e. point prevalence)	666	629	591 <sup>6</sup>	591 <sup>6</sup>
Number on monotherapy (all drugs)	227	213	213	229
Number on combination therapy (all drugs)	291	270	248	218

Number on monotherapy (Paying drugs) <sup>4</sup>	227	213	216	230
Number on combination therapy (Paying drugs)	291	270	245	217
Number on Trial/Compassionate drug as part or all of therapy	19	6	9	7
Number not on any treatment <sup>5</sup>	64	64	55	60
Number referred to Papworth for assessment	28	36	35	31
Number operated for pulmonary thromboendarterectomy	17	15	13	11
Number accepted for BPA	█	0	█	█
Number of BPA procedures	█	█	6	█
Number referred for assessment for lung transplant (Freeman)	█	█	12	8
Number operated for lung transplant (Freeman)	█	█	█	0
Number on active transplant list (Freeman)	█	█	█	█

Table 2

- <sup>1</sup> Number of patients discharged – includes all patient types and all sites.
- <sup>2</sup> This is the total number of patients newly diagnosed with PAH during the period.
- <sup>3</sup> Active means referred to us but not yet discharged, deceased, lost to follow up or transferred to another PH centre.
- <sup>4</sup> When Trial/Compassionate drugs are excluded some combination patients become monotherapy, so the mono paying number can potentially be higher than the mono all treatments number!
- <sup>5</sup> This is a snapshot figure at the end of the period. This only includes patients diagnosed as PH due to PAH/CTEPH/Mis).
- \* Includes repeat right heart catheterisations

**Trend Graphs**

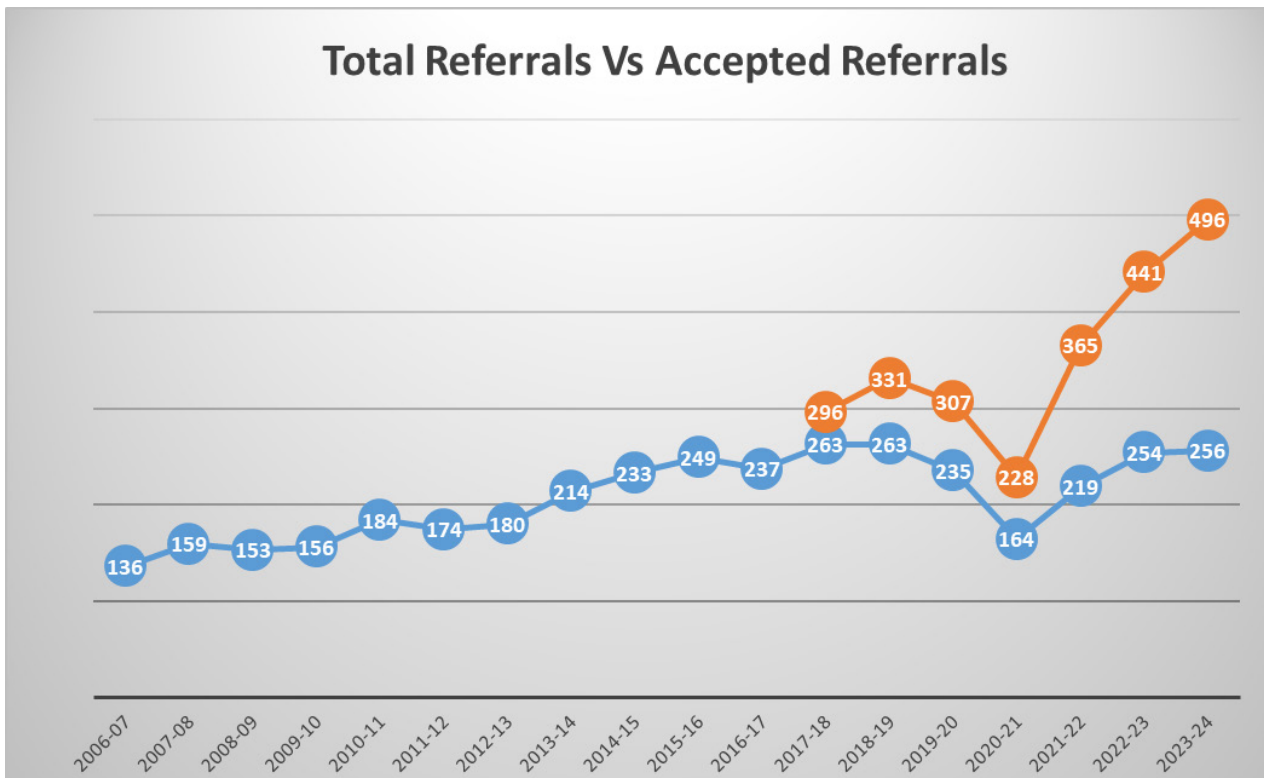


Figure 2: Total referrals are in orange and accepted referrals in blue.



