

**Scottish Paediatric Cardiac Service**

**Annual Report**

**2021/22**

****

**Greater Glasgow & Clyde**

**Table of contents**

[Executive Summary - 3 -](#_Toc7535693)

[1. Service Delivery - 4 -](#_Toc7535694)

[2. Activity Levels - 5 -](#_Toc7535695)

[3. Performance and Clinical Outcomes - 11 -](#_Toc7535696)

[3.1 Equitable - 11 -](#_Toc7535697)

[3.2 Efficient - 12 -](#_Toc7535698)

[3.3 Timely - 14 -](#_Toc7535699)

[3.4 Effectiveness - 16 -](#_Toc7535700)

[3.5 Safe - 20 -](#_Toc7535701)

[4. Quality and service Improvement - 25 -](#_Toc7535702)

[5. Governance and Regulation - 26 -](#_Toc7535703)

[5.1 Clinical Governance - 26 -](#_Toc7535704)

[5.2 Risks and Issues - 26 -](#_Toc7535705)

[5.3 Adverse Events - 27 -](#_Toc7535706)

[5.4 Complaints and Compliments - 27 -](#_Toc7535707)

[5.5 Equality - 27 -](#_Toc7535708)

[6. Financial reporting and workforce - 28 -](#_Toc7535709)

[7. Audit & Clinical Research / publications - 35 -](#_Toc7535710)

[8. Looking ahead - 40 -](#_Toc7535711)

[Appendices - 43 -](#_Toc7535712)

*Please refer to Guidance Notes for completion of the Annual Report prior to submission*

*The completed Annual Report should be sent electronically by 31 May to:*

*Email: nss.nsd-reports@nhs.net*

# Executive Summary

The Scottish Paediatric Cardiac Service (SPCS), hosted by NHS Greater Glasgow and Clyde at the Royal Hospital for Children (RHC) has been the nationally designated centre treatment of children with congenital and acquired heart disease since July 2000. The national service incorporates all cardiac surgery and interventional cardiology, with the exception of heart transplantation and surgery for Hypoplastic Left Heart Syndrome (HLHS). The previously established pathway for HLHS patients is currently paused however the team are working towards re-establishing this aspect of the programme.

SPCS also delivers Fetal cardiology services nationally in conjunction with the Fetal Medicine team based at the Queen Elizabeth University Hospital and the paediatric cardiologist based in Edinburgh. The dedicated Fetal Cardiologist provides weekly clinics for prenatal patients requiring specialist advice. In addition, there is a well-established telemedicine link for remote (fetal and paediatric) cardiac diagnosis. The cardiac imaging team deliver specialist cardiac MRI and cardiac CT for the national SPCS programme at the RHC. This is the only centre within Scotland able to deliver this service. This service has been bolstered by the recent appointment of an internationally trained Paediatric Cardiologist with expertise in cross-sectional imaging, to work alongside the Consultant Radiologist team to develop the cardiac cross-sectional imaging team.

The cardiac catheterisation suite has been replaced this year following a significant capital investment. The clinical team are currently undertaking a review of cardiac catheter clinical pathways to ensure the benefit of this investment is maximised for all our patients.

Multiple quality improvement plans have been developed and are in progress in line with standards agreed across the paediatric cardiac centres in the United Kingdom and Ireland. Many of these have been developed through the recently established bi-monthly Cardiac Theatre and Cardiac Catheter Suite Team Performance meetings. Part of this process has involved the multi-disciplinary development of pathways for a novel method of closure of atrial septal defects and the development and roll out of an Ebstein’s physiology pathway.

Outpatient cardiology clinics are held both within RHC and in outreach centres in conjunction with the Paediatric Cardiologist based in Edinburgh and local paediatricians with an expertise in paediatric cardiology in many hospitals throughout Scotland. The section “Geographical Referrals and Outreach Clinics” provides more information on this. Two specialist multidisciplinary clinics for pulmonary arterial hypertension (PAH) and hypertrophic cardiomyopathy (HCM) are hosted at RHC in collaboration with specialists from Great Ormond Street Hospital. Outreach cardiology clinic activity undertaken by the SPCS team is integral to the seamless care of children provided by the nationally commissioned service and is part of the service agreement with NSD.

At the other end of the age spectrum, the Golden Jubilee National Hospital (GJNH) hosts the Scottish Adult Congenital Cardiac Service (SACCS). This centre has well established links with both RHC and the Queen Elizabeth University Hospitals for the management of patients transitioning from paediatric to adult services and also for high-risk pregnancies. Many of the SPCS clinical team provide a service to both paediatric and adult patients. For the vast majority of patients treated by SPCS they have a lifelong condition so an effective transition process to adult care is of vital importance nationally. The transfer of ongoing cardiological care by colleagues in the adult sectors, either within SACCS team or local adult cardiology teams, is delivered over a number of years in the outpatient setting and is led by a paediatric cardiac nurse specialist and a consultant paediatric cardiologist in tandem with colleagues in the adult sector. There is a workstream underway to develop this process nationally. The SPCS are asked to provide an effective and efficient transition in the service level agreement and work is underway to reduce national variability in the delivery of this vital aspect of the congenital cardiac service.

SPCS and SACCS both participated in the Peer Review process run bun the Quality Surveillance Team from NHS England. This review highlighted serious concerns round the ad hoc nature of the transition to adult services and the inability of the cardiac nurse specialists to support outreach. Both areas are the focus of ongoing service development which need funding to move forward. The lack of a managed network for paediatric cardiac services in Scotland has led to historical challenges. The SPCS are now working closely at both clinical and managerial levels with colleagues in the Royal Hospital for Children & Young People, Edinburgh and SACCS to develop these cohesive pathways and links. This will involve working to join up IT and data systems to ensure national access to clinical notes as well as shared clinical pathways.

The recent withdrawal of the SPCS data submission and benchmarking to the United Kingdom wide national congenital heart disease audit (NCHDA) programme has resulted in a significant amount of ongoing time and effort being needed to develop local solutions, alongside colleagues in Public Health Scotland and SACCS. The development of the cardiac data team will be integral to the success of this process alongside the ability to benchmark current data with teams across the United Kingdom.

A review of the service agreement between GGC and NSD on how to deliver a national paediatric cardiac service has been halted due to the pandemic. When re-started this will provide a valuable opportunity to improve the care that is delivered to the children and families diagnosed and treated for heart disease in Scotland.

Contact Details:  
Dr Mark Davidson  
Clinical Director  
Scottish Paediatric Cardiac Services  
1345 Govan Rd  
Glasgow  
G51 4TF

# Service Delivery

The Paediatric Cardiac Services covers a large geographical area across Scotland. The estimated population of Scotland as at mid-2020 was 5,466,000 showing an increase of 0.05% (2,700 people), the slowest since mid-2003. This was mainly due to higher numbers of deaths and lower levels of net migration. The number of births registered during 2020 was 48,700 which was 4% less than the previous year.

**Reference**  
*National Records of Scotland, Scotland’s Population 2019, Infographic report, August 2020*

The service routinely accepts referrals for all eligible patients from the ante-natal period up to 16 years of age and will treat older patients with pre-authorisation from NSD.

Where it can be shown that no local child will be disadvantaged by such an arrangement and with the prior approval of NSD and the patients’ local healthcare provider, facilities can be utilised for patients’ who do not reside in Scotland.

The patient pathways for Paediatric Cardiac Services are outlined in the following:

Appendix 1 - Antenatal Cardiac Diagnosis Pathway

Appendix 2 - Postnatal Cardiac Diagnosis Pathway

Appendix 3 – Prenatal Cardiac Pathway

**Outreach Clinics**

The SPCS provides extensive outreach clinics across NHS Scotland in tandem with the Paediatric Cardiologist based in Edinburgh and paediatricians with an expertise in cardiology as per the current service agreement.

The SPCS strongly advocates that to deliver consistent care to all of our patients irrespective of their postcode the delivery of outreach care needs to be included and fully funded in order to further develop the high level of service offered to our patients and families. Unfortunately, the service is unable to supply activity figures for each Health Board but this table provides the number of clinics by NHS Board, frequency, location and consultant in attendance.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Board** | **Hospital** | **Consultant** | **2021/22** | **2020/21** | **2019/20** |
| Dumfries & Galloway | Dumfries & Galloway Royal Infirmary | Dr M Ilina | 10 | 8 | 7 |
| Ayrshire and Arran | University Hospital Crosshouse | Dr P Noonan/Dr B Smith | 14 | 17 | 21 |
| Ayrshire and Arran | University Hospital Ayr | Dr P Noonan | 8 | 8 | 8 |
| Lanarkshire | Wishaw General Hospital | Dr B Knight | 7 | 12 | 8 |
| Lanarkshire | Wishaw General Hospital | Dr L Hunter | 10 | 6 | 9 |
| Tayside | Ninewells Hospital | Dr K McLeod | 16 | 11 | 11 |
| Shetland | Shetland Hospital | Dr B Knight | 1 | 1 | 2 |
| Forth Valley | Forth Valley Hospital | Dr B Smith | 11 | 11 | 11 |
| Greater Glasgow & Clyde | Royal Alexandria Hospital | Dr B Knight | \*\* | \*\* | 6 |
| All | Clinic HCM | Dr M Ilina | 2 | 2 | 2 |
| **Total** |  |  | **380** | **196** | **231** |

**Note:** The number of clinics is an estimate. Accurate information is recorded on local Patient Applications Systems.

\* Clinic covered by local consultants

\*\* Paused

Cardiology outreach clinics are also provided by the paediatric cardiologist based in Edinburgh according to local service level agreement. These are as follows:

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Board** | **Hospital** | **Consultant** | **2021/ 22** | **2020/ 21** | **2019/ 20** |
| Highland | Raigmore Hospital | Dr M Walayat | 8 | 7 | 8 |
| Tayside | Ninewells Hospital | Dr M Walayat | 7 | \* | 14 |
| Grampian | Aberdeen Royal Infirmary | Dr M Walayat | 13 | 14 | 22 |
| Fife | Victoria Hospital | Dr M Walayat | 12 | 7 | 10 |

The newly appointed SPCS Paediatric Cardiologist will assume responsibility for the Raigmore clinics over the next 6 months. Through an enhanced managerial structure and oversight we are looking to ensure the Borders General Hospital also is supported with Cardiology Outreach from the Edinburgh team in the next financial year.