## Number attending clinic with pulmonary hypertension (end of year snapshot)

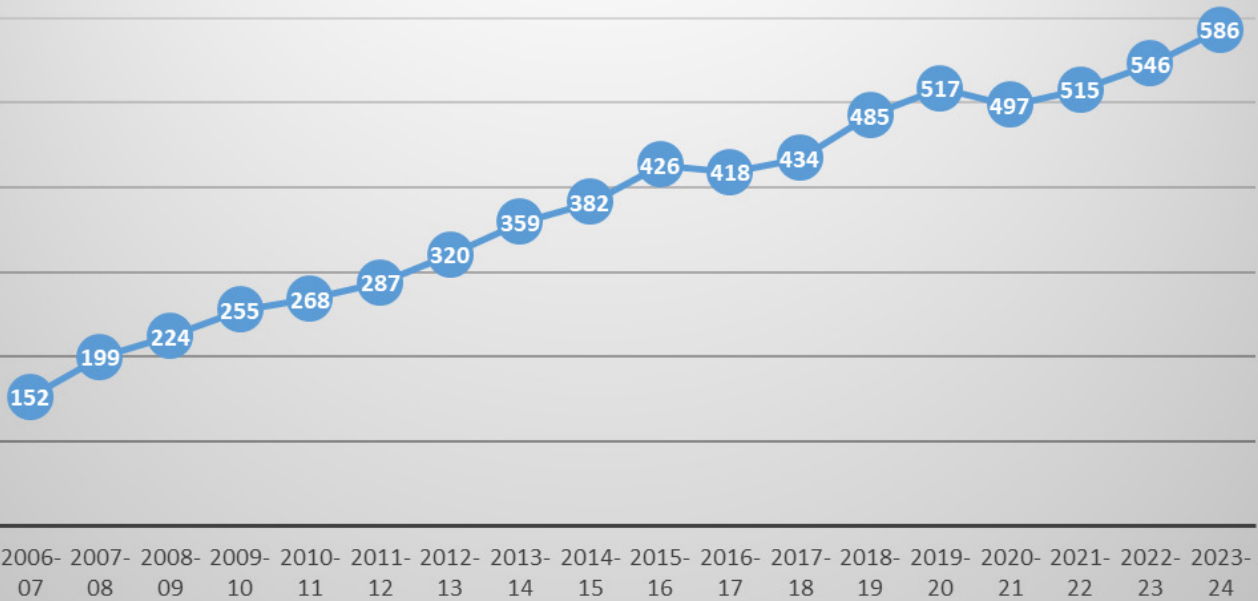


Figure 3

## Incidence - New cases PAH/CTEPH and CTED/Misc

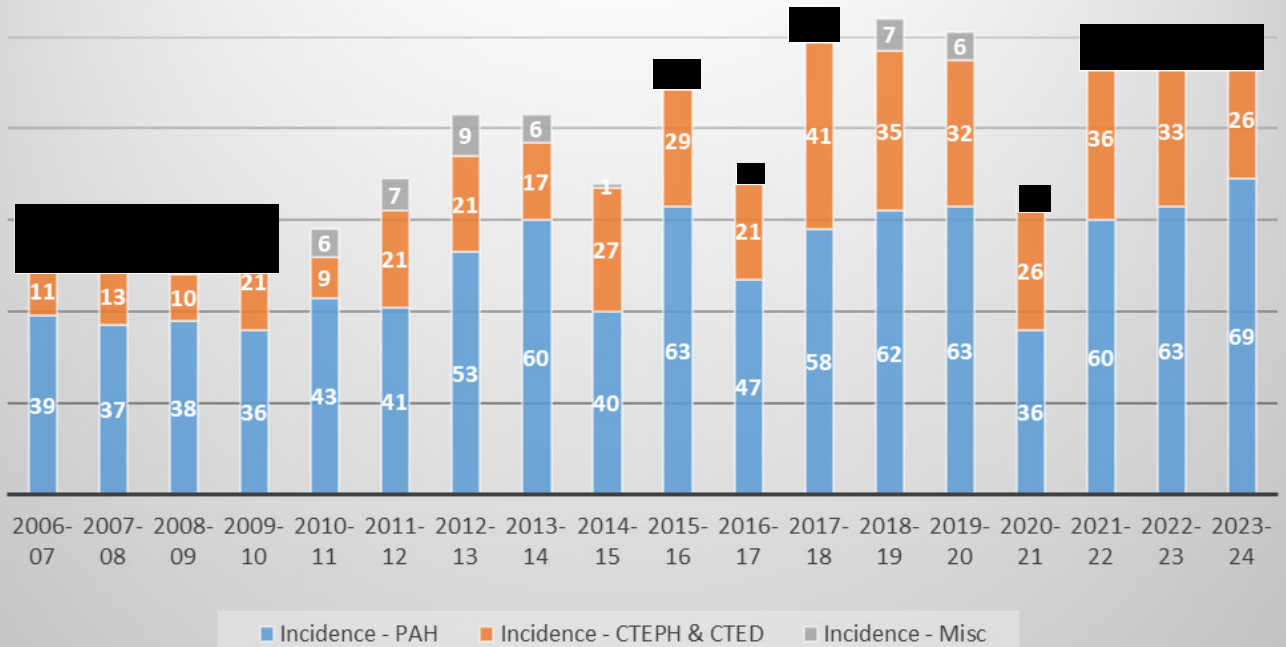


Figure 4

## Prevalence - PAH (end of year snapshot)

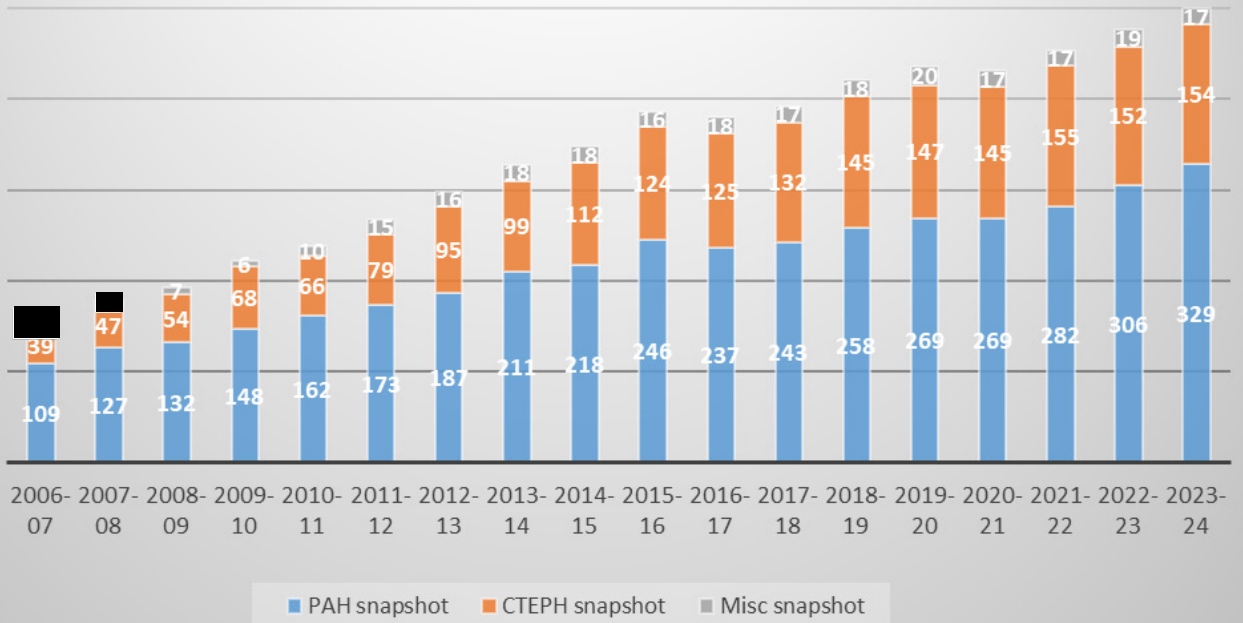


Figure 5

## Occupied Bed Days

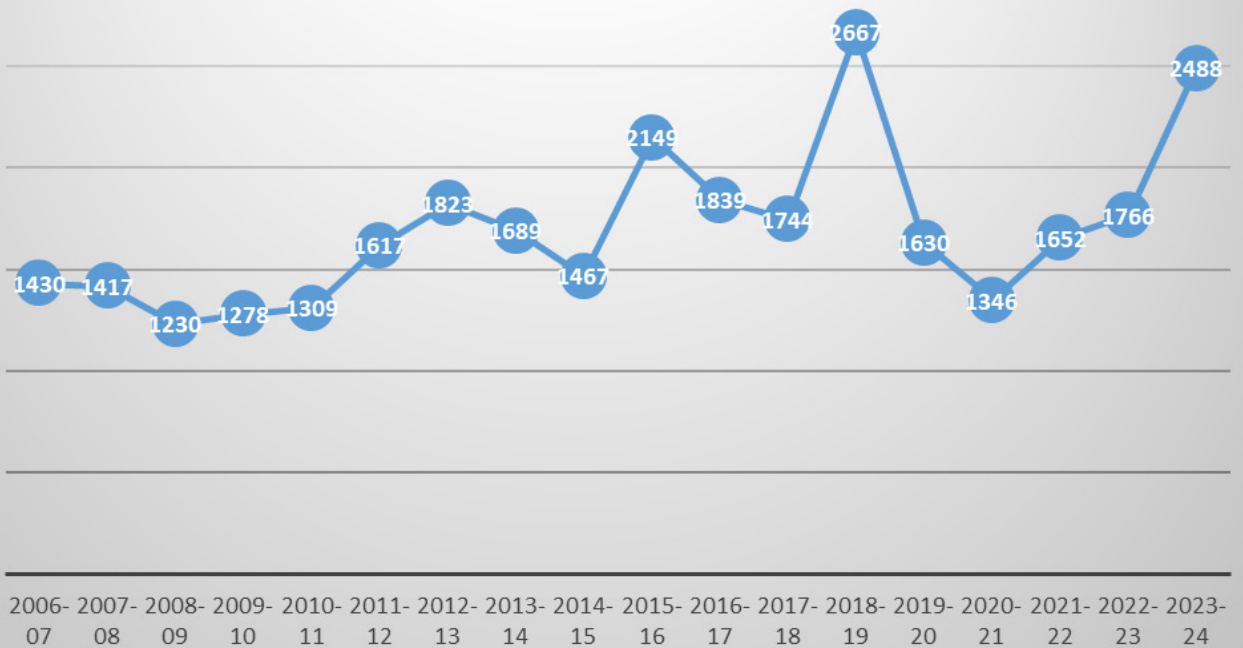


Figure 6

## Number of Right Heart Caths

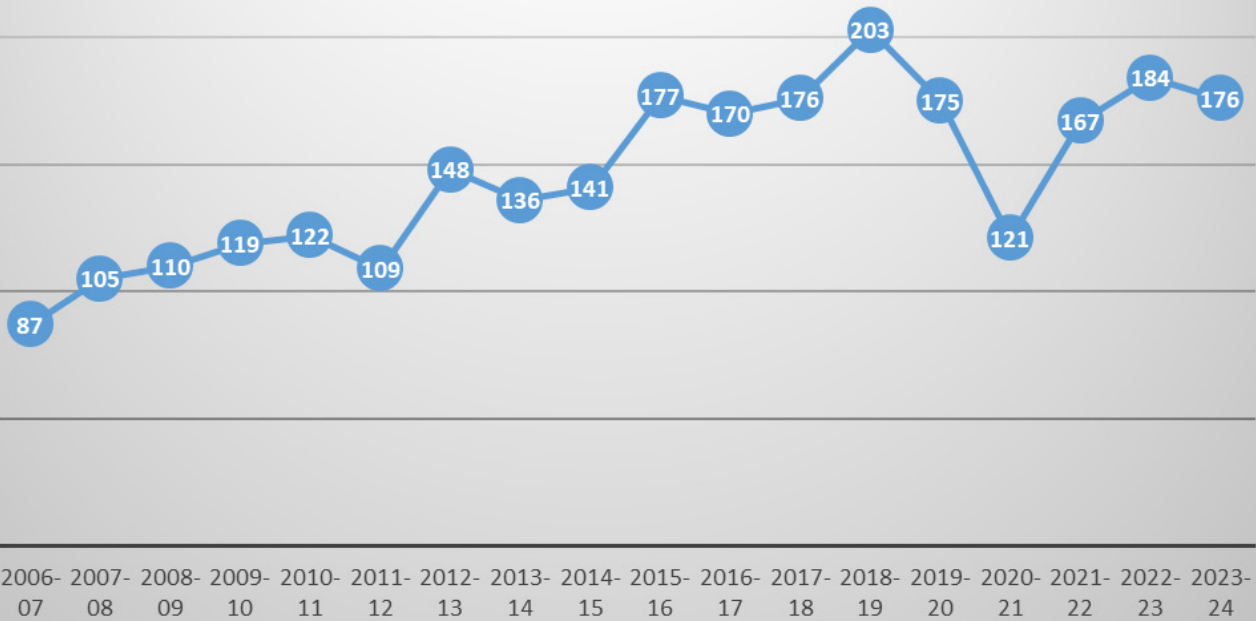


Figure 7

## Treatment Type (end of year snapshot)

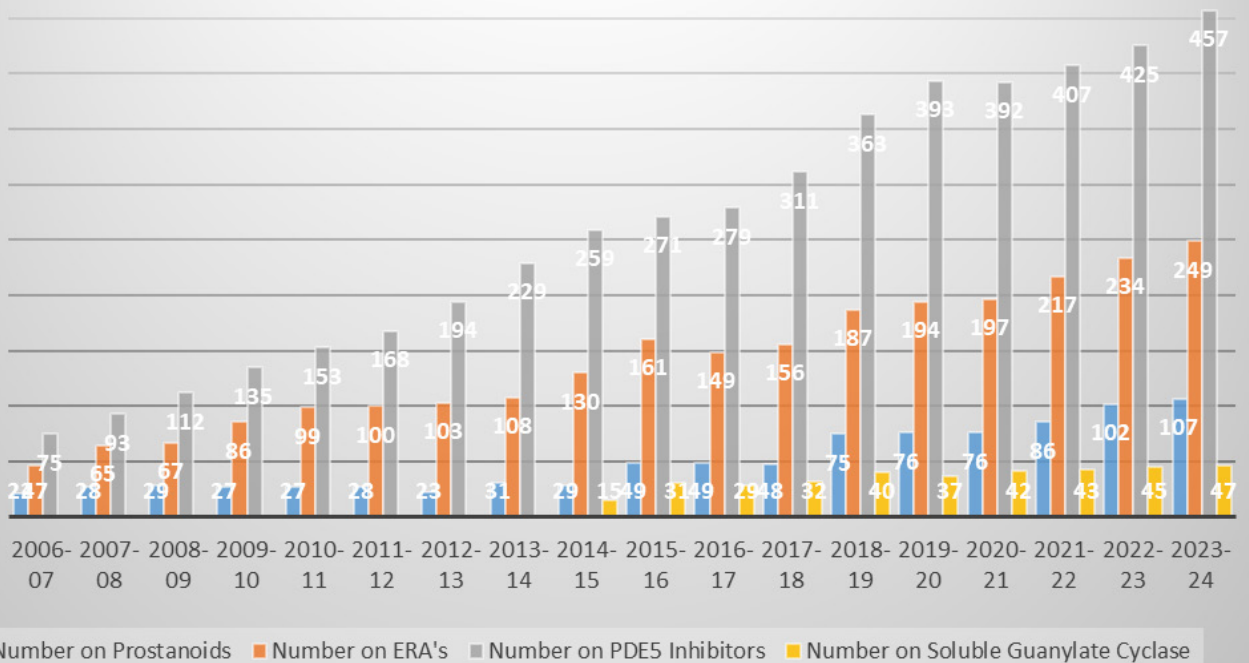


Figure 8

## Percentage of treated on Combination Treatment (end of year snapshot)

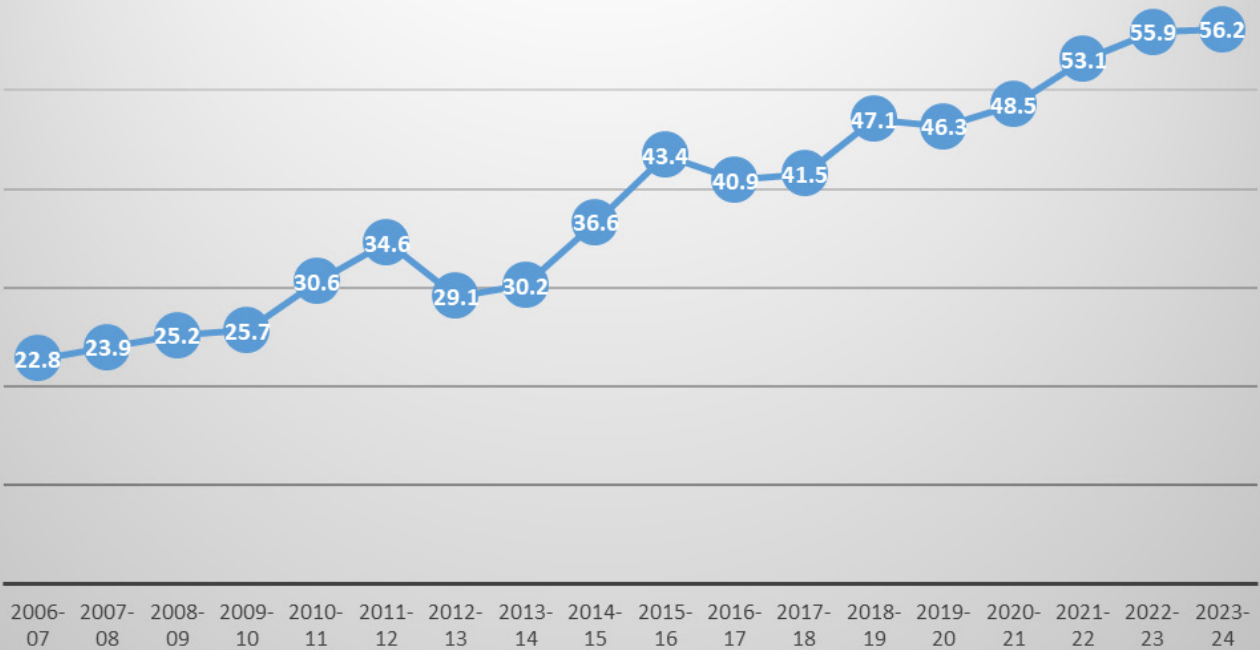


Figure 9

Combinations includes trial treatments – without trials the 2023 figure is still 56.2%

### Trends In Treatment Combination Type

Count of patients		Snapshot date		
		31/03/2022	31/03/2023	31/03/2024
Degree	Combination category			
<b>1- Mono</b>		<b>216</b>	<b>213</b>	<b>226</b>
	01 - Sildenafil	176	169	184
	02 - Tadalafil	18	17	13
	02a(30) - Riociguat	13	16	18
	03 - Ambrisentan	█	█	█
	04 - Bosentan	█	█	█
	05 - Epoprostenol	█	█	█
	40 - Macitentan	█	█	█
<b>2- Dual</b>		<b>207</b>	<b>223</b>	<b>243</b>
	01 - Sildenafil + 03 - Ambrisentan	54	68	85
	01 - Sildenafil + 04 - Bosentan	19	11	6
	01 - Sildenafil + 05 - Epoprostenol	22	25	27
	01 - Sildenafil + 11 - Iloprost - Inhaled	█	6	█

01 - Sildenafil + 40 - Macitentan	42	46	40
01 - Sildenafil + 50 - Selexipag	6	10	14
02 - Tadalafil + 03 - Ambrisentan	21	21	25
02 - Tadalafil + 04 - Bosentan	█	█	█
02 - Tadalafil + 05 - Epoprostenol	█	█	█
02 - Tadalafil + 11 - Iloprost - Inhaled	█		
02 - Tadalafil + 40 - Macitentan	8	7	14
02 - Tadalafil + 50 - Selexipag		█	█
02a(30) - Riociguat + 03 - Ambrisentan	7	█	█
02a(30) - Riociguat + 04 - Bosentan	█	█	█
02a(30) - Riociguat + 05 - Epoprostenol	█	█	█
02a(30) - Riociguat + 40 - Macitentan	9	9	6
02a(30) - Riociguat + 50 - Selexipag	█	█	█
03 - Ambrisentan + 05 - Epoprostenol	█		█
11 - Iloprost - Inhaled + 40 - Macitentan	█	█	
<b>3- Triple</b>	<b>38</b>	<b>47</b>	<b>49</b>
01 - Sildenafil + 03 - Ambrisentan + 05 - Epoprostenol	█	█	█
01 - Sildenafil + 03 - Ambrisentan + 23 - Treprostinil - Infusion (subcutaneous)			█
01 - Sildenafil + 03 - Ambrisentan + 50 - Selexipag		█	6
01 - Sildenafil + 04 - Bosentan + 05 - Epoprostenol	█	█	█
01 - Sildenafil + 04 - Bosentan + 50 - Selexipag	█	█	█
01 - Sildenafil + 05 - Epoprostenol + 40 - Macitentan	9	9	10
01 - Sildenafil + 11 - Iloprost - Inhaled + 40 - Macitentan	█	█	█
01 - Sildenafil + 40 - Macitentan + 50 - Selexipag	6	7	█
01 - Sildenafil + 50 - Selexipag + 50 - Selexipag		█	
02 - Tadalafil + 03 - Ambrisentan + 05 - Epoprostenol	█	█	█
02 - Tadalafil + 03 - Ambrisentan + 11 - Iloprost - Inhaled	█	█	█
02 - Tadalafil + 03 - Ambrisentan + 23 - Treprostinil - Infusion (subcutaneous)			█
02 - Tadalafil + 03 - Ambrisentan + 50 - Selexipag	█	█	█
02 - Tadalafil + 04 - Bosentan + 11 - Iloprost - Inhaled	█		
02 - Tadalafil + 40 - Macitentan + 50 - Selexipag		█	█
02a(30) - Riociguat + 03 - Ambrisentan + 05 - Epoprostenol		█	█
02a(30) - Riociguat + 03 - Ambrisentan + 11 - Iloprost - Inhaled	█	█	█
02a(30) - Riociguat + 03 - Ambrisentan + 50 - Selexipag	█	█	█
02a(30) - Riociguat + 05 - Epoprostenol + 40 - Macitentan	█	█	█
02a(30) - Riociguat + 40 - Macitentan + 50 - Selexipag	█	█	█
<b>Grand Total</b>	<b>461</b>	<b>483</b>	<b>518</b>

Table 3

## Summary

Referral activity is the highest this year that we have seen as is the number of patients discharged at MDT. Diagnostic capacity has not yet been overwhelmed because of the more robust MDT process that we now follow. All referrals are discussed at the MDT before their path through our system is established. This multidisciplinary assessment by PH consultants, cardiologist and PH radiologist has increased the discharge rate at the MDT point. Otherwise service numbers are relatively steady including the number of patients diagnosed with Groups 1, 4 and 5 pulmonary hypertension.

An increase in occupied bed days has been experienced, at QEUH. This increase is multifactorial and reflects a generally sicker patient group at the point of treatment, requiring inpatient and occasionally HDU level management. This has been contributed to further by challenges of repatriation of patients to their base hospital.

The number of new outpatient Did Not Attends (DNAs)/late cancellations has risen this year, and is the highest we have seen in the last 4 years. Future work will look to more accurately categorise these clinic outcomes as either DNA or late cancellation. The empty new outpatient slots are utilised to absorb the overbooking of return patient clinic appointments.

### 3. Performance and clinical outcomes

#### 3.1 Equitable

We have previously analysed the association between social deprivation score and prognosis in IPAH/ HPAH, CTDPAH and CTEPH patients. We found that the prevalence was higher or equivalent in the worse social class groups and that social deprivation did not worsen prognosis suggesting equitable access to the service and treatment independent of social background.

We, as a Unit, strive to deliver a service that embraces all aspects of Equality and Diversity which is a core component to the delivery of high quality care, providing equal quality to everyone with consistency across all settings, aiming for a single standard of quality and excellence for all our patients.

The Learning Disabilities Standards group has provided work towards meeting the action plan around QIS LD standards for Vulnerable People. SPVU are working towards identifying those patients with LD so that the appropriate support is available for these patients on arrival either in clinic or within the wards.

NHS Board	Referrals (accepted)			Diagnostic Inpatient assessment			Diagnosis of Gp 1, 4 or 5 PH		
	23/24	22/23	21/22	23/24	22/23	21/22	23/24	22/23	21/22
Ayrshire & Arran	16	14	11	12	9	7	6	6	█
Borders	█	█	█	█	█	█	0	█	█
Dumfries & Galloway	8	6	6	7	█	█	█	█	█
Fife	16	12	13	█	6	9	█	6	8
Forth Valley	17	12	8	16	8	█	10	6	█
Grampian	33	22	17	17	18	12	12	11	12
Greater Glasgow & Clyde	76	98	83	43	61	51	23	27	27
Highland	12	9	10	10	█	8	8	█	6
Lanarkshire	23	18	19	19	14	16	15	9	13
Lothian	29	36	32	17	24	20	8	17	13
Orkney	0	█		0	0	0	0	0	0
Tayside	23	18	13	12	12	11	12	8	6
Shetland	0	█	█	█	█	█	0	0	█
Western Isles	0	0	0	0	0	0	0	0	0
<b>Total</b>	█	<b>254</b>	<b>219</b>	<b>161</b>	<b>165</b>	<b>149</b>	<b>99</b>	<b>96</b>	<b>103</b>

Table 4

Health Authority	Bosentan	Tadalafil	Ambrisentan	Sildenafil	Macitentan	Riociguat	IV Epoprostenol	Selexipag	Nebulised lioprost	Treprostinil	Grand Total
Ayrshire & Arran	█	8	12	25	█	7	█	█			63
Borders	█		█	12	█	█		█			21
Dumfries and Galloway		█	6	12	█	█	█				26
Fife	█	6	11	24	7	6	█	6			66
Forth Valley			6	23	7	█	6	█		█	51
Grampian	█	█	18	45	7	█	8	█			93
Greater Glasgow & Clyde	█	24	27	93	24	12	9	9	█		202
Highland	█	█	10	26	6	█	7	█	█		59
Lanarkshire	█	8	22	39	8	█	9	█			94
Lothian	█	10	17	56	15	█	█	6	█	█	119
Orkney		█	█								█
Shetland				█							█
Tayside	█	█	11	33	█	█	█	█	█		58
Western Isles				█							█
Grand Total	19	67	144	390	86	47	58	37	6	█	856

Table 4.1: Drug treatments by health board

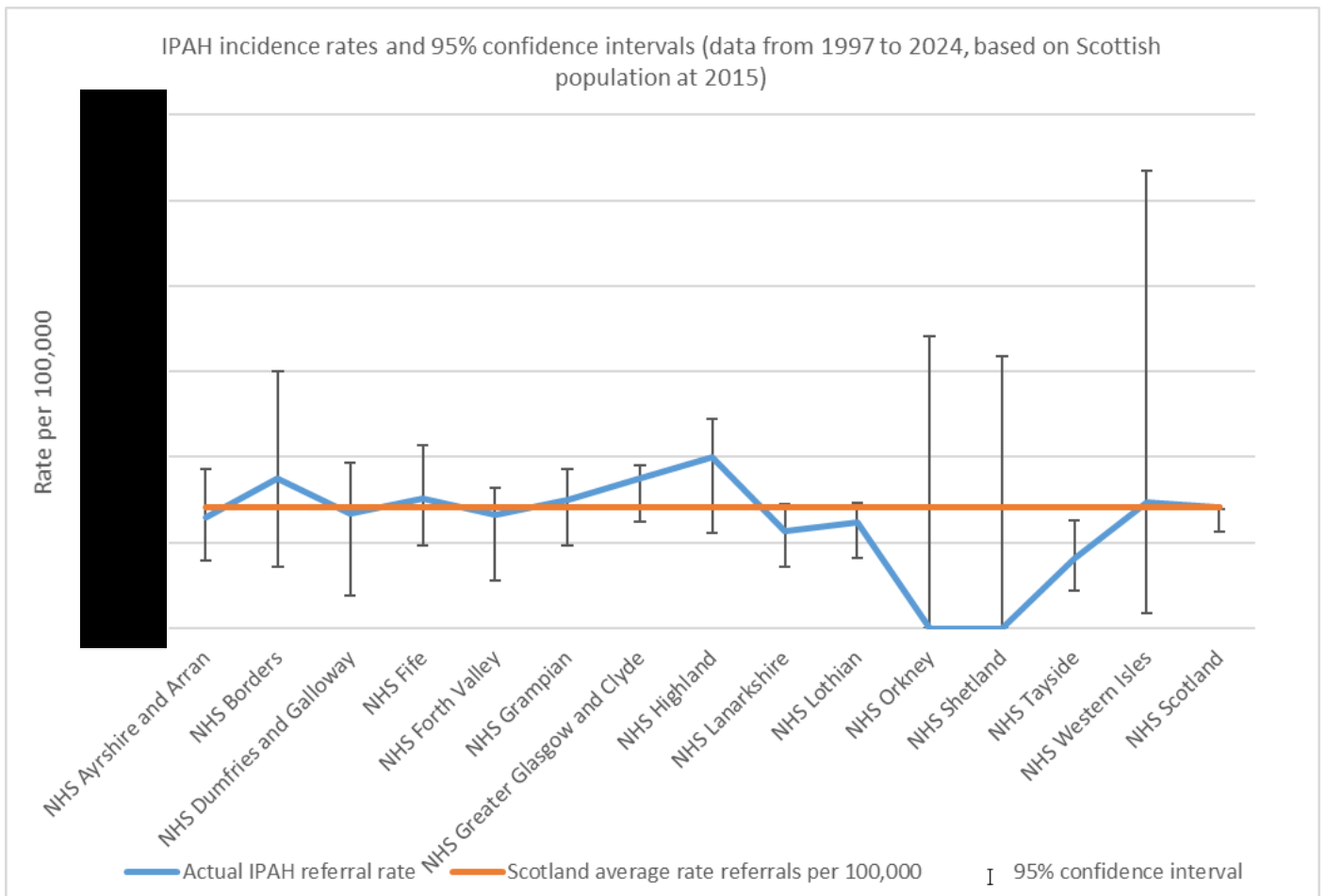


Figure 14



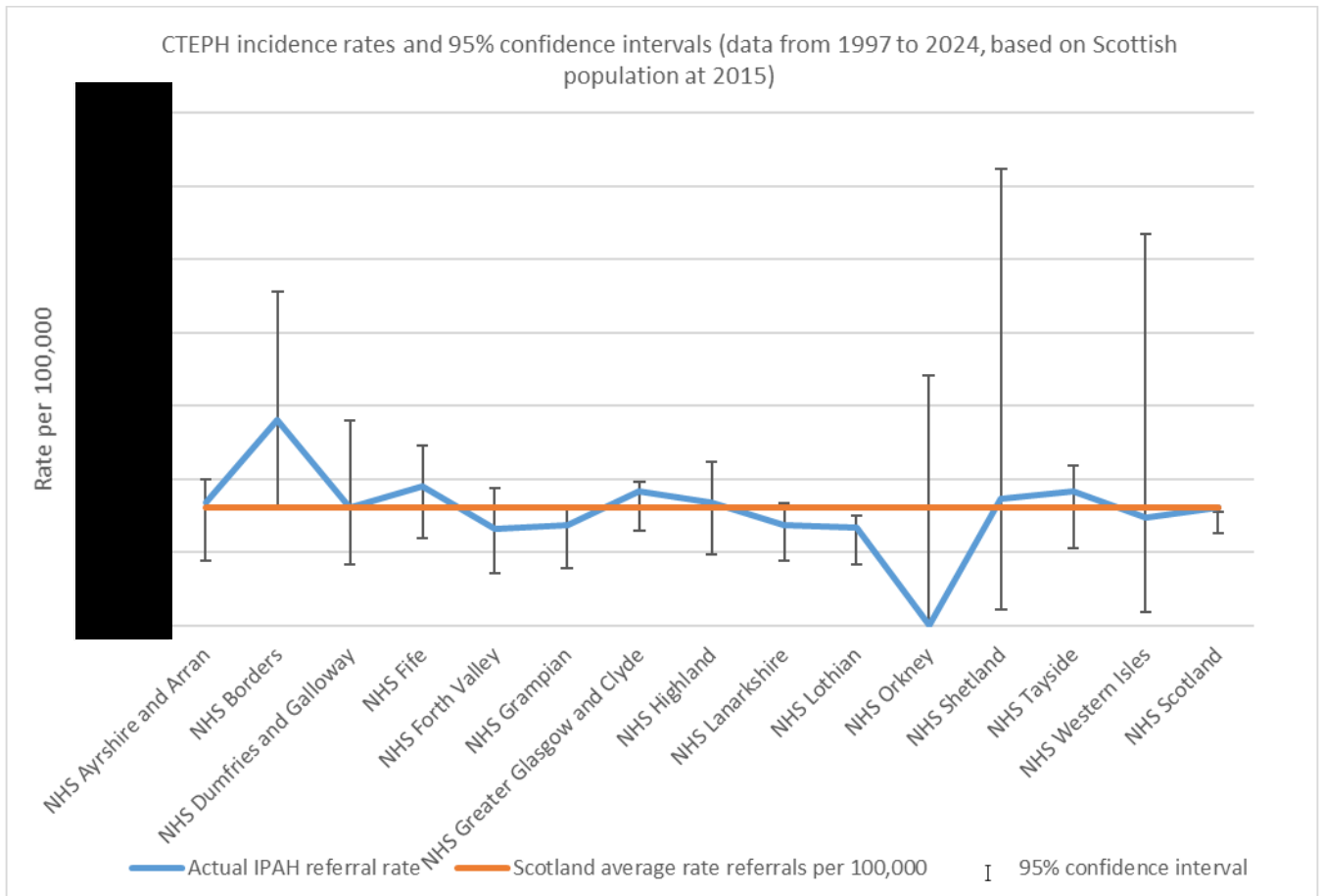


Figure 15

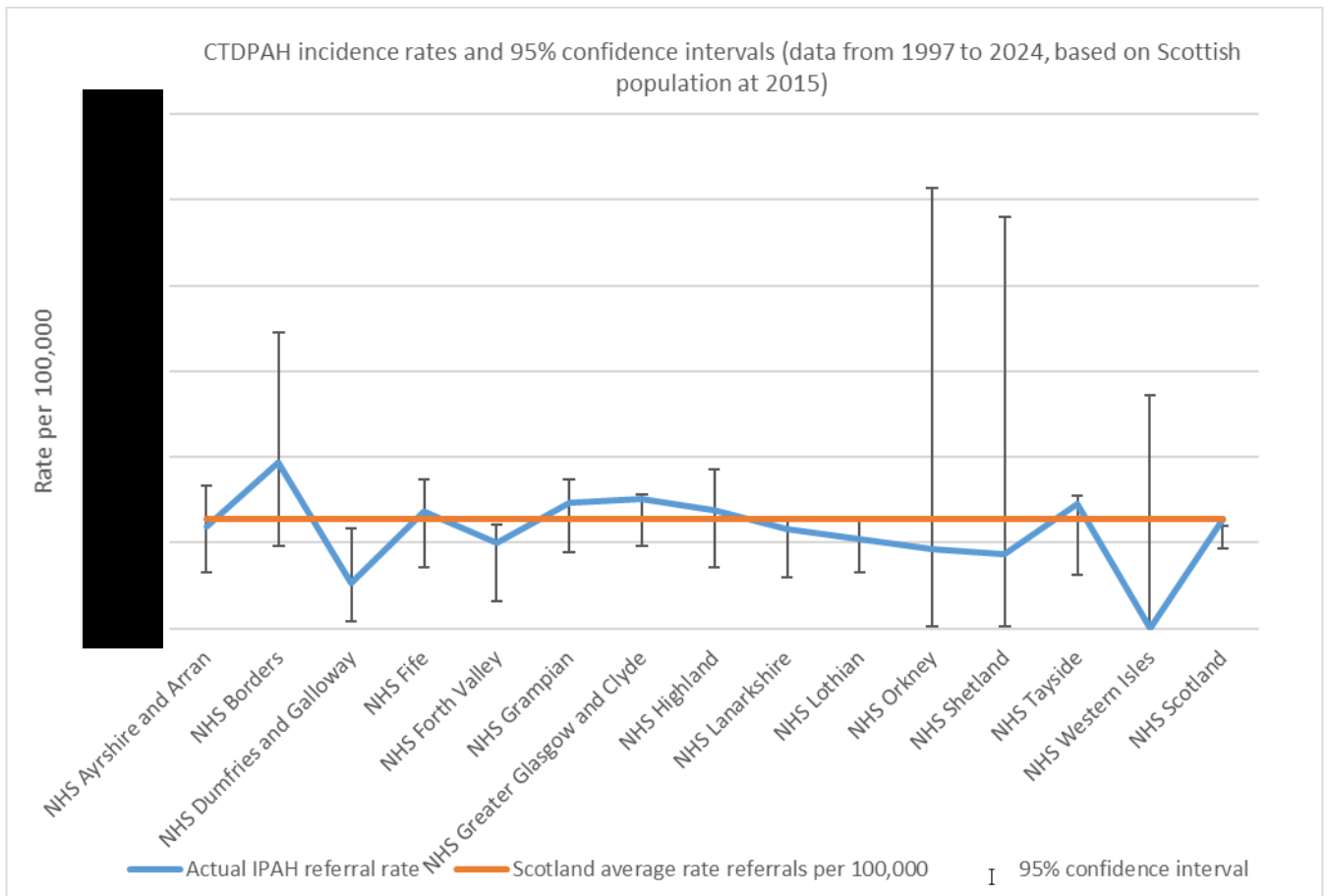


Figure 16

## Summary

Although there is referral mismatch from the Scottish health boards, there is no major and increasing mismatch of diagnostic prevalence. Social deprivation is not a barrier to management of PH in Scotland.

### 3.2 Efficient

National Audit Targets	NPHA Target	2023-24	2022-23	2021/2022	2020/21
% receiving a PH drug who had a PH diagnosis recorded	99		100	99	99
% whose firstline therapy was a PDE5 inhibitor	80		91	91	94

Table 5: 2023-24 data will be available end June

Over the last 3 years, we have changed our practice in reviewing new referrals. We have extended our weekly MDT to discuss most new referrals at the written referral stage. This means that before seeing a new referral in person we already have SPVU respiratory, cardiology and radiology consensus on the likely diagnosis. This has resulted in earlier decision making in the diagnostic pathway with a reduction in GJUNH diagnostic admissions (as a percentage of referrals).

<b>Conversion Rates (see further analysis below)</b>	2023/24	2022/23	2021/22	2020/21	2019/20
From total referral to accepted referral		58%	60%	72%	77%
From total referral to GJNUH diagnostic admission		34%	41%	46%	56%
From total referral to diagnosis of PH (Gps 1,4,5 and CTED)		20%	28%	32%	33%
From accepted referral to GJNUH diagnostic admission		59%	68%	65%	73%
From accepted referral to diagnosis of PH (Gps 1,4,5 and CTED)		35%	47%	46%	43%
From GJNUH diagnostic admission to diagnosis of PH (Gps 1,4,5 and CTED)		59%	69%	70%	60%
Length of stay – GJUNH					
Mean	2.91	2.94	2.85	2.6	2.9
Median	3	3	3	3	3
Range	1-3	1-3	1-4	1-5	1-4
Length of stay – QEUH					
Mean	13.11	11.8	11.56	12.0	9.8
Median	10	9	10	8	8
Range	1-103	1-43	1-44	1-86	1-41

Table 6

### 3.3

	2022-2023		2021-2022		2020-2021	
	Absolute Number	% of Total Referrals	Absolute Number	% of Total Referrals	Absolute Number	% of Total Referrals
<b>Total referrals</b>	441		365		225	
<b>Accepted referrals</b>	254	58	219	60	161	
<b>Declined referrals</b>	187	42	146	40	64	28
<b>Seen as new patient</b>	168	38	147	40	95	42
<b>GJUNH admissions (assessment)</b>	165	37	149	41	105 <sup>1</sup>	47
<b>Repeat right heart cath</b>	17		18		16	
		<b>% of admissions</b>		<b>% of admissions</b>		<b>% of admissions</b>
<b>Group 1, 4 or 5 Diagnoses (including CTED<sup>2</sup>)</b>	97	59	103	69	74	70
<b>Group 2, 3 or no PH Diagnoses</b>	68	41	46	31	31	30

Table 6.1: 2023-24 data will be available end June

#### Notes

1. Lower than Table 2 as excludes repeat right heart catheterisations
2. Chronic thromboembolic disease

### Timely

National Audit Targets	NPHA or SLA Target	2023/24	2022/23	2021/22	2020/21
% with diagnosis within 6 months	95		100	100	96
% new patients seen or discharged within 30 days	50		68	77	81
% new patients seen or discharged within 12 weeks	95		98	98	96
% new patients beginning drug therapy within 10 weeks	80		93	85	94
% with CTEPH waiting less than 4 months for surgery	90		0	0	█

Table 7: 2023-24 data will be available end June

The tables below show the numbers of patients on the outpatient and inpatient waiting list and length of time waiting.