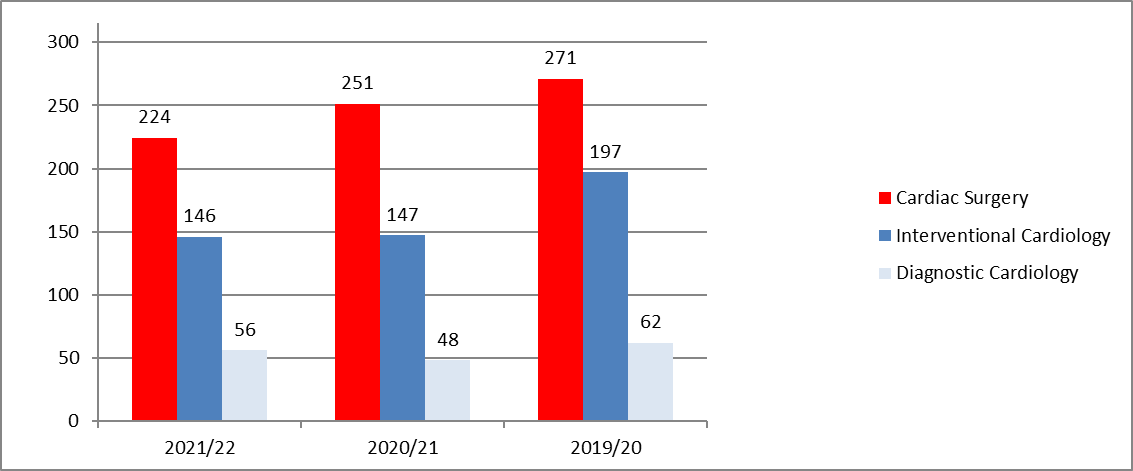
# Activity Levels

The service agreement is based on the number of surgical and/or interventional procedures completed and discharged during the period 1st April 2021 – 31st March 2022. The service levels agreements are set at 300 cardiac surgery, 220 interventional cardiology and 70 diagnostic catheter procedures per year. In 2021/22, the service achieved 224 cardiac surgical discharges, performed 146 interventional cardiology procedures and 56 diagnostic catheterisations.

**Interventions and Procedures**

The table and chart below illustrate cardiac surgery, interventional and diagnostic cardiology activity over the last three years. It is important to note the impact of the pandemic on the availability of cardiac intervention theatre sessions

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **SA level** | **2021/22** | **2020/21** | **2019/20** |
| Cardiac Surgery | 300 | 224 | 251 | 271 |
| Interventional Cardiology | 220 | 146 | 147 | 197 |
| Diagnostic Cardiology | 70 | 56 | 48 | 62 |



**Cardiac Surgery**

**Referrals**

Depending on the patient’s diagnosis and pathway some may have more than one referral to surgery over the year.

|  |  |  |  |
| --- | --- | --- | --- |
|  | **2021/22** | **2020/21** | **2019/20** |
| Cardiac Surgery | 328 | 284 | 349 |

**Cardiac Surgery by Complexity**

Cardiac surgery procedures are reported within six categories based on procedure complexity. In 2021/22 PCS discharged 224 cases where a patient had received a cardiac surgical procedure.

|  |  |  |  |
| --- | --- | --- | --- |
| **Category** | **2021/22** | **2020/21** | **2019/20** |
| Closed Simple | 15 | 7 | 7 |
| Closed Complex | 66 | 72 | 85 |
| Open Simple | 10 | 17 | 14 |
| Open Intermediate | 48 | 70 | 84 |
| Open Complex | 85 | 84 | 80 |
| Hybrid |  | 1 | 1 |
| **Total** | **224** | **251** | **271** |

**Cardiac Surgery Complexity by Age Range of Patient**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Closed** | | **Open** | | | |  |
| **Age Range¹** | **Simple** | **Complex** | **Simple** | **Intermediate** | **Complex** | **Hybrid** | **Total** |
| Neonate | 4 | 18 |  |  | 18 |  | 40 |
| Infant < 1 Year | 10 | 24 | 2 | 30 | 30 |  | 96 |
| Child > 1 Year | 1 | 21 | 7 | 18 | 33 |  | 80 |
| 16 Years and Over |  | 3 | 1 |  | 4 |  | 8 |
| **Total** | **15** | **66** | **10** | **48** | **85** | **0** | **224** |

¹Age group categories are defined as Neonates as 30 days and under, Infants < 1 as 31 days – 365 days, Child > 1, 16 Years and Over.

**Interventional and Diagnostic Cardiology**

**Referrals**

Depending on the patient’s diagnosis some may have more than one referral to surgery over the year.

|  |  |  |  |
| --- | --- | --- | --- |
|  | **2021/22** | **2020/21** | **2019/20** |
| Interventional and Diagnostic Cardiology | 210 | 177 | 212 |

**Interventional and Diagnostic by Procedure Type**

Interventional and diagnostic cardiology is reported within ten categories, these are as follows:

**Atrial Septostomy** The creation of a tear in the muscle between the two top chambers of the heart

**Balloon** Inflatable balloon on the end of a catheter to enlarge arteries or valves using a key-hole approach

**Pacemaker** Small metal box (generator), connected to the heart by a wire, which provides electrical stimulation to the heart when the heart conductive system isn’t working.

**Stent** Metallic scaffolding which is crimped on to a balloon then inflated in a narrowed artery to enlarge it

**Occlusion (Coil)** Metallic coil-shaped wire used to block off unnecessary arteries or synthetic tubes (for example, a shunt)

**Occlusion (Device)** Highly engineered device used to block holes in the heart or to block larger arteries or veins

**Radiofrequency Ablation** Ablation -radiofrequency energy to burn abnormal electrically conducting pathways in the heart

**Electrophysiology Study** EP - Mapping of the electrical activity in the heart using specialised electrode catheters

**Diagnostic** A catheter is used to take pressure and blood samples from all cardiac chambers, body and lung arteries. Angiograms are also taken to assess cardiac anatomy and function

|  |  |  |  |
| --- | --- | --- | --- |
| **Procedure Type** | **2021/22** | **2020/21** | **2019/20** |
| Atrial Septostomy | 10 | 8 | 10 |
| Balloon | 32 | 40 | 49 |
| Pacemaker |  |  | 3 |
| Stent | 18 | 14 | 20 |
| Occlusion - Coil | 7 | 6 | 12 |
| Occlusion - Device | 28 | 21 | 38 |
| Ablation | 21 | 29 | 26 |
| EP | 6 | 7 | 6 |
| Other | 24 | 22 | 33 |
| Diagnostic | 56 | 48 | 62 |
| **Total** | **202** | **195** | **259** |

**Interventional and Diagnostic Cardiology by Age Range of Patient**

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Age Range¹** | **Atrial Septostomy** | **Balloon** | **Pacemaker** | **Stent** | **Occlusion - Coil** | **Occlusion - Device** | **Ablation** | **EP** | **Other** | **Diagnostic** | **Total** |
| Neonate | 10 | 3 |  | 3 |  |  |  |  | 1 | 2 | 19 |
| Infant <1 |  | 13 |  | 3 | 2 | 11 |  |  | 2 | 8 | 39 |
| Child >1 |  | 16 |  | 7 | 4 | 17 | 19 | 5 | 17 | 42 | 127 |
| 16 Years and Over |  |  |  | 5 | 1 |  | 2 | 1 | 4 | 4 | 17 |
| **Total** | **10** | **32** | **0** | **18** | **7** | **28** | **21** | **6** | **24** | **56** | **202** |

¹ Age group categories are defined as Neonates as 30 days and under, Infants < 1 as 31 days – 365 days, Child > 1, 16 Years and Over.

**Combined Specialty Procedures by NHS Board**

The table below shows the total number of cardiac surgery and interventional catheter procedures split by age group and NHS Board.

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Health Board** | **Paediatric Cardiac Surgery** | **Paediatric Interventional Cardiology** | **Paediatric Diagnostic Catheter** | **Neonatal Cardiac Surgery** | **Neonatal Interventional Cardiology** | **Neonatal Diagnostic Catheter** | **Total** |
| Ayrshire & Arran | 10 | 8 | 2 | 2 |  |  | 22 |
| Borders |  | 1 |  |  | 1 |  | 2 |
| Dumfries & Galloway | 5 | 6 | 1 |  |  |  | 12 |
| Fife | 9 | 6 | 6 | 1 | 2 |  | 24 |
| Forth Valley | 9 | 4 | 4 | 2 | 1 | 1 | 21 |
| Grampian | 15 | 14 | 6 | 8 | 3 |  | 46 |
| Greater Glasgow & C | 54 | 37 | 21 | 5 | 3 |  | 120 |
| Highland | 20 | 7 | 1 | 2 | 3 | 1 | 34 |
| Lanarkshire | 25 | 18 | 7 | 8 | 1 |  | 59 |
| Lothian | 26 | 18 | 3 | 11 | 3 |  | 61 |
| Orkney | 1 | 2 |  |  |  |  | 3 |
| Shetland |  |  |  |  |  |  | 0 |
| Tayside | 9 | 7 | 3 | 1 |  |  | 20 |
| Western Isles |  |  |  |  |  |  | 0 |
| Other UK | 1 | 1 |  |  |  |  | 2 |
| **Grand Total** | **184** | **129** | **54** | **40** | **17** | **2** | **426** |

**Fetal or Obstetric Patients**

Studies have shown that if congenital heart disease is detected before birth, there are significant benefits for babies, their families and for medical services around the time of birth. Our service has a dedicated, fetal cardiology team, provided by a fetal cardiologist working in conjunction with the fetal medicine team, co-located at the QEUH. Obstetric and fetal medicine teams throughout Scotland refer to the fetal cardiology service if there is a suspicion of a structural or rhythm abnormality detected during the routine Fetal Anomaly Screening Programme (FASP) scan.  To be able to comply with UK wide NHSE standards for delivery of fetal cardiology assessment and counselling SPCS are currently preparing to advertise for a second fetal cardiologist.  If this post is filled it would be expected that the ongoing funding for this post will be agreed with NSD. The current fetal cardiologist has recently returned from maternity leave, and greater resilience for the service will come from the aforementioned appointment of a second fetal cardiologist.

Assessment involves both the cardiologist and fetal medicine consultant. Fetal echocardiography is undertaken to confirm the diagnosis, provide risk stratification of cardiac lesions and detailed counselling of families to provide immediate and longer-term prognosis of the cardiac condition. Follow up scans are arranged throughout pregnancy to assess progression of the cardiac abnormality, to provide an agreed perinatal plan regarding location and timing of delivery and develop a postnatal management plan. The plan for impending birth of babies with significant congenital cardiac pathologies is shared with the wider SPCS team on a weekly basis at the joint cardiac conference. The service is supported by two specialist midwifes in fetal medicine and the Paediatric Cardiac Nurse Specialist team(PCNS).  The PCNS team provide support whether delivery is scheduled at the QEUH or a local hospital.  The recorded numbers of fetal echocardiographs for the last three years are as follows (please note these figures may be an underestimate due to recording failures as a result of staff cross-covering duties for the maternity leave of the lead fetal cardiologist):

|  |  |  |  |
| --- | --- | --- | --- |
|  | **2021/22** | **2020/21** | **2019/20** |
| Fetal echocardiographs (QEUH) | 274 | 123 | 250 |

In a bid to increase the prenatal detection of congenital heart disease in Scotland, the fetal cardiology/fetal medicine team continue to provide education to the referring teams in the form online tutorials and a twice yearly ‘hands on’ fetal echocardiography course, this was paused during the current pandemic but aims to recommence later in 2022. The fetal team have also worked closely with the charity ‘Tiny Tickers’ to boost sonographer training throughout Scotland.Through the support of the fetal cardiology and fetal medicine team obstetric screening programs throughout Scotland have been able to improve delivery of their local services. Ongoing benchmarking of the fetal service is an important part of our ongoing quality improvement and service development.

The latest audit data for 2019/20 show a continuing positive trend in Procedures with Prenatal Diagnosis (PPD) rates of all infants requiring a procedure with a successful antenatal detection. The detection rate remains at 50% for all infants requiring a procedure in the first year of life. The percentage of infants who were antenatally diagnosed and underwent a procedure in the first year of life for any cardiac malformation was 53% for patient’s resident in Scotland.

The fetal cardiology team are involved in research and development projects and are currently participating in the Prenatal Right Aortic Arch and Double Arch (PRAADA) study, a UK national, multicentre retrospective study.  In addition, the team have recently completed their data collection for the International 22q Perinatal Outcomes Study in conjunction with Columbia University, USA.

**MRI Provision**

It is estimated that the annual requirement for cardiac MRI from the national cardiac service will continue to increase. In line with best practice there will be an increasing need for cross sectional imaging provision. The complexity and the data yield from every scan will continue to increase as the service develops. Many of these patients have historically required their imaging to be carried out under a general anaesthetic however the RHC cardiac imaging team have developed multiple strategies to reduce the need for general anaesthetic which in turn has led to a marked reduction in waiting times, with most cardiac MRI’s now being delivered within 6 weeks of the request. There have been significant pressures on the capacity of the MRI service at RHC however the service is now robust with four Radiologists with an interest in cardiac cross-sectional imaging now working with the newly appointed paediatric Cardiologist with an expertise in MRI. Over the next 12 months the cardiac imaging team aims for the cardiac imaging team to enhance cross-working with the SACCS cross-sectional imaging team.

|  |  |  |  |
| --- | --- | --- | --- |
| **NHS Board** | **2021/22** | **2020/21** | **2019/20** |
| Ayrshire & Arran | 12 | 10 | 8 |
| Borders |  | 1 | 2 |
| Dumfries & Galloway | 4 | 5 | 7 |
| Fife | 2 | 1 | 2 |
| Forth Valley | 3 | 9 | 4 |
| Grampian | 2 | 6 | 2 |
| Greater Glasgow | 29 | 30 | 30 |
| Highland | 4 | 3 | 1 |
| Lanarkshire | 22 | 16 | 23 |
| Lothian | 6 | 4 | 20 |
| Orkney |  |  |  |
| Tayside | 6 | 2 | 3 |
| Western Isles |  |  |  |
| Other UK | 1 |  |  |
| **Grand Total** | **91** | **87** | **102** |

# Performance and Clinical Outcomes

## 3.1 Equitable

**Cardiac Surgery Referrals by NHS Board**

|  |  |  |  |
| --- | --- | --- | --- |
| **NHS Board** | **2021/22** | **2020/21** | **2019/20** |
| Ayrshire & Arran | 11 | 15 | 27 |
| Borders |  |  | 4 |
| Dumfries & Galloway | 6 | 9 | 12 |
| Fife | 16 | 16 | 26 |
| Forth Valley | 16 | 14 | 25 |
| Grampian | 35 | 28 | 22 |
| Greater Glasgow & Clyde | 91 | 91 | 90 |
| Highland | 28 | 15 | 19 |
| Lanarkshire | 47 | 33 | 42 |
| Lothian | 55 | 39 | 66 |
| Orkney | 1 | 1 |  |
| Shetland |  |  |  |
| Tayside | 20 | 22 | 16 |
| Western Isles |  | 1 |  |
| Other UK | 1 |  |  |
| **Total** | **327** | **284** | **349** |

**Interventional and Diagnostic Cardiology** **Referrals by NHS Board**

|  |  |  |  |
| --- | --- | --- | --- |
| **NHS Board** | **2021/22** | **2020/21** | **2019/20** |
| Ayrshire & Arran | 13 | 11 | 16 |
| Borders | 2 | 4 | 3 |
| Dumfries & Galloway | 7 | 4 | 6 |
| Fife | 15 | 10 | 15 |
| Forth Valley | 12 | 12 | 20 |
| Grampian | 23 | 12 | 9 |
| Greater Glasgow & Clyde | 58 | 49 | 48 |
| Highland | 7 | 11 | 7 |
| Lanarkshire | 26 | 22 | 34 |
| Lothian | 28 | 30 | 34 |
| Orkney | 1 |  |  |
| Shetland |  | 1 |  |
| Tayside | 17 | 11 | 18 |
| Western Isles |  |  | 2 |
| Other UK | 1 |  |  |
| **Total** | **210** | **177** | **212** |

## 3.2 Efficient

**Cardiac Surgery**

The total number of bed days utilised by cardiac surgery patients in 2021/22 was 4640.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Length of Stay** | **Total Stay** | **Ward** | **Paediatric Intensive**  **Care Unit** | **Neonatal Intensive**  **Care Unit** |
| Mean Length of Stay (Days) | 11.7 | 11.3 | 10.2 | 20.6 |
| Median Length of Stay (Days) | 6 | 7 | 5 | 10 |
| Range of Length of Stay (Days) | 1-132 | 1-79 | 1-132 | 1-86 |