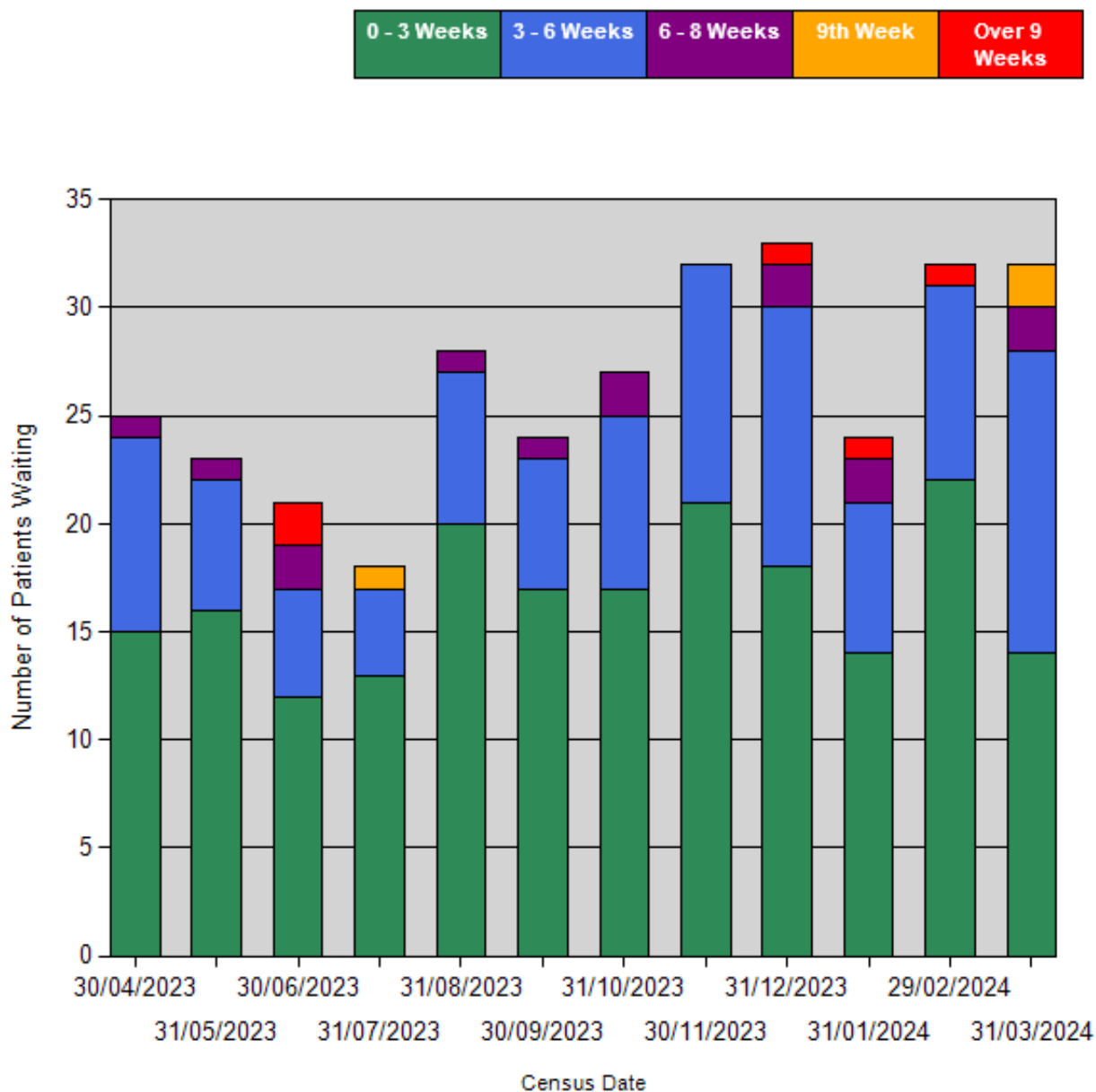


Figure 17: Numbers of SPVU New patients on the outpatient waiting list – 2023-24

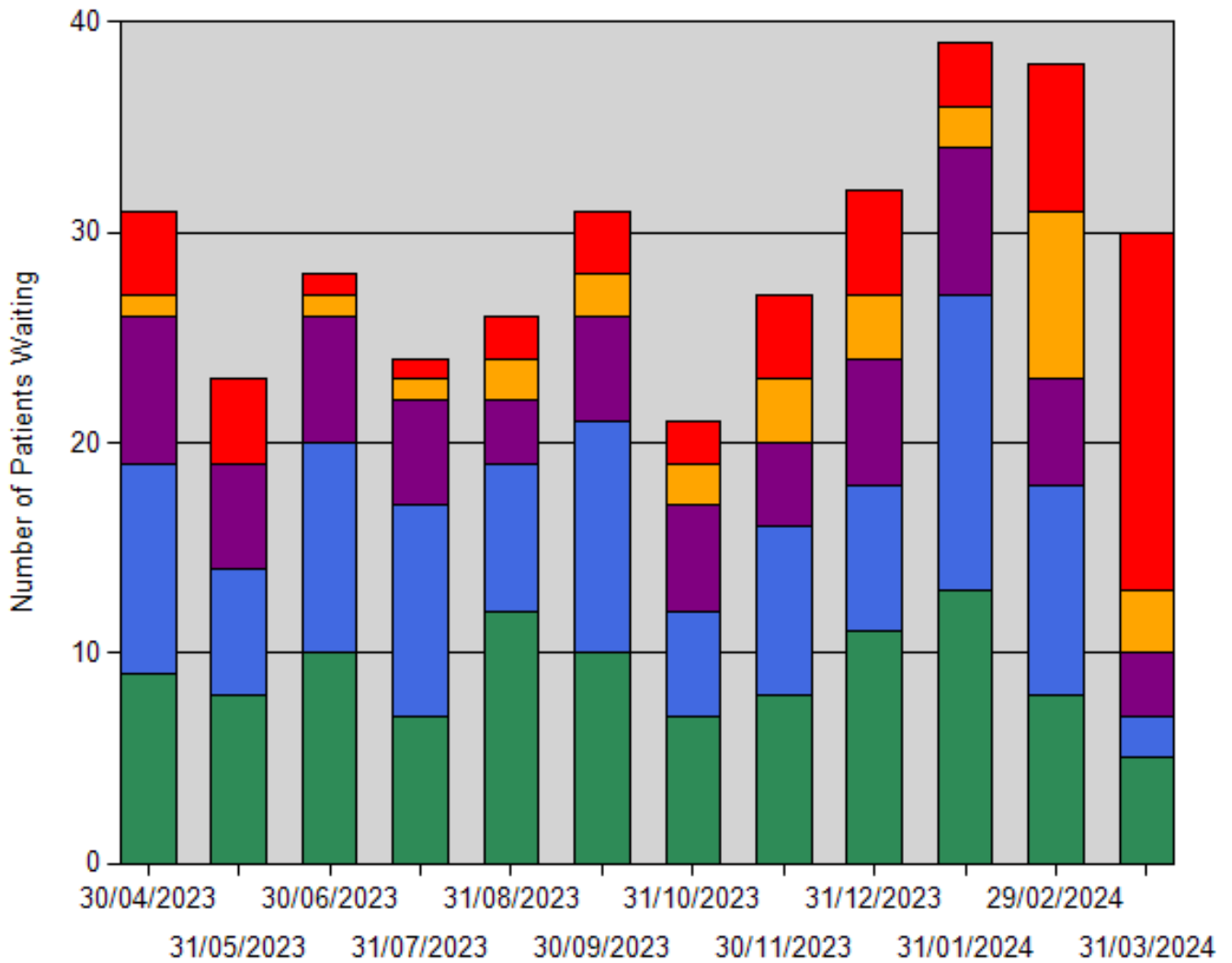


Figure 18: Numbers of SPVU new patients on the inpatient waiting list – 2023-24

### 3.4 Effectiveness

We have 3 monthly meetings focused on mortality, morbidity and clinical governance. External benchmarking is achieved by contribution of our patient data to the National Audit of Pulmonary Hypertension.

National Audit Targets	NPHA Target	2023/24	2022/23	2021/2022	2020/21
% with pre-treatment functional class and 6mwt	90		99	99	92

Table 9: 2023-24 data will be available end June

**Functional Class**

Treatment significantly improves functional class (n=1088).

**Effect of Treatment on Functional Class  
All treated patients**

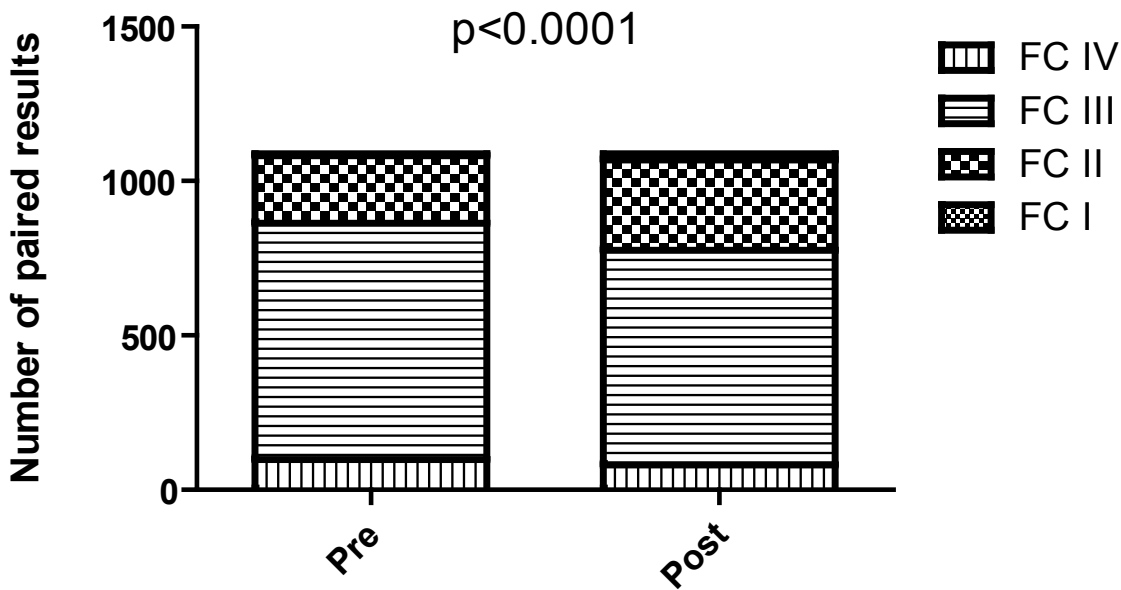


Figure 19

Treatment effect by type of pulmonary hypertension

	% FC I/II		Number of paired results	p-value
	Pre	Post		
Idiopathic/Heritable	16	26	310	0.006
Connective tissue disease	17	24	263	0.09
Portopulmonary	29	40	63	0.03
Chronic thromboembolic (medical treatment)	27	35	268	NS

Table 10

## 6-minute walk distance

Treatment significantly improves 6 minute walk distance (by a mean change of 31.0 m). (n=795)

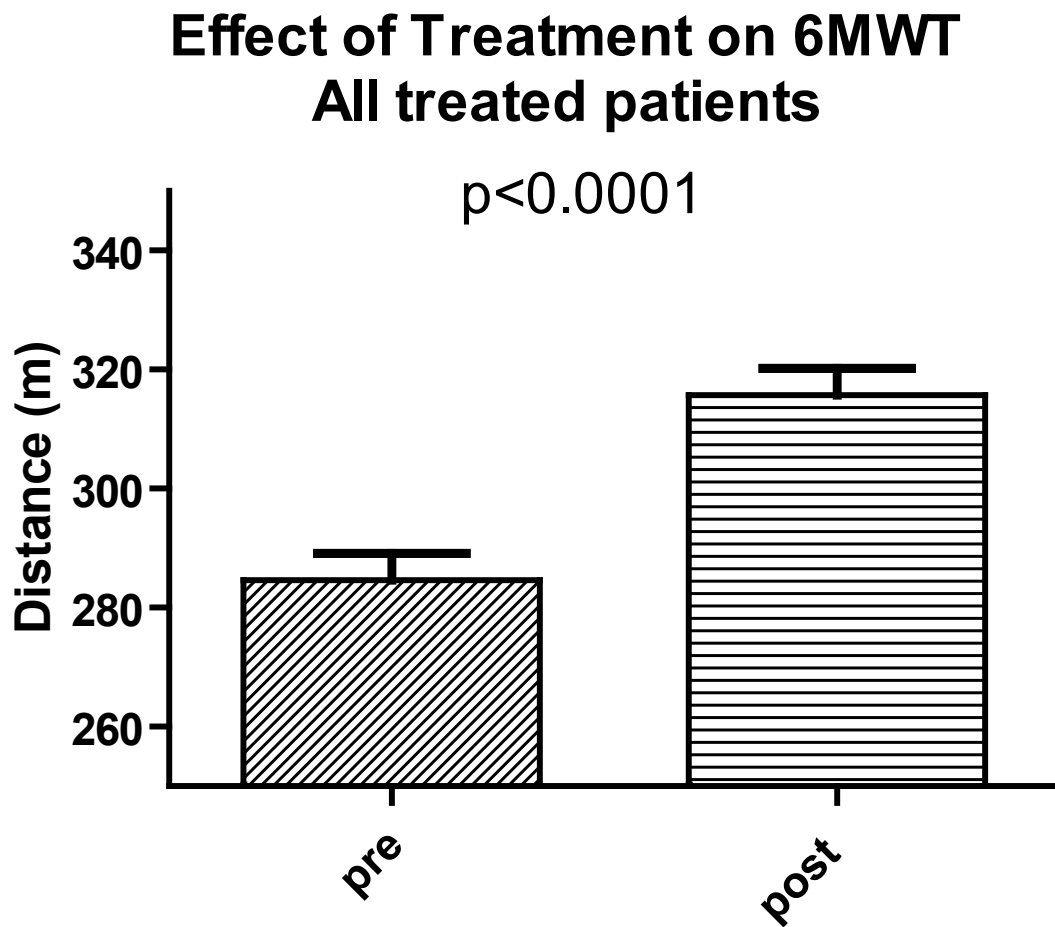


Figure 20

Treatment effect by type of pulmonary hypertension

	Mean Improvement in Walk Distance (m)	Number of paired results	p-value
Idiopathic/Heritable	45	234	<0.0001
Connective tissue disease	27	174	<0.0001
Portopulmonary	39	47	0.003
Chronic thromboembolic (medical treatment)	24	175	<0.0001

Table 11

## Quality of life

Treatment significantly lowered EMPHASIS-10 score by 2.2 points (n=490).

### Effect of Treatment on EMPHASIS-10 All treated patients

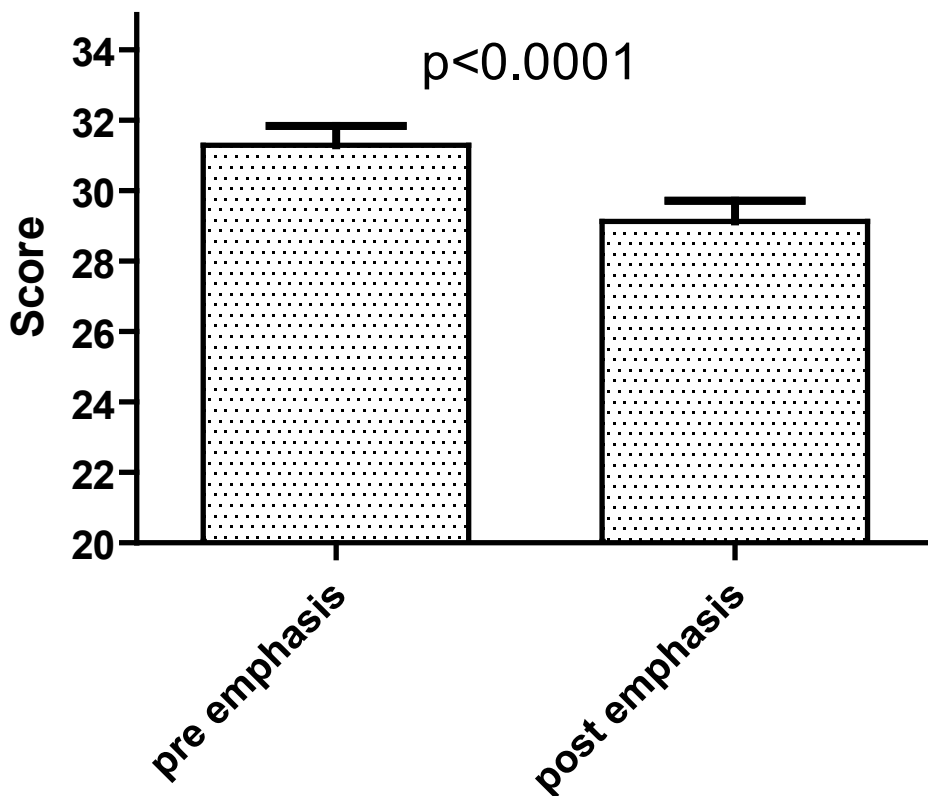


Figure 21

	Mean Improvement in Emphasis – 10	Number of paired results	p-value
Idiopathic/Heritable	5.4	132	<0.0001
Connective tissue disease	2.6	109	0.01
Portopulmonary	-2.7	22	NS
Chronic thromboembolic (medical treatment)	0.0	118	NS

Table 12

## NTproBNP

Treatment produces a fall in NTproBNP from a median value of 1414 to 701 ng/L (n=861)



## Effect of Treatment on NTproBNP All treated patients

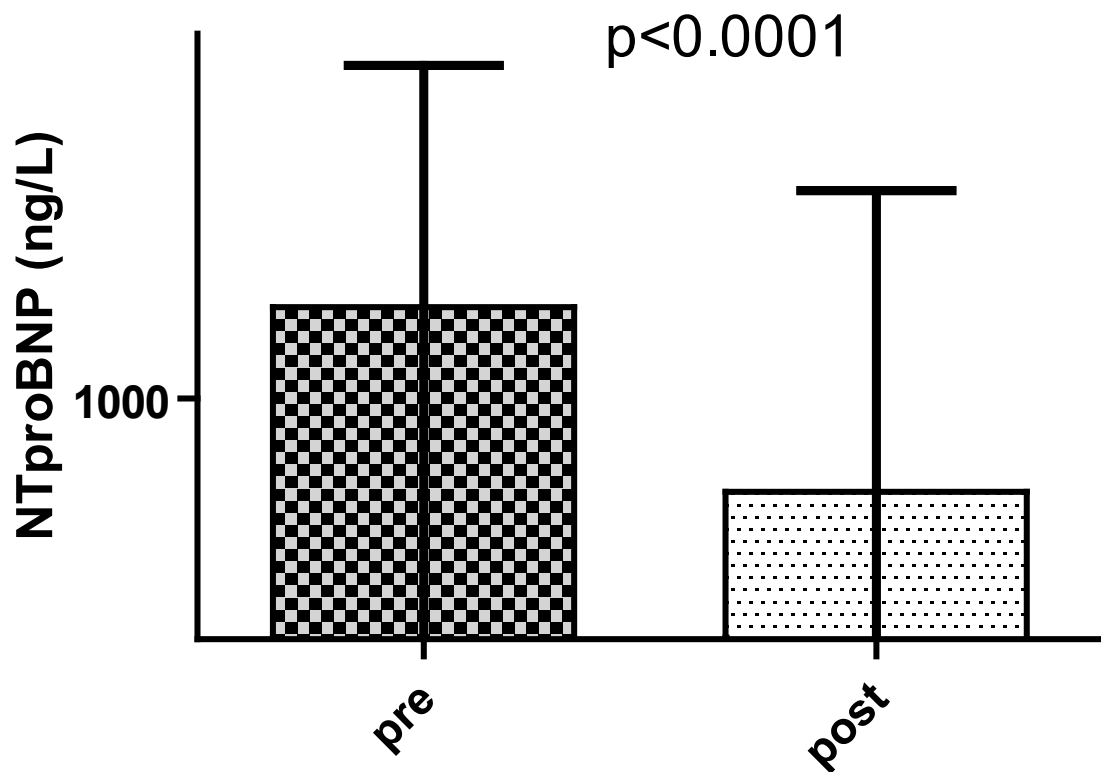


Figure 22

Treatment effect by type of pulmonary hypertension

	Median NTproBNP (ng/L)		Number of paired results	p-value*
	Pre	Post		
<b>Idiopathic/Heritable</b>	1814	662	250	<0.0001
<b>Connective tissue disease</b>	1876	850	201	<0.0001
<b>Portopulmonary</b>	325	168	48	0.05
<b>Chronic thromboembolic (medical treatment)</b>	1182	672	214	<0.0001

Table 13

\* Statistical test done on log (NTproBNP) values

## Treatment Epoch

The following tables show changes in treatment outcomes over time. It can be seen that in the most recent period compared with earlier ones that:

- baseline outcome values are generally worse (smaller proportion of FC II patients, lower walk distance, higher NTproBNP);
- post-treatment outcome values are stable; and
- changes brought about by treatment are larger.

These results have been achieved despite an older (by 8 years) cohort in the most recent data collection period. We believe that this supports our strategy of more aggressive and earlier combination treatment with disease targeted therapy.

	% FC I/II Pre	% FC I/II Post	Number of paired results	p-value*
<b>2005-2009</b>	22	29	180	0.03
<b>2010-2014</b>	20	27	256	0.09
<b>2015-2019</b>	18	25	306	0.09
<b>2020-2024</b>	24	32	298	0.05

Table 14

\* chi-squared complete functional class table looking at change within epoch

	Walk Distance Mean Pre	Walk Distance Mean Post	Mean Improvement in Walk Distance	Number of paired results	p-value*	p-value**
<b>2005-2009</b>	291	319	28	127	<0.0001	
<b>2010-2014</b>	287	305	18	182	0.0006	
<b>2015-2019</b>	286	320	33	229	<0.0001	NS†, 0.01††
<b>2020-2024</b>	268	316	48	191	<0.0001	0.07†††

Table 15

\* 1 value t-test; mean improvement > 0 within epoch

\*\* unpaired t-test, most recent epoch compared with earlier

† 2015-2019 vs 2005-2009

†† 2015-2019 vs 2010-2014

††† 2020-2023 vs 2015-2019

	NTproBNP Median Pre	NTproBNP Median Post	Median Change in NTproBNP	Number of paired results	p-value*	p-value**
2005-2009	1076	761	-72	116	0.004	
2010-2014	1615	1107	-119	225	<0.0001	
2015-2019	1407	642	-331	266	<0.0001	0.003†, 0.002††
2020-2024	1442	432	-619	243	<0.0001	0.01†††

Table16

\* analysis done on log NTproBNP values; 1 value t-test; mean change < 0 within epoch

\*\* analysis done on log NTproBNP values; unpaired t-test, most recent epoch compared with earlier

† 2015-2019 vs 2005-2009; †† 2015-2019 vs 2010-2014; †††2020-2023 vs 2015-2019.

N.B. Epochs are Jan to Dec

### Survival Analysis

The survival of patients with IPAH/HPAH managed in the SPVU is shown below with the 25 year period divided into 6 epochs (consistent with earlier annual reports).

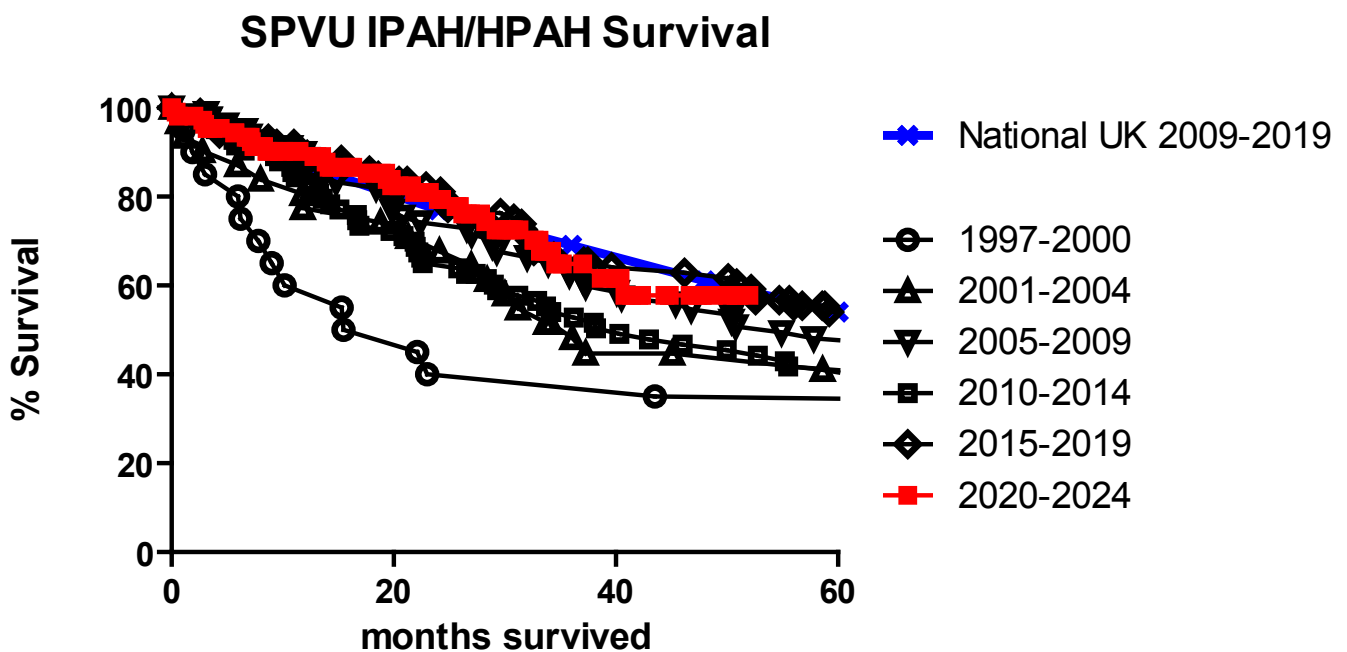


Figure 23

Survival for the last 12 years is shown below compared with national figures. 5 year survival currently sits at approximately 54%.

## SPVU IPAH/HPAH Survival

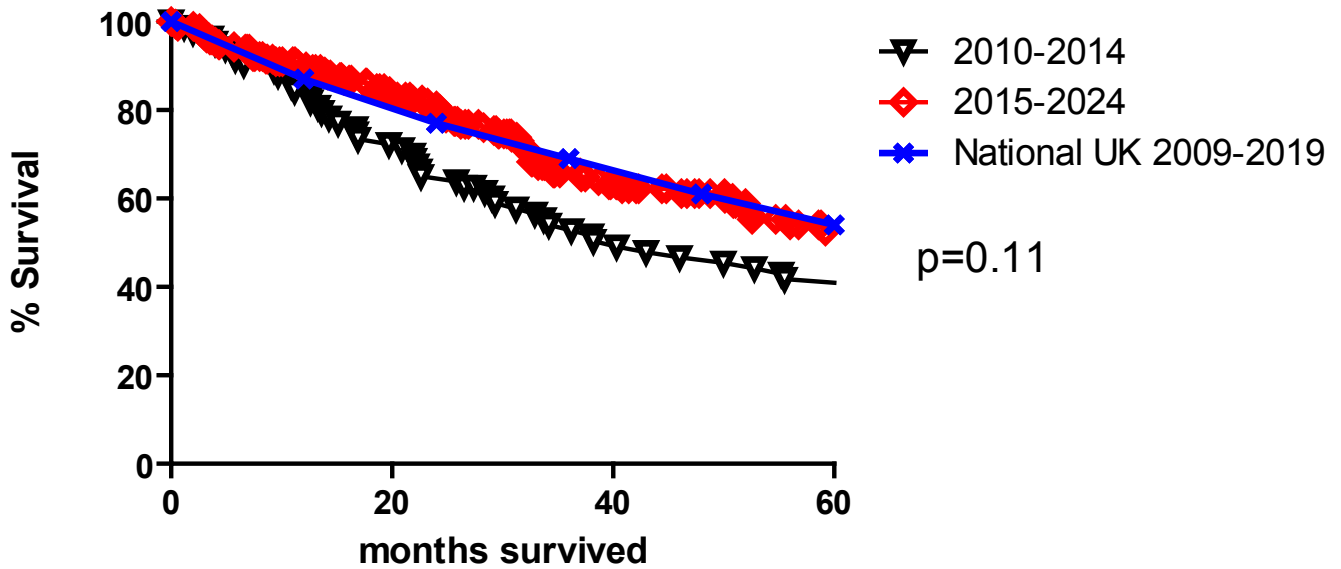


Figure 24

Major independent baseline factors predicting poor survival are:

- increasing age;
- male sex;
- lower diffusing capacity (TLCO);
- higher right atrial pressure (RAP);;
- lower cardiac output (CO)
- lower 6 minute walk distance (6MWD); and
- higher NTproBNP.

## SPVU IPAH/HPAH Survival Effect of Age at Diagnosis

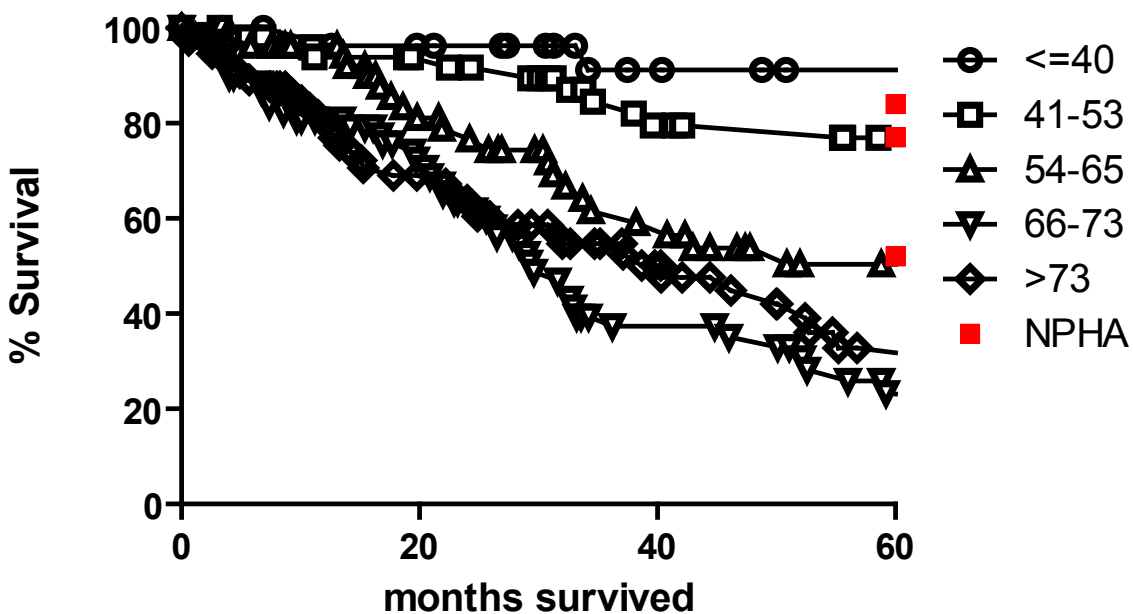


Figure 25

The effect of age on survival is illustrated above. NPHA figures at 5 years are for IPAH/HPAH without comorbidities (so best possible results). Valid comparison of survival in the cohorts requires these variables to be matched (see figure below). It can be seen that more recent cohorts are older with worse TLCO (and appear to have adverse trends in other variables such as 6MWD and NTproBNP). NTproBNP is significantly higher in the most recent cohort.

	1997-2000	2001-2004	2005-2009	2010-2014	2015-2019	2020-2024	p-value
n	20	31	79	82	87	108	
Age (years)	51.6	54.7	56.3	60.0	61.9	64.6	0.0008
Proportion male (%)	45	29	43	35	41	47	NS
TLCO (% predicted)	65.5	53.8	43.7	43.8	46.9	45.1	0.03
RAP (mmHg)	8.8	8.6	7.2	9.5	8.2	9.2	NS
CO (L/min)	3.3	3.9	3.8	3.6	3.8	3.5	NS
6MWD (m)	374	233	274	270	244	226	NS
NTproBNP (ng/L)*	-		1515	1679	1583	2981	NS

Table 17 \*Median

### Summary

When inspected from several angles, measures of effectiveness appear to be improving particularly when factors such as the increasing severity of PH at diagnosis and age are considered. The data on outcome measures split by treatment epoch are particularly compelling.

### 3.5 Safe

National Audit Targets	NPHA Target	2023/24	2022/23	2021/22	2020/21
PH centre should see a sufficient number of patients with PAH and CTEPH	300		556	544	451
% patients receiving a PH drug with a pre-treatment cardiac cath	95		98	99	96
% patients receiving a PH drug who have an annual consultation	95		97	96	92

Table 18 2023-24 data will be available end June

\* **Figure low because of COVID-19**

	2023/24	2022/23	2021/22	2020/21	2019/20	2018/19
Number of Hickman line infections (no per patient day) – positive microbiology	3/21535	2/21360	0/16425	6/13528*	1/13870	1/13140
Significant adverse events	0	0	0	0	1	0

Table 19

\*From the above Table, it can be seen that here was a spike in Hickman line infections in the pandemic year. This has not recurred in the following year and we wonder if this was a pandemic related phenomenon.

The SPVU hold 3-monthly meetings dedicated to clinical governance issues and have a regular clinical governance item on the monthly business meeting. We are enabling participation in this meeting from both QEUH and GJUNH sites by holding a hybrid face to face / Teams meeting.

The 3-monthly meeting agenda includes:

- Discussion of mortality and morbidity cases and figures over the last 6 months;
- Presentation of audits;
- Discussion of DATIX reports and risk register;
- Discussion of complaints and compliments;
- Review of waiting times; and
- Review of unit protocols and Standard Operating Procedures (SOPs).

Mortality figures are analysed in the following manner:

- Deaths between referral and diagnosis;
- Deaths within 4 months of diagnosis;
- Cause of deaths in patients with PAH; and
- Treatment of patients with deteriorating PH – any missed opportunities for use of IV epoprostenol or referral for transplantation.

## Summary

Patient safety is carefully monitored by the service.

### 3.6 Person-centred

We held a Patient Day in October 2022 – this had been postponed from March 2020. This included talks from unit members, a talk from a patient, a panel which answered questions from the floor, workshops and an update from the Scottish oxygen service. There were also “Enriching Lifestyle Sessions” on Massage, Reiki and Reflexology.

The programme is attached as Appendix 2 and a review written by a patient and published in the Spring 2023 edition of the PHA-UK magazine, Emphasis is attached as Appendix 3. We hope to hold another Patient Day within the next 12 months.