**Breakdown of Bed Utilisation by Patient Numbers**

|  |  |
| --- | --- |
| **Ward** |  |
| 0-5 | 62 |
| 6 - 10 | 65 |
| 11 - 15 | 18 |
| 16-20 | 13 |
| 21-25 | 10 |
| 26-30 | 5 |
| 31-40 | 6 |
| 40+ | 5 |

|  |  |
| --- | --- |
| **PICU** |  |
| 0-5 | 99 |
| 6 - 10 | 34 |
| 11 - 15 | 14 |
| 16-20 | 9 |
| 21-25 | 3 |
| 26-30 | 3 |
| 31-40 | 5 |
| 40+ | 9 |

|  |  |
| --- | --- |
| **NICU** |  |
| 0-5 | 6 |
| 6 - 10 | 13 |
| 11 - 15 | 3 |
| 16-20 | 2 |
| 21-25 | 2 |
| 26-30 | 4 |
| 31-40 | 2 |
| 40+ | 5 |

**Interventional and Diagnostic Cardiology**

The total number of bed days utilised by interventional and diagnostic patients in 2021/22 was 824.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Length of Stay** | **Total Stay** | **Ward** | **Paediatric Intensive**  **Care Unit** | **Neonatal Intensive**  **Care Unit** |
| Mean Length of Stay (Days) | 2.9 | 2.4 | 2.6 | 17.4 |
| Median Length of Stay (Days) | 2 | 2 | 1 | 12 |
| Range of Length of Stay (Days) | 1-44 | 1-28 | 1-11 | 1-44 |

**Breakdown of Bed Utilisation by Patient Numbers**

|  |  |
| --- | --- |
| **Ward** |  |
| 0-5 | 171 |
| 6 - 10 | 5 |
| 11 - 15 |  |
| 16-20 |  |
| 21-25 |  |
| 26-30 | 1 |
| 31-40 |  |
| 40+ |  |

|  |  |
| --- | --- |
| **PICU** |  |
| 0-5 | 5 |
| 6 - 10 |  |
| 11 - 15 | 1 |
| 16-20 |  |
| 21-25 |  |
| 26-30 |  |
| 31-40 |  |
| 40+ |  |

|  |  |
| --- | --- |
| **NICU** |  |
| 0-5 | 2 |
| 6 - 10 | 1 |
| 11 - 15 | 2 |
| 16-20 |  |
| 21-25 |  |
| 26-30 |  |
| 31-40 | 1 |
| 40+ | 1 |

## 3.3 Timely

RHC performs with the set delivery agreement between the Scottish Government Health Department and NHS Greater Glasgow & Clyde, based on key ministerial targets.

**Outpatient Appointments**

All patients referred for an outpatient pathway will receive a date for an appointment within two weeks of referral. The appointment date will not exceed maximum Scottish Guidelines.

During the reporting period, the maximum wait for offer of a first Outpatient Appointment was 10 weeks.

RHC operates a partial booking service for Outpatient attendances. On receipt of a non-urgent referral, patients (parents or carers) are invited to contact Medical Records and agree a date for a convenient first Outpatient Appointment, within 12 weeks of the referral.

NHS Boards deliver to agreed efficiencies for 1st outpatient attendance DNA, non-routine inpatient average length of stay, new to return outpatient attendance ratio, same-day surgery and pre-operative stay.

**Waiting Times**

The service will ensure that the waiting time does not exceed Scottish Government Guidelines by communication and engagement with referring clinicians and teams on a regular basis including all external and outreach centres.

Paediatric cardiac surgery and catheterisation are managed on a planned or unplanned basis.

**Planned**

Patients requiring planned surgery or interventions are usually diagnosed and identified during outpatient appointments. Diagnostic testing is undertaken along with the full clinical assessment and is then presented at the weekly Joint Cardiac Conference (JCC) or multi-disciplinary team (MDT) meeting. Options for treatment are discussed and recorded in the minutes of the meeting. If the recommended outcome is surgery or catheter intervention, the patient is informed and added to the waiting list. If it is suitable the patient is invited to attend the Pre-assessment Clinic. During the JCC in the week prior to surgery, the patient is re-presented for confirmation of the planned surgical procedure.

Patients are invited to attend for surgery or catheterisation within 12 weeks of the decision to treat.

**Semi-Planned**

Increasingly, cardiac fetal anomalies are being diagnosed during antenatal assessment. When a serious cardiac condition is discovered, expectant mothers are invited to deliver their babies at The Queen Elizabeth University Hospitals to allow for early assessment and implementation of specialist care. As the neonatal unit and the Paediatric Cardiac Services are co-located there is no need for the risks involved in transport of patients. Delivery can be induced if this is required to treat specific cardiac presentations.

**Unplanned**

Although the Fetal Cardiology services continues to develop, unplanned surgical and catheter interventional treatment may be required. Examples of the need for emergency procedures include undiagnosed new-born cardiac conditions, rapid deterioration in a known patient and, rarely, an urgent new diagnosis in an older child.

**Waiting Times**

The waiting times are analysed and presented by the boards Business Intelligence team who provide information support for areas including clinical purposes, operation management, planning and performance management. There was a change in the scheduling of patients that came into practice between March and April 2019. Previously patients were held on two separate waiting lists, one of which was used to generate waiting time data. In agreement with GGC management the two waiting lists have been combined. Previous data has underestimated the ability of SPCS to deliver cardiac surgery within the agreed 12 week time frame. In discussions with NSD it has been made clear that the major impediment to achieving this goal historically has been access to PICU beds and work is onoing to increase the number of funded PICU beds at RHC and we are seeing the benefits of this already with a large drop in surgical cancellations. Of note surgical and catheter interventions are clinically prioritised by the teams according to clinical need. It may be useful in future to assess the waiting times for patients in each of these priority levels to ensure standards are being kept. Outpatient and Inpatients waiting times are as follows:

**Cardiac Surgery**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **2021/22** | **2020/21** | | **2019/20** |
| Waiting time to 1st appointment |  |  | |  |
| % within target | 100% | 78% | | 99% |
| Maximum (weeks) | 4-10 (69 days) | 18-26 | | 12-18 |
| Mean (weeks) | 0-4 | 10-12 | | 4-10 |
| Waiting time from decision to treat to procedure |  |  | |  |
| % within target | 63% | 44% | | 64% |
| Maximum (weeks) | 52+ (779 days) | 52+ | | 52+ |
| Mean (weeks) | 10-12 | 12-18 | | 4-10 |
| New OP Attendees | 67 | | 29 | 103 |
| New OP DNAs | 3 | | 3 | 4 |
| Average Number of Patients on IP True Waiting List | 33 | | 37 | 58 |
| Minimum Number of Patients on IP True Waiting List | 18 | | 15 | 42 |
| Maximum Number of Patients on IP True Waiting List | 42 | | 60 | 75 |

During the pandemic the surgical outpatients moved primarily to an “attend anywhere” virtual clinic or are combined with pre-assessment in order to reduce clinic footfall and pressures. These changes have been well received by families and will be monitored moving forward to ensure an optimal service is delivered.

**Cardiology**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **2021/22** | **2020/21** | **2019/20** |
| Waiting time to 1st appointment |  |  |  |
| % within target | 82% | 79% | 99% |
| Maximum (weeks) | 18-26 (181 days) | 26-40 | 18-26 |
| Mean (weeks) | 4-10 | 4-10 | 4-10 |
| Waiting time from decision to treat to procedure |  |  |  |
| % within target | 76% | 47% | 75% |
| Maximum (weeks) | 52+ (561 days) | 52+ | 26-40 |
| Mean (weeks) | 4-10 | 12-18 | 4-10 |
| New OP Attendees | 1198 | 1106 | 1340 |
| New OP DNAs | 132 | 147 | 151 |
| Return OP Attendees | 2476 | 2060 | 2747 |
| Return OP DNAs | 504 | 456 | 526 |
| New/Return Ratio (Attendees only) | 1:2.1 | 1:1.9 | 1:2.1 |
| Average Number of Patients on IP True Waiting List | 26 | 35 | 27 |
| Minimum Number of Patients on IP True Waiting List | 21 | 21 | 21 |
| Maximum Number of Patients on IP True Waiting List | 37 | 50 | 32 |

## 3.4 Effectiveness

**National Congenital Heart Disease Audit (NCHDA)**

As of April 2021 the Scottish Government ceased funding for the congenital cardiac surgery and intervention data to be submitted to NICOR. In its place we are currently working with Public Health Scotland to develop a bespoke data submission and analysis system and are seeking comparative benchmarking agreements with the NICOR team. We aim to use this to drive forward local data utility and quality improvement whilst still ensuring we benchmark against other UK centres. This is a substantial piece of work and is placing additional pressures on the team. To assist with this process, we have formed a multi-disciplinary Congenital Cardiac Audit Steering group with which includes colleagues form PHS and the GJNH in order to develop this new pathway to develop and define our data assurance and governance pathways. For this reason there has been no Scottish data in the NICOR report from March 2020 and we have not been able to benchmark with contemporaneous data from peers across the United Kingdom and Ireland.