## PROMs

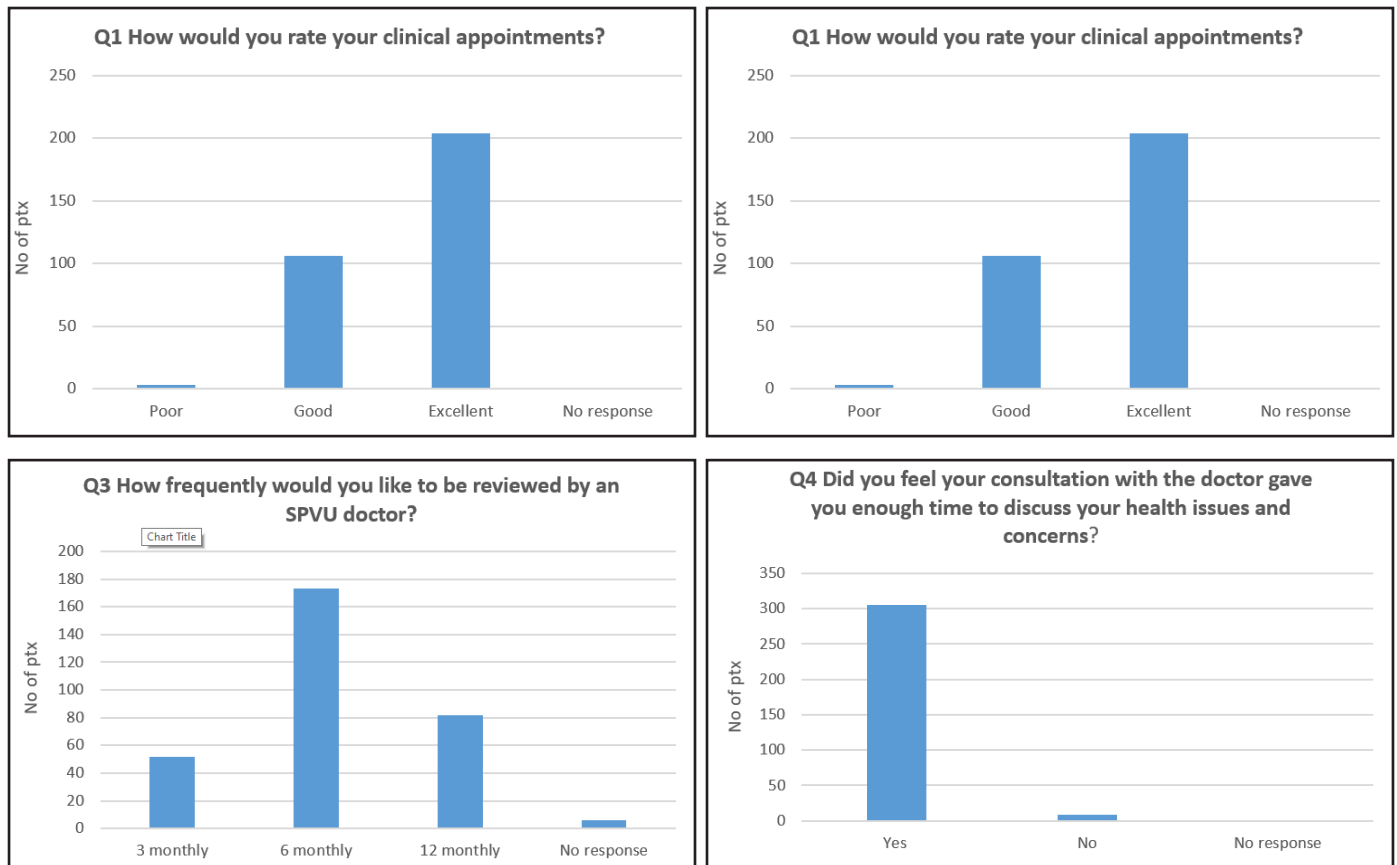
National Audit Targets	NPHA Target	2023/24	2022/23	2021/22	2020/21
% patients where quality of life recorded within last year	90		80	79	81

Table 20: 2023-24 data will be available end June

Last year we missed the standard on assessment of quality of life, scoring 81% compared with the standard of 90%. This was because it proved very difficult to obtain quality of life measurements during telephone consultations despite sending out the Emphasis 10 questionnaires in advance and doing a mailshot of patients with no recorded quality of life. We are looking at alternative ways of achieving this target in the future.

**PREMs** – the latest SLA states “25% of patients should be asked about their patient experience related to their inpatient or outpatient care”.

Consequently, our nursing and admin staff have recently conducted a postal survey of the modified outpatient process both at GJUNH and at our 2 outreach sites in Edinburgh and Aberdeen. This explored overall satisfaction with the clinic experience, acceptability of telephone appointments, views on frequency of review and asked for suggestions for improvements. There were 313 respondents, approximately 50% of our patient population. There was general satisfaction with the clinic experience but there is always room for improvement.



We asked for suggestions whether and in what way the clinics could be improved. The majority (84%) did not think improvements were required. Of the suggestions for improvements that were made, there were only 3 which occurred with any frequency. These were:

- Reducing waiting time at clinic (8 respondents);
- More time seeing the clinic medical staff (4 respondents); and
- Refreshments in the clinic waiting room (3 respondents).

### 3.6.1 Patient Carer / Public Engagement

Within NHS Golden Jubilee, our public engagement and Equality and Diversity activity comes under the Involving People Strategy as mentioned in previous reports and this work continues.

We have a dedicated Equality and Service Design lead. The heart of this role is around hearing the voices of our existing service users and carers, potential service users and staff are heard while taking forward innovation and developing our services.

## Interpretation and translation

In the last year, NSD has had 34 patients who have been unable to communicate in English. The GJUNH has provided daily Interpretation services for the following languages. Arabic, British Sign Language (BSL), Dari, Krio, Kurdish Sorani, Malayalam, Polish, Portuguese, Punjabi, Urdu, Romanian, Spanish, Tamil and Ukrainian. It should be noted that our Interpretation and translation services are, not only for our patients, but for their carers and families too.

Interpretation services have provided translation for information booklets, appointments and discharge letters, use of medications and other form of written communication in all of these languages.

## Volunteers

A key element in how we deliver our Involving People Strategy is our Volunteer Service.

The Volunteer Service has supported the work of NHS Golden Jubilee for over 14 years. All 10 of the volunteer services have returned with plans to fully return the Quality Walkround Service as Care Experience in the coming months. The Volunteer Manager continues to build partnerships in the local community to increase the number of volunteers from 37 to meet the needs of the Phase 2 Development. Many new volunteers from diverse backgrounds are supporting the current services together with longstanding volunteers.

Many volunteers fulfil patient-facing roles including Pastoral Care and Patient Peer Support. Volunteers continue to support the Eye Centre and the 'Meet and Greet Service' and 'Outpatient Support Service' are developing in preparation for their role in The Surgical Centre when it opens in 2024.

In 2023, there was an increase in our activity as services returned and our volunteer service provided:

- 988 volunteer sessions;
- 2267 volunteer hours of support to patient focussed services; and
- Support to 15,027 patients .

Our Volunteer Forum meets quarterly and is chaired by 1 of our Non-Executive Directors. This acts as a consultative group for support and development of the volunteer service and the aim is to have each volunteer service represented at the meetings.

We are most proud of these aspects of our volunteer service:

- An increase in the number of volunteers through partnership working, resulting in a diverse mix of volunteers together with the recruitment of more young people.
- The development of the Patient Peer Support Service with 4 volunteers who support patients in SNAHFS, SACCS and the thoracic departments.
- The continued growth of the Pastoral Care Service which the aim of volunteers visiting patients morning, afternoon and evening over 5 days. There are a total of 12 volunteers who are active or training for the role.

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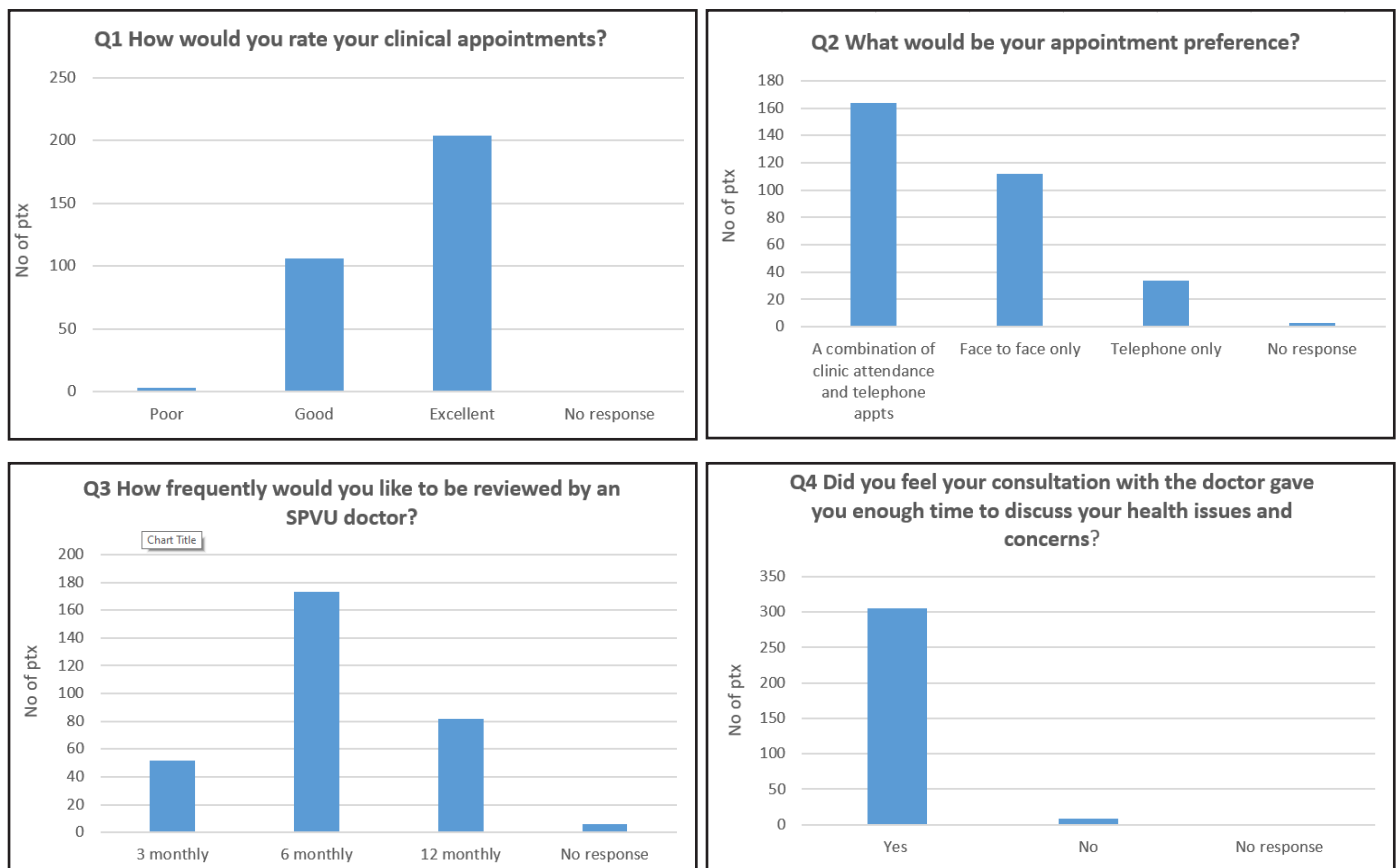
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The aims for the volunteer service moving forward:

- To provide Meet and Greet and Outpatient Support Volunteers for the Surgical Centre when it opens. These volunteer services will also continue to be provided in the main hospital.
- To continue to fulfil The Volunteer Strategy 2023-2026 and achieve the milestones to build and expand the volunteer service.
- To provide training for volunteers to develop their skills and meet the needs of patients, e.g. Dementia Awareness and Autism Training.
- To raise awareness of the volunteer service and the contribution volunteers make to the hospital through our Comms Team and social media.

## 4. Quality and service improvement

There is a continuing trend in the patients that we manage that they are both older and sicker at point of diagnosis and this is demonstrated clearly in our outcome measures, particularly the longitudinal analysis. Despite this, survival figures are currently holding steady and other outcomes improving. Our results are very similar to those published in the National Audit both in terms of patient prognosis and our performance relative to the National PH standards. We believe this to be a consequence of the detailed assessment and holistic management (including medical, nursing, pharmacy and psychological) that we try to provide for this patient group.

### Nursing staff

- We now have 4 Band 7 specialist nurses, 2 of whom are working part-time. This enables us usually to have a simultaneous nursing presence at both QEUH and GJUNH, enhancing the productivity of the service.
- The nursing staff continue to consolidate their specialist practitioner role. This is particularly noticeable in the nurse-led clinics, management of Epoprostenol, Iloprost and now Treprostinil therapy and acting as a first-line telephone triage and advice service for any queries from our patient population.
- The process of converting patients from CADD Legacy to CADD Solis pumps is well underway and is managed exclusively by the nursing staff and pharmacist. This should be completed by the end of 2024.
- We have moved our inpatient base at GJUNH from Level 3 East (Cardiothoracics) to Level 2 East (Cardiology). This new inpatient location is a much improved fit for our patient group and has involved our nurses delivering an education programme to GJUNH nursing staff.
- The administrative process for access to benefits in terminally ill patients has recently changed to a new system (BASRiS). Our nursing staff are developing a process for disseminating this information to our patients as many of them fit into the category of having a terminal illness.
- Over the past year the SPVU CNS team have started a new initiative to review patient's oxygen requirements annually. We now have an accurate record of the total number of patients under our care on oxygen on our site register which is accessible to all staff within the team. This will also allow for participation in any LTOT service evaluation to ensure service quality and improvements.

### Pharmacy

- Over the last 12 months we have been fortunate to have a seconded pharmacist covering maternity leave for the SPVU pharmacist.
- This has produced a number of SOPs to improve the practice of our unit, including:
  - Reconciliation, prescribing and administration of SPVU medicines
  - Conscious sedation
  - Outpatient empirical initiation of PDE-5 inhibitors
  - Outpatient titration of intravenous epoprostenol (Flolan)
  - Use of intravenous furosemide infusion in patients with Pulmonary Hypertension
- Prescribing, reconstitution and administration of intravenous epoprostenol in a ward setting
- 1 SOP produced by our pharmacists in collaboration with our nursing staff has been for the administration of sc Treprostinil. This has enabled 2 of our young patients to receive parenteral prostanoid when otherwise they would have had to go without.
- Our pharmacist continually reviews cost-effectiveness and works with external stakeholders including homecare companies and pharmaceutical industry to ensure timely access to medicines at the minimum cost.
- The Apodi service for uptitration of selexipag is now well embedded in our practice, increasing the reliability of this process and freeing up pharmacist time for other activities.
- Pharmacist input has been very useful in a number of unit audits. This includes an audit on generic prescribing which demonstrated that over 70% of our PH drug prescriptions are for generic drugs. Also we looked at anticoagulant prescribing in IPAH to identify patients where the risk benefit ratio was not in their favour and anticoagulation should be stopped.

- With the availability of generic endothelin receptor antagonists we have been transitioning patients off Bosentan which requires monthly blood test monitoring and now have only 19 patients continuing on this drug.
- The pharmacist contributes to the education programme organised by our nurses.

## **Psychology**

- The Psychology service continues to mature.
- We have been developing the referral process along 2 lines, namely referral by a health care professional (doctor, nurse, etc) prompted by a PHQ4 score or self-referral prompted by a patient information leaflet that our psychologist has developed.
- The psychology service is also starting a research study on “Interoception” which means the correct interpretations of symptoms or signals from your body.

## **Inpatient services**

- The weekly MDT is increasingly active. We review approximately 15 to 20 cases now each week. As can be seen from the activity figures, we have seen referrals increase by 35% since 2021/2022. Despite this the number of diagnoses of Group 1 and Group 4 PH has remained remarkably constant at ~ 100 per year. This large increase in workload has only been accommodated in 2 ways. We critically review and reject a proportion of referrals at the MDT stage (now sitting at approximately 50% of referrals). This year we have been treating some of the more frail patients referred to us empirically with a ceiling of care of generic medication. Whilst this is efficient, the downside is that this may ultimately have an adverse impact on our performance against national standards.
- There are now very few of our IPAH patients who have not had screening for genetic markers.

## **Outpatient services**

- We continue to be able to see new outpatients within 30 days of referral. We are able to maintain this standard by admitting the more clearcut patients directly, bypassing the new outpatient appointment step in the process. We have also run new patient clinics in Glasgow concurrently with the outpatient clinic in Aberdeen.
- Return outpatient slots are oversubscribed and the Glasgow clinic is always overbooked.
- We have trialled POCT of NT-proBNP in our clinic. We find it to have acceptable accuracy and to accelerate the decision making process. We hope to introduce this as a regular feature of the clinic this year.

## **Clinical database**

- We have now returned to 1 full-time data manager which is improving the collection of data on our patients.
- Unfortunately the server housing the database has not yet been replaced and so we are still working with a Windows 7 version of Infoflex software.

## **Research**

- Activity of CTIMP studies has picked up with the unit participating in several globally important clinical trials of promising new medications.
- 2 of our research staff have recently been replaced and the new staff are working well.

## Financial statement

- The annual cost of the service has increased. This reflects the numbers of patients on treatment which is currently increasing annually by 10%, largely driven by increased prevalence (diagnosis vs death) rather than incidence which is static. A further increase this year was in occupied bed days at QEUH which were up by 50%. This figure is not the highest that we have seen and does vary from year to year. We think that some of this year's increase is due to the increasing severity of the patient's condition at point of diagnosis which leads to an admission to stabilise the patient at that point in their pathway. This in turn could be a direct consequence of the longer wait patients are experiencing between referral and treatment.

## Quality assurance – reporting compliance

NHS Golden Jubilee has extensive involvement in the Scottish Patient Safety Programme. This includes monitoring of pressure ulcers and falls outcomes as reported in the following table. Healthcare associated infections along with catheter associated urinary tract infection and venous thromboembolism bundles are in place and monitored. The structured response to the deteriorating patient and septic patient are in use and aid communication particularly through the hospital at night structure.

The Senior Charge Nurses continue to have overarching responsibility to ensure sustained compliance with safety essentials; nursing staff within individual areas have key roles to audit compliance with the safety essentials relevant to their areas. Over 2022/23 there has been continued focus on audit compliance with increased support locally from Clinical Governance to ensure and sustain improvement where required within the ward teams.

The CNM and the Infection Control Nurse Manager usually carry out HEI peer reviews to ensure assess compliance with SPSP and infection Control standards. This programme was restarted in June 2021 following a pause due to the initial phase of the COVID-19 pandemic.

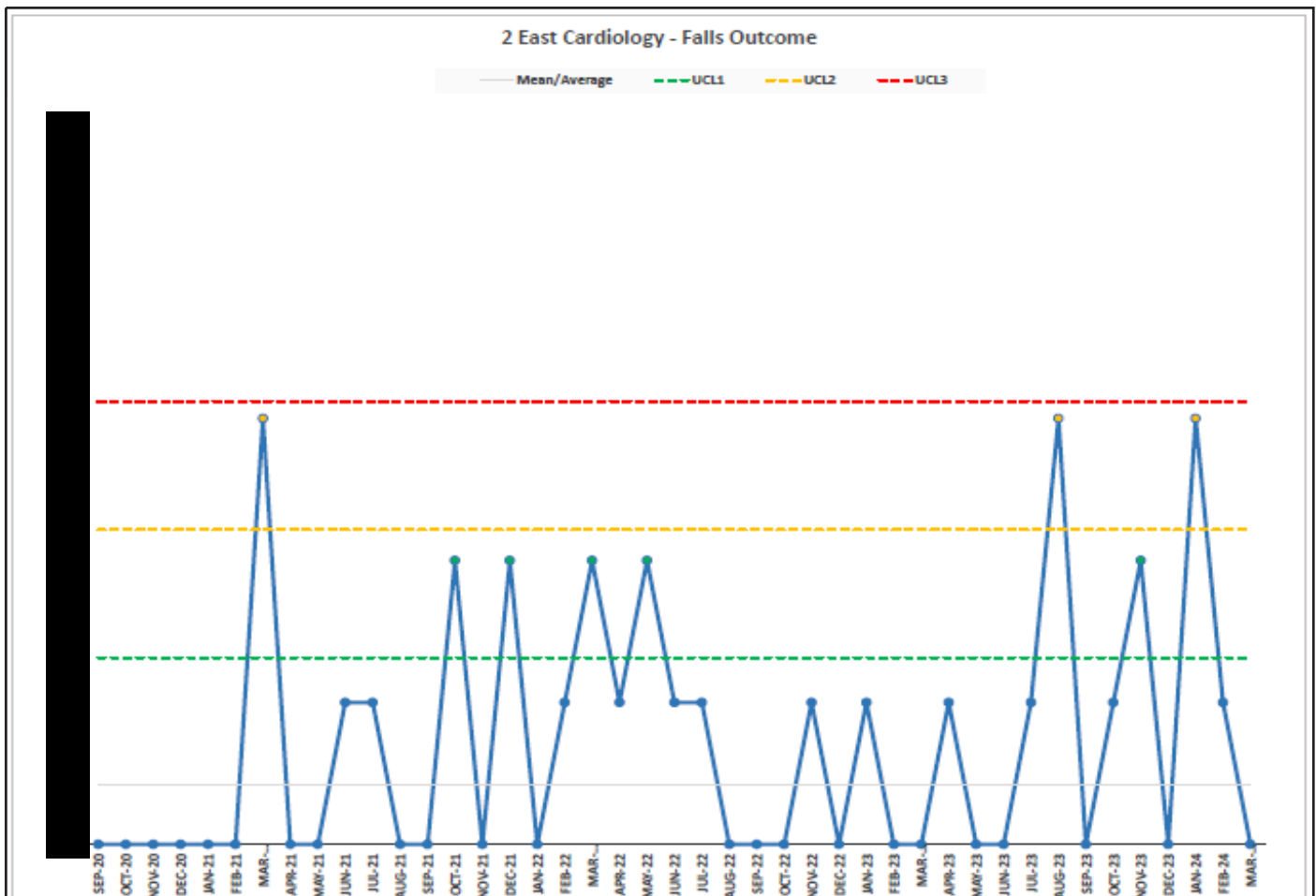
Ward 2 East currently report on eleven process measures.

1. Wards current SPSP and EIC data collection plan												
Falls FP1+2	Pressure Ulcer RPP4 PUP 1 SDU	PVC Maint	PCC Maint	OVC Maint	Safety Briefs	CAUTI Maint	CAUTI Ins	NEWS Acc.	VTE	SSR	Medi Rec	PVC/Infection
M		M	M	SU	SD	SU	SU	SU		SU	M	M
SD	Stepdown measure	M	Maintained measure	SU	Stepped up measure							

Owing to sustained reliability (over a period of years), the NHS Golden Jubilee implemented a 'stepdown' process for many of the monthly process measures recorded by clinical areas.

These 'stepped down' measures are no longer routinely reported on since August 2020, but mechanisms are in place to restart if associated outcome measures breach agreed limits.

All unit's senior nursing leadership receives a monthly report from Clinical Governance on performance, with follow up communication if any issues are being highlighted as challenges to the unit. This local ownership of the data and improvement work, and the 2-way communication and support with CGD is seen as a very positive and proactive process.



- Ward 2 East reported 12 inpatient falls for the timeframe reported on. This is an increase from the 9 reported for 2021 – 2022.
- None of these falls related to an SPVU inpatient.

Ward 2 East have reported no grade 2 - 4 pressure ulcers for the timeframe reported on.

### Clinical audits / QIPs

The following audits are ongoing or have been performed this year:

**Title: National Audit of Pulmonary Hypertension**

Rolling national audit, measuring and comparing practice at UK centres.

**Title: Genetics Register**

We are routinely testing patients with IPAH for genetic mutations which predispose to pulmonary hypertension. We now know the genetic status of ~ 90% of our patients. This information may well allow a personalised medicine approach in the future and thereby improve the care that we can provide.

**Title: Surgical Outcomes in Pulmonary Hypertension**

Analysis of outcomes of patients with PH who undergo surgery at GJNUH

**Title: Monitoring of antiphospholipid syndrome (APS) testing in patients with CTEPH**

Assessing frequency of APS in CTEPH patients and completeness of testing for this condition in this cohort.

**Title: A review of generic drug prescribing by the Scottish Pulmonary Vascular Unit**

This audit found that generic prescribing accounts for just over 70% of our PH drug prescriptions and that this is also true of national practice.

**Title: Anticoagulation in IPAH**

This audit looked at the risk benefit ratio for anticoagulation in IPAH patients with the aim of identifying patients where anticoagulation should be stopped because of increased risk of bleeding.

**Healthcare Associated Infection (HAI) and Prevention and Control of Infection**

Robust prevention and control of infection measures are in place within the GJUNH, which apply to each point in the patient pathway. Each area that the patient may visit is subject to regular environmental audits and compliance monitoring to establish compliance with standard infection control precautions and transmission based precautions.

The Senior Charge Nurses throughout the organisation have a specific focus within their remit to ensure ongoing compliance and attention to measures to combat HAI are in place, audited and acted upon.

CNM Peer Reviews continue to quality assure the SCN Standard Infection Control Precautions compliance monitoring process

**Staphylococcus aureus bacteraemia (SAB)**

Historically SAB rates are very low within the Board despite the vulnerability of patients and essential device use. The Prevention and Control of Infection Team continue to work closely with the clinical teams, Clinical Governance Department (CGD) and clinical educators to gain insight into the sources of SAB acquisition and associated learning. Each SAB is subject to an enhanced surveillance process involving the PCIT, SCN and responsible consultant to determine any learning from the source of the SAB. During the period 23/24 only █ noted within 2 East, source identified as PVC related.

**Clostridioides difficile**

Clostridioides difficile is an organism which is responsible for a large number of healthcare associated infections, although it can also cause infections in people who have not had any recent contact with the healthcare system. NHS Boards in Scotland carry out surveillance of Clostridioides difficile infections (CDI), and there is a national target to reduce these. █ (5.75 per 100,000 total occupied bed days ) cases was noted in the organisation 23/24, well below national quarterly rates ranging between 14-16 per 100,000 total occupied bed days.

**Multi Drug Resistant Organism Screening**

All patients are risk assessed and screened where required for MRSA and Carbapenemase producing enterobacteriaceae (CPE) on admission to the GJUNH.

**NHS Golden Jubilee Expansion Programme**

As part of the Scottish Government's investment of £█ million to meet demand for elective surgery, NHS Golden Jubilee has been focusing its plan to expand its services in a phased approach.

Construction on Phase 2 Surgical Centre started late 2020 - delivering 5 additional orthopaedic theatres, a new endoscopy and endoscopy decontamination unit, surgical admissions unit and a new larger CSPD. To support the additional activity refurbishment will take place in a number of locations across the organisation.



## 5. Governance and regulation

### 5.1 Clinical Governance

#### GJUNH

- Ad-hoc clinical governance issues are discussed at the weekly MDT.
- Clinical governance is a standing item on the agenda for the **monthly** unit meeting where any new/ outstanding Datix issues and the Risk Register are discussed.
- There is a **3 monthly** SPVU clinical governance meeting (detailed earlier)
- SPVU staff attend the **monthly** GJUNH Divisional Clinical Governance meeting where all aspects of clinical governance are discussed.

#### QEUH

- The respiratory unit at QEUH has **3 monthly** clinical governance meetings to discuss issues arising from the respiratory wards. These have been occurring with reduced frequency this year although there are plans to restart imminently.
- The medical directorate at QEUH has **2 monthly** meetings to discuss issues at a higher level.

### 5.2 Risks and issues

This is the current SPVU Risk Register.

Title	Description	Controls in place	Status
Admin Support for AHPs	If there is insufficient administrative support for AHPs, they have either to do the work themselves or it can be performed in a suboptimal manner.	AHPs perform many administrative duties themselves. AHPs keep us informed of problems arising from inadequate administrative support.	Ongoing risk
Admin support for SPVU especially electronic filing of correspondence	If there is insufficient administrative support for electronic filing of correspondence, then important correspondence on a patient will be missed when they are reviewed in clinic.	SPVU secretaries file the correspondence from remote sites which increases their workload and leads to delays in other administrative duties. Some but not all correspondence is available via Regional Portal and SCI store. Secretaries keep us informed of problems arising from inadequate administrative support.	Ongoing risk
Admin support to SPVU	Lack of admin resource results in inability to send correspondence within 10 days of outpatient review and within 5 days of inpatient discharge. Bid was submitted to NSD for additional funding but this was unsuccessful – current cost pressure which prevents appointment of permanent staff.	Part time and additional hours. Currently exploring voice recognition for the nursing team to relieve the pressure on the admin team	Ongoing risk

Database manager access to Inflex database	The SPVU database managers have suboptimal access to the Inflex database which holds the information for our patients and is vital in the smooth running of our department. This is because: 1. The version of Inflex is out of date and works only partially with Windows 10 2. The Inflex server cannot be accessed by Windows 10 laptops because of security issues and needs to be upgraded.	Only one database manager can do all tasks.  He is accessing the database remotely via a Windows 7 system.  Database managers keep me informed of any issues affecting data quality.	
Echo images from distant sites	If Dr Rush is unable to review images from distant sites in a timely manner, then the quality of care given to SPVU patients will be degraded because of suboptimal diagnostic decisions.	When required we have echo images sent to us by DVD. Dr Ruch is keeping us informed if he has problems accessing images.	

**Table 22**

### 5.3 Adverse events

Any adverse event is captured through the Datix system. In 2023/2024 there was 1 significant adverse event reported via Datix relating to SPVU patients. The events related to SPVU patients were reviewed via the Serious Adverse Event Review (SAER) process. The outcome code for the completed SAER's are detailed below.

Ref	Description	Result
DW-10788	[REDACTED]	Near Miss by Intervention

### 5.4 Complaints and compliments

#### Complaints

There are no open complaints, and no complaints received .

#### Compliments

The Team receive positive feedback via cards and verbal thanks. This is not always captured via the Clinical Governance process. This has been highlighted to the Team as this ensures all feedback is displayed and captured, which allows positive feedback to be celebrated.

There are 3 compliments recorded on Datix for 2023/2024, 1 patients family thanking the team for their care and compassion. Another received by feedback form that acknowledges 'Great Hospital. Great staff.' The other compliment relates to the multiple thank you cards recived from patients.

## 5.5 Equality

NHS Golden Jubilee is a progressive organisation with a strong track record of promoting diversity and working with staff to ensure we establish an inclusive workplace culture.

We recognise the value a diverse workforce brings in offering different perspectives in how we deliver high quality, [safe](#), [effective](#), [person-centred](#) care and maintain a healthy, vibrant, and inclusive culture throughout our organisation.

Our Diversity and Inclusion Strategy 2021-2025 features an ambitious set of deliverables and associated outcomes to further strengthen NHSGJ's long-standing position as a leader in the field of equality, diversity, and inclusion. The 4 year Strategy and 2023 Midpoint Report are available to download now by clicking on the below link:

### **NHS Golden Jubilee Equalities publications**

[Equalities :: NHS Golden Jubilee](#)

Each outcome has specifically been designed to create the conditions to act as a catalyst to embed cultural change across the organisation and are divided into 3 distinct themes.

#### **Theme A: Diversify Talent**

The outcomes associated with Theme A, are strategically targeted towards rebalancing the demographics of the workforce to establish a more even representation of people with Protected Characteristics. In order to achieve this, we have focused on a number of key deliverables, taking a holistic approach encompassing all areas of the organisation to build strong foundations for change.

- Establishment of Executive Leads for Protected Characteristics;
- Revised Diversity and Inclusion governance;
- Revised Diversity and Inclusion web pages;
- Establishment of additional professional memberships;
- Adopter of the NHS Scotland Pride badge;
- Equality audits of NHS GJ policies;
- Enhanced workforce monitoring statistics and reporting;
- Reduction of digital inequalities and access to online learning;
- Establishment of staff diversity networks; and
- Active participant in the GCIL Equality Academy graduate trainee programme.

#### **Theme B: Wellbeing and cohesion**

The outcomes associated with Theme B are strategically targeted towards creating an inclusive workplace culture. Education fosters knowledge which creates understanding. We have therefore taken an intersectional approach to develop and deliver a suite of training focusing on the 9 Protected Characteristics, unconscious bias and preferred behavioural styles. This is complimented by the introduction of new policies and the ongoing development of a Reasonable adjustment health passport for staff to ensure that an individualised person centred approach to staff wellbeing is adopted.

- Development of Staff Reasonable Adjustment Health Passport;
- Introduction of Reasonable Adjustment Policy;
- Inclusion of unconscious bias and preferred behavioural styles within mandatory diversity training;
- Rollout of new diversity training focusing on race equality, disability awareness, neurodiversity, and LGBT+ allyship.

## **Theme C: Inclusive Service design**

Our equality outcomes associated with Theme C are primarily targeted at enhancing the inclusivity and accessibility of our services to create an exemplar delivery model focused on person centred care. We are achieving this through strengthened governance of our Equality Impact Assessment (EQIA) process to reduce health inequalities and ensure that the needs of everyone represented by a Protected Characteristic are taken into account at the conceptual stage of service improvement proposals. Our new EQIA template and associated eLearning module provide the foundations, with further exciting developments planned in the final year of our strategy to further embed cultural change within the organisation. In addition, we continue to engage with external stakeholders to introduce technological advances to increase the accessibility and inclusivity of our services to promote independence and wellbeing in line with the principles of the social model of disability.

- Introduction of new EQIA template;
- Launch of bespoke EQIA eLearning module;
- Development of strengthened EQIA governance;
- Launch of WelcoMe app for disabled service users;
- Inclusive wayfinding strategy for Phase 2 expansion and Orthopaedic refurbishment;
- Design for dementia audits; and
- Inclusive design awards and conference presentations.