Prior to this significant process change the SPCS have submitted data to National Congenital Heart Disease Audit from April 2000 to March 2020 which is managed by the National Institute for Clinical Outcome Research (NICOR) with Barts Health. It is the largest and most comprehensive national audit of its kind in the world and is now in its 22nd year. The audit collects data from all centres undertaking congenital cardiac surgery and interventional procedures in the UK. Among the information provided on the portal are profiles of every congenital heart disease centre in the UK, including the number and range of procedures they carry out and survival rates for the most common types of treatment.

Patients, parents and carers have until recently been encouraged to view the information on the website as a useful resource. This knowledge can then be used together with the information they receive from their family doctor and heart specialist in making any decisions on treatment options.

The last NCHDA validation visit took place in November 2020 and assessed data from April 2019 – March 2020. Given the removal of Scottish data we have not undergone data validation since this time. We have agreed with PHS that these visits will restart in due course. During these visits the NCHDA team chose a random sample of 20 patient case notes. The 20 patients had undergone 28 procedures, 19 surgical procedures and 9 catheter interventions.

We pride ourselves on our data quality and this has been shown given the Data Quality Indicator Score for the SPCS relating to Congenital Procedures for 2019/20 was 99.0%. This score has been consistent over several years with RHC having one of the highest scores for data quality in the entire United Kingdom.

The following conclusions from the NCHDA 2020 visit were noted as:

* “On the whole the NCHDA data was accurate, well documented in the hospital electronic notes, and good quality.
* The DQI score has yet again been maintained at 99% which is excellent and demonstrates that there continue to be robust methods and processes for clinical audit data quality maintenance and data collection at RHS. There were just 4 data discrepancies in 999 variables.
* The Reviewers would again like to commend the dedication and conscientiousness of the database manager who has worked very many extra hours to ensure that only good quality complete data were submitted for the year 2019/2020. There have been a number of technical and practical challenges during this pandemic through this data collection period, not all of them yet resolved. It also appears that there is no analytic support identified to the database manager to run the R Code software for the Specific Procedures and Activity algorithms used by NCHDA. R Code is freeware and supported by the NHS. It is a specialist analytical programme that requires appropriate knowledge and expertise.
* The bound operating theatre log books, as previously reported, are very well kept, being very neat and a concise record of activity. As previously reported, it was noted that on occasions the name of procedure performed appeared to be taken from the operating list for the day rather than completed at the end of the procedure with the precise description of the operation that had occurred. At times the descriptions of procedures in the cath labs appeared to be a little vague and imprecise.
* As reported at the 2018 and 2019 NCHDA Validation visit, the Validation Team are concerned to report that there still appears to be just a 1.0WTE Database Manager post dedicated to the NCHDA data collection at RHC. As stated at the beginning of this report, it is a recommended national standard, that in line with the New Congenital Heart Disease Review (NHSE July 2015) recommendation B32(L1) that each Specialist Surgical Centre must have a minimum of 1.0 WTE dedicated paediatric cardiac surgery/cardiology data collection manager, with at least 1.0 WTE assistant, responsible for audit and database submissions in accordance with necessary timescales.
* This is further underpinned by The Report of the Independent Review of Childrens’ Cardiac Services in Bristol (June 2016 Grey, Kennedy 1.22(2) and Ch17).
* It is noted by the Reviewers that although Scotland is not subject to the NHSE Surgical Standards for Congenital Cardiac Surgery (2016), colleagues at RHS and National Services Scotland (NSD) opted to participate in the initial Review in 2015 and again sought feedback on their service from NHSE Panel in July 2019.”

This is an excerpt from the report which can be viewed in full here: [NCHDA Summary Report 2021](https://www.nicor.org.uk/national-cardiac-audit-programme/congenital-heart-disease-in-children-and-adults-congenital-audit/)

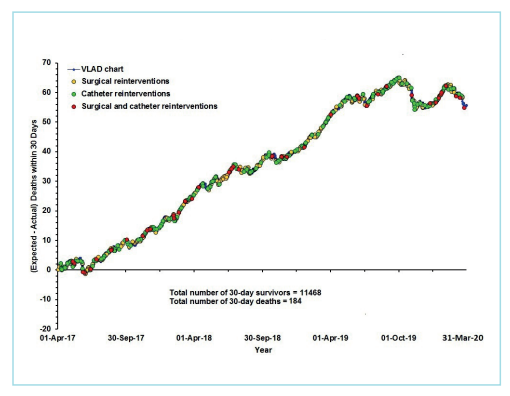
**Variable Life Adjusted Displays (VLAD)**

Specialist cardiac centres use Variable Life Adjusted Displays (VLAD’s), depicting the predicted minus the actual number of survivals at 30 days post-surgery, as well as re-interventions within 30 days of the surgery, to monitor their own outcomes. The benchmarking in the VLAD is based on the Partial Risk Adjustment in Surgery (PRAiS) model, which was revised and improved in June 2016 (PRAiS2), as well as recalibrated using the 2009/10-2015/16 Congenital Audit outcomes, with improved statistical performance.

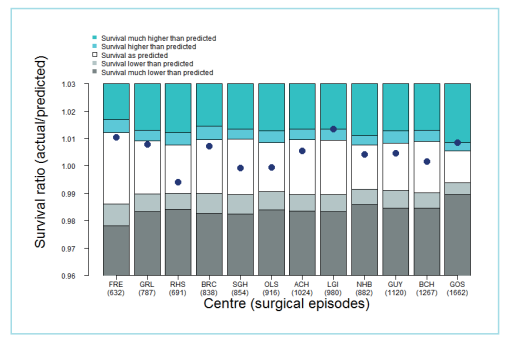
The risk model (PRAiS2) essentially benchmarks the unit’s outcomes against recent national outcomes in paediatric heart surgery accounting for all the important medical aspects of case mix complexity. A positive value (line going up) following an individual patient’s operation indicates improved survival in comparison with what would be predicted based on that patient’s congenital heart malformation and the presence of any associated cardiac and-or non-cardiac risk factors (so-called case mix). So, the estimated risk of death for a patient is small and this means that the VLAD will rise much more slowly for a run of survivors than it will fall for a run of deaths. Despite this being one of the most complex areas of surgery and lifesaving for the children involved, the UK and Republic of Ireland continue to have excellent outcomes with very low mortality rates.

The following charts are validated and produced by NCHDA:

*Figure 1: Variable Life Adjusted Display (VLAD) Chart for all 12 paediatric centres in the UK and Republic of Ireland undertaking procedures in patients under 16 years of age, 2017/18 – 2019/20*



*Figure 2: Actual vs Predicted Survival for all 12 centres undertaking cardiac procedures in patients under 16 years of age in the UK and Republic of Ireland, using PRAiS2 risk adjustment methodology, 2017/20*



*Note: Outcomes are adjusted for age, weight, diagnosis, comorbidities and procedures performed. Abbreviations: FRE, Newcastle, Freeman Hospital; GRL, Leicester, Glenfield Hospital; RHS, Glasgow, Royal Hospital for Sick Children; BRC, Bristol Royal Hospital for Children; SGH, Southampton, Wessex Cardiothoracic Centre; OLS, Dublin, Our Lady’s Children’s Hospital; ACH, Liverpool, Alder Hey Children’s Hospital; LGI, Leeds General Infirmary; NHB, London, Royal Brompton Hospital; GUY, London, Evelina London Children’s Hospital; BCH, Birmingham Children’s Hospital; GOS, London, Great Ormond Street Hospital for Children.*

**Local Quality Dashboard**

The Royal Hospital for Children PICU Quality Dashboard, launched in January 2014, is a key driver for quality improvement across the Cardiac faculty.  Mortality figures for children admitted to Paediatric Intensive Care continue to fall, as demonstrated in the latest PICANet report.  Coupled with the latest NCHDA report which confirms that 30-day survival post cardiac surgery in all of the UK units is within the predicted national average, the focus has shifted from mortality to morbidity. This initiative enables the systematic monitoring of the most important PICU related morbidities.

Over the last two years the multi-disciplinary PICU dashboard team has refined the data capture collated and now focuses on 26 PICU related morbidities. Definitions of all morbidities are published by PICU in a document entitled 'Morbidity Definitions Dictionary' and these are aligned with the NCHDA definitions of complications.  Patients are screened for the development of these morbidities on a daily basis by the medical team in PICU. There is a rigorous data validity programme. Each month, as part of the Team Based Quality Review Meeting, 2 morbidities are reviewed in detail while the relevant cardiac morbidity data is shared on a quarterly basis to the wider cardiac faculty at CME. Every 6 months 2 morbidities are identified as key audit projects, linked to key quality improvement projects as agreed by the Cardiac Risk & Quality Group. An example of the key work currently underway using this data includes streamlining the pathway for investigation and follow up of children who have suffered a neurological injury, developing a stroke guideline and consideration of use of a functional neurological scoring strategy to assess patient neurodevelopmental status both pre and post-operatively. We also use the dashboard to highlight excellence with the development of “catch of the day” where positive behaviours and interactions are shared as learning with the wider team.

While the purpose of the dashboard is for the monitoring of PICU related morbidities, the ultimate aim is for them to undergo a structured interrogation which will inevitably assist in a reduction of their incidence and will thus contribute to improved quality and safety within our services.**3.5 Safe**

**Healthcare Associated Infection (HAI)**

The Paediatric Cardiac Service facilities are both formally and informally inspected on a regular basis for compliance this includes:

* Local infection control guidelines and policies
* National policy on hospital acquired infections
* National standards from the health environment agency

**Scottish Patient Safety Programme (SPSP)**

RHC participates in The Scottish Patient Safety Paediatric Programme (SPSPP) which was established in 2010 this consists of seven key aims of SPSPP.

**Infrastructure** Setting up the team dynamics in order to deliver the Programme.

**SBAR** SBAR stands for “Situation – Background – Assessment – Recommendation”. SBAR is a communication tool that when applied consistently allows for a very effective hand-over of information between parties.

**PEWS** PEWS stands for “Paediatric Early Warning Scores” and is a patient assessment tool, which when consistently applied to all patients provides clinical staff with an early indication of whether there are any potential issues for the patient.

**Critical Care** The work stream associated with Critical Care (Paediatric Intensive Care Unit) involves standardising many of the invasive techniques that patients may require upon admission to PICU.

**Paediatric Trigger Tool** This is a tool that measures the reduction in adverse events in paediatric hospitals and was introduced during June 2013.

**PVC Bundles** PVC stands for “Peripheral Vascular Catheter” and the bundle is the documented tool whereby all patients on ward will be checked to ensure PVC’s are functioning safely.

**Safety Brief** Ward safety briefs are held twice a day during shift handover.

**Risk Register**

The risk register is held centrally and updated at the Clinical Governance Group Meeting where risks for Paediatric Intensive Care and Theatre are also discussed.

**Clinical Governance**

The Paediatric Cardiac Service Programme participates in the following Governance committees.

* **GGC Women and Children’s Directorate Clinical Governance Forum (monthly)**

This meeting is chaired by W&C Chief of Medicine and includes the general manager and lead nurse. All of the clinical directors within hospital paediatric and neonatology as well as obstetrics and gynaecology present update from their areas focussing on current challenges and outcomes. The terms of reference are to provide clinical governance and this meeting reports back to the Health Board of GGC. Novel procedures and pathways are reviewed and approved through this group.

* **Cardiac Risk and Quality Group (CRAG) (quarterly)**

The CRAG is a multi-disciplinary forum for monitoring and ensuring adequate clinical governance across the cardiac faculty. It encompasses the previous Audit and IT group by overseeing all areas of audit and quality improvements within the SPCS.

The CRAG faculty have developed and revised the Cardiac Learning Review tool which is based on the level 4/5 incident review form. This allows identification of incidents or events that are reviewed through a rapid review process with agreed tight timelines to identify areas for improvement but also to highlight areas of excellence. This process has been very useful in also facilitating and educating subsequent mortality reviews and SAER investigations when they are required and works in tandem, with the established learning from excellence framework in place across RHC.

There are multiple areas of oversight delivered by the CRAG team including reviewing all Datix’s within the cardiac faculty as well as ensuring Serious Adverse Event Reviews (SAER’s) are completed and fedback to families as well as the wider clinical group within an agreed and appropriate timeline that is in line with national standards.

The CRAG team oversee quality improvement work in the cardiac faculty.

* **Cardiac Nursing Team Meeting**

This is a new group that plan to discuss professional nursing issues, service development and improvements. Terms of reference for this group are being established and this will outline the frequency.

* **SPCS morbidity/mortality forum (monthly)**

The multi-disciplinary meeting is attended by the entire Cardiac team plus invited guests from other specialties / other centres to discuss all patients who have either died or had a significant clinical event.

* **Consultant Meetings**

A combined cardiology and cardiac surgery consultant meeting takes place quarterly to discuss wider service issues. The Cardiology Consultant forum also takes place bi-weekly, to discuss Cardiology service issues. There is also a weekly meeting of the surgical team to schedule cases and review service issues.

* **Fetal Medicine Meeting (weekly)**

A combined meeting takes place weekly between the fetal medicine team, fetal cardiology and neonatology teams to discuss and plan the delivery and acute management of fetuses with congenital cardiac disease at the QEUH.

* **Cardiac Theatre & Cath Lab Performance Group Meeting (bi-monthly)**

This is a multi-disciplinary meeting focussed on education, quality improvement and service review and development of the theatre aspects of the cardiac patient pathway. We undertake a performance review of the previous month’s cases in order to share and highlight learning or areas to develop.

* **Cardiac Guidelines Group Meeting (quarterly)**

This is a multi-disciplinary group tasked with overseeing and assisting with the development and update of all the cardiac guidelines and pathways whilst ensuring they are accessible on the RHC guidelines app for local and other team members elsewhere in the network.

* **Cardiac Equipment Group Meeting (quarterly)**

This is a multi-disciplinary group tasked with overseeing efficient and targeted equipment updates across the faculty.

**Adverse Events**

Datix is the software used by NHS Greater Glasgow & Clyde for (clinical and non-clinical) incident reporting, and for managing complaints and legal claims. Datix incidents for Paediatric Cardiac Surgery are reviewed regularly as part of the Cardiac Risk and Quality Group in particular to focus on severity 4 and 5 incidents to ensure learning objectives are carried through to completion including feed back to the wider clinical teams. CRAG updates are recorded at the clinical governance meeting.

**Mortality**

The following figures are calculated as a percentage of the number of cardiac surgery or interventional cardiology cases.

|  |  |  |  |
| --- | --- | --- | --- |
|  | **2021/22** | **2020/21** | **2019/20** |
| Cardiac Surgery - 30 day patient survival | 97.8% | 98.4% | 98.2% |

|  |  |  |  |
| --- | --- | --- | --- |
|  | **2021/22** | **2020/21** | **2019/20** |
| Interventional Cardiology - 30 day patient survival | 98.6% | 100% | 99.5% |

Note: This figure is calculated as a percentage of the total number of surgical or catheter cases without considering multiple procedures or complexity.

**The Quality Surveillance Programme (QSP)**

Specialised Services Quality Dashboards (SSQD) are designed to provide assurance on the quality of care by collecting information about outcomes from healthcare providers. SSQDs are a key tool in monitoring the quality of services, enabling comparison between service providers and supporting improvements over time in the outcomes of services commissioned by NHS England (NHSE). Through the Quality Surveillance Program (QSP), NHSE started a process of peer review of all Congenital Heart Centres in England. NSD agreed for SPCS to be involved in this process and the peer review visit occurred in July 2019.

The service was measured against an agreed set of quality indicators which were developed in line with the national standards for congenital heart centers in England. There were 3 serious concerns identified by the review team and are listed below.

1. Surgical capacity – directly related to PICU bed availability.
2. Cardiac Nurse Specialist provision – insufficient to be able to support outreach clinics and not in line with NHSE standards.
3. Transition pathway – linked to CNS provision and concerning the variable delivery of transition in outreach centres.

There has already been an agreed increase in the funding for PICU beds in RHC. The issues pertaining to CNS provision and Transition will be picked up in ongoing discussions about the service agreement for SPCS.

## 3.6 Person centred

**Patient, Carer and Public Involvement**

* Young people are invited to participate in the “Youth Voices” forum which encourages feedback, ideas and innovative thinking about the delivery of NHS services in a way that best meets the needs of the service. Youth Voices has been pivotal in directing the development of works for RHC.
* RHC delivers a Person Centred Health and Care (PCHC) feedback program. Patients, parents and carers are also encouraged to participate in informal, anonymous feedback by way of “How are we doing?” and Patient Experience questionnaires.
* The SPCS team are also developing active feedback through the Care Opinion service offered in tandem with the health board.

Through PCHC, SPCS is able to provide Patient Reported Experience Measures (PREMs). Both the “How are we doing?” and patient experience questionnaires are given to parents, carers and the patients on a continual basis. The target of 5 surveys returned every week is consistently met.

**“How are we doing?”**

This questionnaire is provided in 3 separate formats across a range of ages. The questionnaires ask similar questions but use language that s appropriate for adults, adolescents and younger children. The surveys are collected by the senior charge nurse and prominent themes are published on a ward notice board including any actions that have been taken to rectify areas for improvement. This survey continues to receive positive feedback and ward 1E is considered a “gold standard” within RHC setting standards for other wards to work towards.

**Patient Experience**

The patient experience questionnaire is administered through the PCHC department at RHC. The questionnaire covers a number of areas of patient experience and is scored on a numerical scale. A monthly report is provided to the cardiac ward 1E detailing the results of the questionnaire. The Patient experience is currently being reviewed by PCHC but the previous questionnaires include questions from several domains:

* Information and communication
* Nursing staff and your care
* Environment, comfort

The graph below illustrates weekly results from the April report and is typical of the reports received by the Cardiac ward.

**Better Together Programme**

“Better Together” is an NHS Scotland (NHSS) change programme intended to improve the patient experience of healthcare.  The key policy driver underpinning the programme is the NHSS healthcare Quality Strategy and in particular the quality ambition relating to 'Person-Centeredness'.  The overall aim of the programme is to support NHS Boards improve the quality of patient centeredness in healthcare delivery by focusing on areas that patients believe are important to them. Paediatric Cardiac Service conforms to actions arising from the GG&C Better Together Action Plan.