### **Staff diversity networks**

NHS Golden Jubilee recognise the benefits that staff networks can bring towards fostering an inclusive workplace culture. Over the past 3 years, we have embarked on an ambitious journey to establish a family of networks to represent the 9 protected characteristics and Fairer Scotland duty.

There are currently 7 staff networks established including Ethnic minority, Ability, LGBTQ+, Spiritual Care, Women's, Young Person's and Armed Forces.

As a demonstration of our organisation's commitment to elevating the voices of staff from under-represented groups, staff networks are endorsed from a senior leadership level through the creation of Executive leads and mentoring support from our board chair.

On 10 May 2023, our board joined hundreds of other organisations across the UK to mark National day for staff networks to celebrate and recognise the valuable contribution that networks make towards improving the corporate health of the organisation through their insight, innovation and intelligence. In doing so, influencing the conversation to ensure they are seen as business critical and effective mechanisms for voice, innovation and change.

Our progressive approach establishes a critical contributor to workforce engagement to provide an insight into unseen barriers to devise practical, creative and viable solutions to help address systemic challenges faced by certain groups through the integration of hospital communities to strengthen the diversity and inclusion agenda at NHSGJ.

Staff network	Protected Characteristic	Executive lead
Ethnic minority	Race	<b>Medical Director</b> Mark MacGregor
Ability	Disability	<b>Director of Transformation, Strategy, Planning and Performance</b> Carole Anderson
LGBT+	Sexual orientation Gender reassignment (trans status)	<b>Director of Nursing</b> Anne Marie Cavanagh
Spiritual Care	Religion and belief Marriage and civil partnership	<b>Director of People and Culture</b> Laura Smith
Women's	Sex Maternity and Pregnancy	<b>Director of Operations</b> Carolynne O' Connor
Young Person's	Age Socio-economic status	<b>Director of Finance</b> Graeme Stewart (Interim)
Armed Forces	Intersectional	<b>Director of Communication</b> Sandie Scott

## Spiritual Care

Spiritual Care is person centred, meaning that we are here for everyone (patients, families, carers and our staff and volunteers). We are delighted that our highlight report of our local Spiritual Care Strategy highlights the significant impact being made in delivering Spiritual Care at the NHS Golden Jubilee.

Spiritual Care throughout the hospital includes a listening ear, Spiritual and Religious Care as well as a Spiritual Care Centre to come for some quiet, reflection, spiritual and religious reading and prayer.

We continue to provide wellbeing activities in the Spiritual Care Centre including Mindfulness, Meditation and Breathe in to the weekend all very well attended.

As part of our strategy, we launched a Bereavement Service that provides support to individuals who experienced a bereavement.

## Our Values

We continue to work with a range of staff, patient representatives and managers to discuss and promote our shared values, which help us all to deliver the highest quality of care and service across the organisation. These values are closely linked to our responsibilities around Diversity and Inclusion: Our values are:

- Valuing dignity and respect;
- A 'can do' attitude;
- Leading commitment to quality;
- Understanding our responsibilities; and
- Effectively working together

To ensure that our teams have had the opportunity to explore what embedding those values mean in their place of work we have developed a "values toolkit". The aim of this is to help teams identify which behaviours are, and are not, in line with our equality and diversity policies and with our 5 values.

## 6. Financial reporting and workforce

Golden Jubilee National Hospital SPVU - NSD 2023/24 Finance report				
	Profile 2023/24	Profile 2023/24	Actual Mar'24	Actual Mar'24
	w.t.e.	£	w.t.e.	£
<b>AHP</b>				
Psychologist (Band 8a)	1.00		1.00	
Cardiac Physiologist (Band7)	0.40		0.40	
MRI Reporting	0.10		0.05	
	<b>1.50</b>		<b>1.45</b>	
<b>A&amp;C</b>				
Data Manager (Band4)	1.0		0.82	
Secretary (Band4)	1.0		1.11	
Admin support (Band4)	0.7		0.73	
Booking Clerk/scheduler (Band3)	0.5		0.60	
	<b>3.20</b>		<b>3.26</b>	
<b>Other</b>				
MDT Members	-		0.10	
<b>Total staffing establishment</b>	<b>4.70</b>		<b>4.81</b>	
<b>Variable</b>				
Diagnostic (RHC) session at GJNH	Max 126		181	
Occupied Bed Days for the pod	Max 410		588	
Daycases (GJNH)	110		207	
Hotel OBD			11	
<b>Total Ward &amp; Clinic Costs</b>				
GJNH Capital Charges				
Travel costs (medical and nursing staff)				
<b>Additional Developments</b>				
Software Licenses for Infoplex Licences (Supplier CIVICA) 1/04/2023-31/03/2024				
<b>Total Funded Value</b>	<b>4.70</b>			

Table 23

NHS Greater Glasgow & Clyde Acute Division  
 South Sector  
 SPVU – NSD  
 2023/24 Finance report

SPVU Staff Title		Grade	Profile 23-24 £	Mar-24 WTE	Mar-24 Actual
		WTE			
<u>Medical</u>	Consultant	0.50		0.50	
	Consultant	0.50		0.50	
	Consultant	0.80		0.80	
	On-call				
	Specialist Reg\SHO3	2.00		2.00	
	Specialist Reg\SHO3	1.00		1.00	
		<b>4.80</b>		<b>4.80</b>	
<u>Nurse</u>	Clinical Nurse Specialist	1.00	Band 7	1.00	
	Clinical Nurse Specialist	1.00	Band 7	1.00	
	Clinical Nurse Specialist	1.00	Band 7	1.00	
		<b>3.00</b>		<b>3.00</b>	
<u>AHP</u>	Pharmacist	1.00	Band 8a	1.00	
		<b>1.00</b>		<b>1.00</b>	
	MRI reporting	0.10		0.2	
	MDT AHP (Radiology & Cardiology)				
	<b>Total Staffing</b>	<b>8.90</b>		<b>9.00</b>	
SPVU	<b>Ward and clinic costs</b>				
		Indicative Activity	Profile 23-24 £	YTD Activity	Actual
<u>Variable</u>	Occupied Bed Days (OBD) treatment area at QEUH	1112		1,913	
	Occupied Bed Days QEUH HDU				
	Day case at GGH/QEUH	110		0	
	<b>Total Ward and clinic costs</b>				
	QEUH Homecare				
	RHSC Y Homecare				
	QEUH Wards				
	RHSC Y wards				
	Drug & home delivery costs SPVU				
	<b>Total Drug costs</b>				
	Capital Charges				
	<b>Total Capital charges</b>				
	CADD pumps				
	<b>Total Service Costs for GG&amp;C SPVU</b>				

## 7. Audit and clinical research / publications

The commercial/external CTIMP studies currently active within the department include ADVANCE OUTCOMES (ralinepag), HYPERION/SOTERIA (sotatercept), INSIGNIA (inhaled guanylate cyclase agonist), IMPAHCT (inhaled imatinib), INS1009-202 (inhaled treprostinil), TROPOS and PROSERA (inhaled serralutinib). We are co-organisers of a national study on remote blood testing for NTproBNP (THRIVA). There are also a number of national and international observational studies underway including IMPULSE, PHOENIX, EXPOSURE, EDUCATE and COHORT.

We have 15 patients currently enrolled in CTIMP studies.

### Papers

#### [Sendaway capillary NT-proBNP in pulmonary hypertension.](#)

Stubbs HD, Cannon J, Knightbridge E, Durrington C, Roddis C, Gin-Sing W, Massey F, Knight DS, Virsinskaite R, Lordan JL, Sear E, Apple-Pinguel J, Morris E, Johnson MK, Wort SJ  
*BMJ open respiratory research.* 11(1), 2024 Mar 22.

#### [Remote exercise testing in pulmonary hypertension \(PHRET\).](#)

Stubbs H, Lua S, Ingram J, Jani BD, Brewis M, Church C, Johnson M  
*Pulmonary Circulation.* 13(4):e12325, 2023 Oct.

#### [The MRC Dyspnoea Scale and mortality risk prediction in pulmonary arterial hypertension: A retrospective longitudinal cohort study.](#)

Arogundade F, Jani B, Church C, Brewis M, Johnson M, Stubbs H  
*Pulmonary Circulation.* 13(3):e12257, 2023 Jul.

#### [Pulmonary Embolism \(PE\) to Chronic Thromboembolic Pulmonary Disease \(CTEPD\): Findings from a Survey of UK Physicians.](#)

Pepke-Zaba J, Howard L, Kiely DG, Sweeney S, Johnson M  
*Advances in Respiratory Medicine.* 92(1):45-57, 2024 Jan 09.

#### [Predictors of outcomes in mild pulmonary hypertension according to 2022 ESC/ERS Guidelines: the EVIDENCE-PAH UK study.](#)

Karia N, Howard L, Johnson M, Kiely DG, Lordan J, McCabe C, Pepke-Zaba J, Ong R, Preiss M, Knight D, Muthurangu V, Coghlan JG  
*European Heart Journal.* 44(44):4678-4691, 2023 Nov 21.

#### [Pulmonary Hypertension: Intensification and Personalization of Combination Rx \(PHoenix\): A phase IV randomized trial for the evaluation of dose-response and clinical efficacy of riociguat and selexipag using implanted technologies.](#)

Varian F, Dick J, Battersby C, Roman S, Ablott J, Watson L, Binmahfooz S, Zafar H, Colgan G, Cannon J, Suntharalingam J, Lordan J, Howard L, McCabe C, Wort J, Price L, Church C, Hamilton N, Armstrong I, Hameed A, Hurdman J, Elliot C, Condliffe R, Wilkins M, Webb A, Adlam D, Benza RL, Rahimi K, Shojaei-Shahrokhbadi M, Lin NX, Wason JMS, McIntosh A, McConnachie A, Middleton JT, Thompson R, Kiely DG, Toshner M, Rothman A  
*Pulmonary Circulation.* 14(1):e12337, 2024 Jan.



## 8. Looking ahead

The primary aims of SPVU are to improve quality of life, morbidity and survival in patients with PH by providing accurate diagnosis, ensuring people are offered the appropriate medical and surgical treatment and to monitor long term outcomes. We believe that the service has offered increasing quality of care in these areas over the last few years. However, we have found this to be a continually evolving target because of:

- growth in the patient population;
- changing national and international evidence-based standards; and
- increasing options for and complexity of treatments for the condition.

In our view SPVU is reaching the limit of what it can improve with greater efficiency. Maintaining care either at its current level or comparable with other PH units will require increased resources.

We would pinpoint the following areas which are under our control to change and we think would make the most difference to our patients

1. Increased resources are needed to diagnose and treat our patients in a timely manner. Currently we can see new patients within 30 days but there is then a wait of 3 months before they can be admitted for diagnostic investigations. In some cases that leads to a 4 month (16-17 week) wait between referral and treatment. A patient with PH can deteriorate significantly in that timeframe and this waiting time needs to be reduced to the national standard of 10 weeks between referral and treatment.
2. Increased resources are needed to identify deteriorating patients. The standard assessment of a PH patient is a face to face appointment (to allow examination), with a 6 minute walk test and assay for NT-proBNP. Clinic review should be every 3 to 6 months in most cases. This is currently at the limit of our clinic capacity to provide and return appointment numbers need to increase. Introducing POC NT-proBNP will allow rapid and informed decision -making in clinic and we are hoping this will be introduced in 2024. The addition of right ventricular imaging in selected cases (ideally by cardiac MRI) would allow us to refine this process further and more accurately identify patients whose treatment should be escalated. This is a strong recommendation in the ESC PH Guidelines 2022 (Table 17) in the case of worsening patients and suggested as good practice on a routine basis in others.
3. PH therapy improves the patient's pulmonary artery haemodynamics. Access to a PH focussed exercise training programme (for example, by a PH dedicated physiotherapist) would enable patients to maximise the functional benefits made possible by the drug therapies.
4. Since most of the cost of our service lies with the medication used, additional pharmacy support in the form of a Pharmacy Technician would allow us to improve further the efficiency and cost-effectiveness of our prescribing.
5. A very effective area to invest resource in our unit which would improve both cost-efficiency and patient satisfaction would be in administrative support. At very little cost, this would improve turnaround of communication with other health care professionals and patients and free up time currently used by nursing and pharmacy staff in administrative roles.

All of these changes require some investment in personnel and investigation time but would produce significant improvements in the function and quality of life of our patients. A business case was submitted to NHS National Services Scotland's National Services Division (NSD) in 2022/2023 outlining the long term investment required to continue to deliver the high quality services to the growing PH population.

# Appendix 1

## SPVU Referral Guidelines

### Introduction

The Scottish Pulmonary Vascular Unit was established in 1999 and is funded by the National Services Division, Scotland. The unit provides diagnosis and management for all patients with pulmonary arterial hypertension (PAH) in Scotland.

New treatments for PAH approved over the last 2 decades have led to major improvements in the symptoms and prognosis of this serious condition. These include endothelin receptor antagonists, phosphodiesterase-5 inhibitors, guanylate cyclase stimulators and prostacyclin agents, both analogues and agonists. Clinical trials of new agents are ongoing.

Specialist supervision of all patients with pulmonary arterial hypertension remains essential. Treatment is increasingly complex and expensive and requires careful ongoing scrutiny.

### Whom to Refer

#### Definitely Refer

1. All suspected cases of pulmonary arterial hypertension (PAH)
  - Idiopathic or familial
  - Connective tissue disease associated (especially scleroderma, SLE, MCTD)
  - Congenital heart disease, pre and post-correction
  - Portopulmonary hypertension
  - Other associated conditions:- HIV, anorexigen use, sickle cell disease.
2. All suspected cases of chronic thromboembolic pulmonary hypertension.

Advice on when to refer based on the echocardiogram and in the absence of lung and left heart disease is shown in the Appendix.

#### Consider Referral

In hypoxic lung disease (COPD, interstitial lung disease, sleep disordered breathing) where the pulmonary artery pressure is excessively high (TRPG > 60 mmHg or PASP > 65 mmHg).

Patients with left heart disease where the severity of pulmonary hypertension is thought disproportionate to the left heart problem again typically TRPG > 60 mmHg or PASP > 65 mmHg)

It should be noted that treatment of pulmonary hypertension in these patient groups is not yet established.

#### Suggested Assessment Prior to Referral

- We prefer all patients to have been seen by consultants in Cardiology or Respiratory prior to referral.
- All patients should have an ECG, chest X-ray, lung function, transthoracic echocardiogram, VQ scan (and CTPA if the VQ scan is positive). We prefer to do cardiac catheterisation in Glasgow. Please do not delay referrals for extensive investigation if it is clear that PAH is the dominant problem.
- Please include copies of reports (especially the echocardiogram) with the referral.

## How to Refer

- Please send or fax the referral to the address below. An email with the referral as an attachment is also acceptable.
- Patients can be admitted directly if clinic review is inappropriate or unnecessary.
- For unwell patients with known or new PH, SPVU medical staff can be contacted for advice via radiopage or the hospital switchboard 24 hours/day and can arrange emergency transfer for assessment and treatment.

If there is doubt about whether to refer or assess further prior to referral, please contact SPVU medical staff to discuss.

## Assessment and Follow-up at SPVU

- After clinic review patients will typically be admitted for full diagnostic assessment including cardiopulmonary exercise testing, cardiac MRI and right heart catheter studies. Pulmonary angiography, vasodilator testing and sleep studies will also be performed where indicated.
- If PAH is diagnosed, a decision will be made during the admission regarding disease-targeted treatment and usually commenced before discharge.
- Patients will usually be followed up at 3 to 6 monthly intervals, sharing care with the referring consultant.

## Contact details

Scottish Pulmonary Vascular Unit  
Golden Jubilee University National Hospital  
Agamemnon Street  
Clydebank  
G81 4DY

Telephone: [REDACTED]

Fax: [REDACTED]

email: [REDACTED]@gjnh.scot.nhs.uk

Website: <https://hospital.nhsgoldenjubilee.co.uk/a-z-services/scottish-pulmonary-vascular-unit-spvu>

Medical Staff: 24 hour advice

Radiopage via switchboard: [REDACTED]

# NHS Golden Jubilee

Golden Jubilee University National Hospital  
Agamemnon Street  
Clydebank  
G81 4DY



@gjnh.scot.nhs.uk



[nhsgoldenjubilee.co.uk](http://nhsgoldenjubilee.co.uk)