# Quality and Service Improvement

The Scottish Paediatric Cardiac Service (SPCS) continues to develop and improve the care that it delivers to their patients and families. In 2013 the service comprised 4 paediatric cardiologists and 3 congenital heart surgeons. Today there are 8 paediatric cardiologists providing a workforce that delivers sub-speciality services in structural heart interventions, electrophysiology, advanced echocardiography, fetal cardiology and cross-sectional imaging. The fetal cardiology service is a vital part of any modern congenital heart service and continues to develop to be able to provide a nationally co-ordinated service. Pre-natal diagnosis of congenital heart defects, counselling and planning for post-natal management has been clearly shown to improve outcomes in patients with congenital heart disease. Cross sectional imaging includes both magnetic resonance imaging (MRI) and computed tomography (CT). These are essential tools in planning complex surgeries in our patients as well as longitudinal follow up. We continue to develop our 3D modelling service and now can produce models within a very short time frame to allow planning for surgery in the most complex heart conditions.

The SPCS now provides sub-speciality services in all areas excluding heart transplant/advanced heart failure and pulmonary hypertension. These services are provided through close links with the quaternary specialist services based at Great Ormond Street, London and The Freeman Hospital, Newcastle. UK national standards for Paediatric Cardiology suggest an average of one cardiologist per 500,000 population. With the development of the fetal cardiology service there has been a need identified to help to achieve standards in the delivery of timely assessment of suspected cases of congenital cardiac disease pre-natally. A fetal cardiology post is currently being developed and with a second fetal cardiologist this will allow the service to develop further and to be able to meet national standards. The SPCS supports the delivery of the paediatric cardiology service in NHS Lothian which is currently provided by a single paediatric cardiologist. This was identified as a serious concern by the QST peer review team from NHSE.

Our **Advanced Nurse Practitioners** (ANPs) continue to be a cornerstone to service development and delivery within the SPCS. They have been identified as a gold standard for development of ANP programs in a number of other congenital heart programs in England. A prime example of this service development is the pre-admission clinic which assesses patients planned for admission for catheter and surgical procedures. This clinic has led to improved efficiency in reducing length of admission with many catheter patients being admitted on the day of procedure significantly reducing bed days utilised. Unexpected cancellations have also been significantly reduced due to early identification of inter-current illness and unexpected abnormal investigations. The work of the ANPs has been recognised within GGC for a Staff Excellence Award. Our team of ANPs are also integral in the development and regular review of unit protocols. They are currently involved in work to develop a website for SPCS.

# Governance and Regulation

## 5.1 Clinical Governance

The SPCS participates in a robust process of clinical governance. This is delivered internally through the Cardiac Risk and Quality Group (CRAG). This group meets quarterly and reviews all governance aspects as well as research and audit activity within the department. Complaints and clinical issues that are recorded through the Datix systems are also reviewed locally by this group. CRAG has developed a Learning Review tool that serves for the clinical team to undergo a rapid review of incidents where there has been an unexpected outcome. We recognised that the formal process of a SAER is not always required but also can take some time to complete. The learning review provides a timely review of events to ensure learning objectives are clearly identified and enacted. It is not to replace the SAER process but can enhance this important process.

At a higher level the Clinical Director report to the Women and Children’s Directorate Clinical Governance Forum. This meeting is held monthly and provides oversight for all clinical governance issues within Women and Children’s Directorate of NHS Greater Glasgow and Clyde. It is chaired by the Chief of Medicine and is attended by general managers and clinical directors from W&C. There is also representation from Risk and Effectiveness, Organisational Development and Health and Safety Executive.

## 5.2 Risks and Issues

Within the last 5 years there has been some variability in cardiac surgical activity including when just over 300 cases were completed in two consecutive years. Surgical activity in recent years has been restricted due to the availability of PICU beds. This is an issue that has been flagged up to management in GGC health board and to NSD as the major cause of lost surgical activity. There is a plan to continue to increase funding for PICU beds and SPCS strongly supports this increase in funding. The COVID pandemic initially placed major restrictions on cardiac surgical throughput however by working across teams and disciplines we have been able to continue a full elective cardiac surgical workload.

Access to the cardiac catheterisation suite has been more of a challenge due to both staffing issues and the ageing equipment which has required significant ongoing repairs. The significant capital investment will result in the new cardiac catheter suite being opened early June ’22.

Historically the surgical waiting list was managed through a combination of the SPCS database (HeartSuite) and the hospital patient management system (TrakCare). Therefore there was a risk of patients falling between the two systems and also a risk that the true waiting list was not being reported to hospital management. The surgical wait list has now been migrated to TrakCare. This is purely a numerical change but this is now a true representation of the difficulty that SPCS has in trying to comply with NHS Scotland targets. The SPCS has worked hard over the last year and successfully reduced waiting times. We are also working with colleagues in the GJNH to align scheduling of higher risk cases in a collegiate fashion.

The demands for data management have always been very high for the SPCS. This continues to increase with additional requirement produced by the work required in tandem with Public Health Scotland. A recent re-alignment of the cardiac database managers line management has helped ensure this individual is able to purely focus on the cardiac data and issues, which is welcomed, however it is clear additional resource should be considered with the changes in audit of the service and to ensure greater system resilience moving forward.

## 5.3 Adverse Events

The Cardiac Risk and Quality group have provided a forum for review of adverse events which did not previously exist within cardiac services. Datix is the IT system that used by GGC health board to record clinical incidents. All incidents that are graded 4 or 5 should be considered for commissioning SAER. Previously this had been the responsibility of a single clinician and this responsibility has been taken on by CRAG. Commissioning of an SAER is now more timely but also the ability to follow up implementation of quality and safety objective and actions that arise from an SAER. Not all level 4 or 5 Datix incidents require SAER but there are still often important learning objectives that can be distilled from these events, CRAG have developed a learning review which does not replace the SAER process but supports the process. A learning review involves the clinical team that were involved in the incident (cardiologist, cardiac surgeon, anaesthetist, intensivist, other MDT staff as required). The completed learning review is fed back to the wider cardiac service through the quarterly dashboard meetings at the cardiac education sessions on a Friday. Identified actions and objectives are followed up with the Clinical Risk team to ensure implementation through ongoing CRAG meetings.

## 5.4 Complaints and Compliments

There were eight formal complaints during the year, two were fully upheld, four were not upheld, one complaint was withdrawn and the other relates to an ongoing SAER which is nearing conclusion. None of the complaints were investigated by the Scottish Public Services Ombudsmen. Two of the eight complaints were related to revision of cardiac surgery dates and this is a regular theme both with formal complaints as well as complaints from parents and carers that are not referred to the formal complaints process. The team have worked hard and successfully to reduce this occurrence.

The cardiac nurse specialist team provide continual support to the families cared for by SPCS. Their support means that a significant number of informal complaints are concluded to the satisfaction of the families without using the formal complaints process.

## 5.5 Equality

The PCS promotes fairness, equity and above all values diversity in dealing with all patients. We are committed to eliminating discrimination on the basis of gender, age, disability, race, religion, sexuality or social class. We aim to provide accessible services, delivered to all in a way that respects the needs of each individual and does not exclude anyone. By demonstrating these beliefs, we ensure to develop a healthcare workforce that is diverse, non-discriminatory and appropriate to deliver modern healthcare.

We embed equality and diversity values into everyday practice, policies and procedures in order that equality and diversity become normal for all. All staff members of the SPCS are expected to undertake mandatory training in equality and diversity.

There have been no concerns regarding inequality of service provision to patients on the basis of gender, age, race, income, faith, or reported sexual identity.

# 6. Financial reporting and workforce

**Financial Reporting**

The service is funded by National Services Division by way of a fixed and variable element, dependent upon patient numbers.

All fixed costs associated with the service were allocated appropriately for the provision of SPCS, within budget.

Supplies and products utilised within the course of the Cardiac Service were purchased in conjunction with the NHS Greater Glasgow & Clyde procurement department, which ensures all products are of appropriate quality and carefully considered for cost. Please refer to Appendix 4 Paediatric Surgery and Interventional Cardiology Twelve Month Financial Report.

**Workforce**

**Medical**

Clinical Director Dr Mark Davidson, Consultant Paediatric Intensivist

Surgical Four full time Cardiac Surgeons

Cardiology Eight full time Cardiologists

A new post in cross-sectional imaging cardiology was recently filled with the successful applicant starting in April ’22. All sub-specialty areas are now delivered locally with the exception of pulmonary hypertension and cardiac transplant. The increase in staff allows for quality improvement projects, service development and refinement which are currently challenging to produce due to the clinical workload.

In addition to the cardiologists based at RHC, one cardiologist is based at RHSC Edinburgh. This cardiologist provides paediatric cardiology service to the Lothian Health Board as well as outreach services to the East of Scotland. He also undertakes Cardiac Service sessions at RHC and forms an integrated part of the national SPCS team.

The SPCS medical team are supported by Medical Trainee posts. These include three National Training Numbers in Paediatric Cardiology which is an increase from previous years. This illustrates the improving profile of SPCS when compared against other UK centres. There are also two Speciality Trainees from General Paediatrics, a Clinical Fellow and Foundation Year doctors. The service is also supported by the development of Advanced Nurse Practitioner posts, a UK leading initiative.

**Paediatric Cardiac Nurse Specialists (PCNS)**

The Paediatric Cardiac Nurse Specialist Team provides support to children and young adults with heart disease and their families both in and out of hospital. They are also involved in educating families on cardiac conditions and what this means to the child/young adult and their families.  The PCNS Team provide an expansive integrated service to the children and their families who are cared for by SPCS throughout Scotland. The team is led by a Coordinator who manages four PCNS who provide a staffing level of 4.6 WTE. Presently the Band 6 PCNS vacancy remains outstanding.

They work collaboratively with the cardiologists, cardiac surgeons and the wider multidisciplinary team on a daily basis to meet the needs of the patients and families. This includes attending cardiology clinic appointments, spending time with newly diagnosed patients and their families. They identify the needs of the patient and their family and refer appropriately to members of the multidisciplinary team within the hospital. The PCNS Team also communicates regularly with agencies that provide care for our patients in the community setting. The PCNS provide a vital line for our patients between the hospital and community.

On a daily basis the team continues to provide on-going support and education to patients and their families within the hospital environment and also in the community. An example of the work that the PCNS provide is the Home Monitoring Programme (HMP). The HMP has been set up and successfully run by the nurse specialists over a number of years to care for a very vulnerable group of patients.  This service has been extended and now includes shunt dependant patients.

The PCNS Team are also involved with providing information, education and support to parents with an ante-natal diagnosis of a cardiac conditions in order to help prepare them for the birth of their child. This care then continues in the neonatal period and throughout the patient journey.

The PCNS have been working alongside the Paediatric Cardiac Advanced Nurse Practitioners in developing a Pre- Procedural Virtual Clinic. This exciting and innovative development gives the opportunity for information gathering and sharing between parents/patients and professionals, in preparation for Surgery.

The team continue to work in conjunction with the adult SACCS service based at the Golden Jubilee National Hospital (GJNH) to establish a robust Transition Pathway from SPCS to the SACCS team and other adult cardiology colleagues elsewhere on Scotland. Transition Pathways and Guidelines have been developed and we have now established nurse specialist-led transition clinics at RHC. This is currently only for patients resident in the Glasgow area but plans are being developed to develop this on a national footing. The PCNS team also support the adult CNS at GJNH with the Transition Open Day where the young adults preparing for transitioning can come and meet the SACCS team and visit their new hospital environment. This service has been significantly limited by staffing shortages due to the unfilled PCNS post.

The PCNS are involved with the specialist clinics provided at RHC by Great Ormond Street Hospital.  These clinics care for children with pulmonary hypertension and inherited/acquired cardiomyopathies.  The PCNS also provide a lead for care of patients post cardiac transplant co-ordinating the shared care of these patients between the transplant centres and SPCS. PCNS also provide a valuable role of support and education throughout the network of hospitals that refer to SPCS.  Close links have also been forged with nurse specialist in the majority of regional centres.

**Advanced Cardiac Practitioner (ANP)**

The cardiology ANP team comprises of three ANPs, 2.5 WTE.  The development of this team is a UK leading initiative and several Congenital Heart Centres from England have used our program as a benchmark.  Their role within the cardiology MDT encompasses clinical, audit and teaching components. They are an excellent team resource providing a high standard of safe and effective patient care and continuity in the service where due to training rotations there is a regular turnover of junior medical staff.

They perform advanced patient assessment including history taking, clinical examination, prescribing, ordering and interpreting chest x-rays, ECGs and blood investigations.   On-call duties are undertaken as part of the registrar rota, taking internal and external cardiology referrals from multidisciplinary teams throughout Scotland.   Utilising skills of advanced communication, clinical knowledge and decision making to effectively manage complex patient care, enabled by the supervision of cardiology consultants. Continuity of care is provided by follow up appointment/clinic review.

At the ANP led pre-assessment clinic children scheduled for cardiac interventions are assessed and prepared for their procedure.  Attendance at this clinic improves the child/family journey, provides continuity of care and reduces in-patient stay, through support, information and access to multidisciplinary teams where appropriate.  The ANPs inform the MDT of patient findings at the joint cardiac conference meeting, elaborating on patient information. Rescheduling of procedures where the child may be unfit for their planned procedure in a timely manner, enabling and promoting appropriate use of cardiac resources is another benefit of this clinic.

The Cardiology ANP team manage a cohort of children who require day admission for initiation and titration of cardiac drug therapy. To promote an effective and efficient episode of care the ANP team developed a guideline involving patient assessment and monitoring, prescribing, requesting and interpreting investigations. These admissions are planned to take into consideration family centred care and the demands of the service.

For children commencing warfarin therapy the ANPs provide a comprehensive teaching package for children and families, ensuring safe monitoring and management of INR levels at home.

Co-ordinating cardiology patient admission for non-cardiology interventions (dental/general surgical procedures/investigations under GA) is also within their remit, liaising with paediatric multidisciplinary teams to ensure appropriate ward placement and patient safety.

The ANPs have initiated service delivery changes including the surgical fast track pathway and individualisation of pre cardiac catheter investigations preventing routine sampling, both initiatives have proven benefits to children and their families and also a financial saving to the NHS. The role of co-ordinating and maintaining the RSV immunisation programme for cardiac children in Scotland, has been continued this season, this involves communicating with cardiac multidisciplinary teams throughout Scotland, families, teams within RHC and being a point of contact and resource for information. The ANPs are currently trialling a pre assessment telephone consult in conjunction with the cardiac nurse specialists. The aim is to highlight and resolve any potential issues prior to listing the children for surgery and to give the family an overview of what to expect during hospital admission for their cardiac procedure. They are also involved in introducing neurological functional assessment scoring and undertaking a quality improvement package on neurodevelopmental care. They continue to be at the forefront of enabling change during the Covid pandemic to ensure efficient running of the paediatric cardiac service.

In addition, the ANPs develop, update and audit clinical guidelines, present at cardiology national conferences, teach on post registration nursing courses and have initiated a weekly teaching programme for the cardiology based nursing team.  They also have trainee ANPs and medical staff working alongside them to learn skills of clinical cardiac assessment and examination.

They achieve their objectives of providing a high standard of safe and effective patient and family care, whilst maintaining continuity. They keep themselves updated by attending and presenting at NMP/AMP forums, attending cardiology teaching sessions and study days/conferences appropriate for their role.

This team is essential to the smooth and efficient running of the cardiac interventional and surgical programmes. It is important to note these posts are all funded by the health board and not through the service level agreement with National Services Scotland.

**Cardiology Physiology Department**

The Cardiac Physiology department delivers advanced Cardiac Physiology support for the SPCS and wider hospital. High quality specialist investigations provided by the department include epicardial and trans-oesophageal assessment in Cardiac Theatre. Cardiac physiology also provides haemodynamic and echocardiographic assessment during both diagnostic and interventional procedures in the cardiac catheter laboratory. Services also include provision of cardiac physiology to the critical care unit encompassing both intensive care and high dependency patients. The investigations include ECG, Echo and Trans-oesophageal Echocardiography. The physiology department also provide support for the busy Cardiac Services Outpatient department with the above tests and also including Exercise Tolerance Testing. Physiology services cover all areas of the hospital.

**Cardiac Theatre Team**

The cardiac theatre team consists of highly skilled and dedicated nurses and operating department practitioners. The team aims to deliver exceptional patient centred peri-operative care to children and young adults undergoing open heart surgery within the Royal Hospital for Children. This cohesive and versatile team are able to adapt to challenging situations with compassion and commitment. As well as working alongside other specialities within the busy theatre department, the cardiac theatre team work closely with and provide surgical support for NICU, PICU, ECLS and the cardiac catheter laboratory.

**Cardiology Catheter Suite Team**

The Catheter Lab is managed by a Senior Charge Nurse (SCN) and is operated as part of the Theatre environment. The entire range of catheter procedures are offered at RHC including Percutaneous Pulmonary Valve Implantation (PPVI) and hybrid procedures where Surgery and Interventional Cardiology combine in a single procedure to provide the best outcome for patients. The cardiac catheter laboratory current being replaced with a state-of-the-art system which will greatly enhance service efficiencies and reduce radiation and contrast exposure. Of the patient and the team. This will include the ability to import other imaging modalities like CT and MRI. The team have formed a taskforce to re-assess and critically appraise all aspects of the cardiac catheter pathway to exhort all benefits from this significant capital investment and the dedicated team.

**Cardiac Ward (1E)**

Inpatient cardiac care is located at RHC, Ward 1E. There are 14 beds which can be utilised for patients admitted for and recovering from surgery and catheter procedures. The ward also admits cardiology patients admitted for non-cardiac procedures (e.g. dental procedures or MRI under general anaesthesia). The ward is managed by a Senior Charge Nurse experienced in the care of cardiac patients. The team have developed the skill set significantly and are now delivering high dependency care to a current maximum of three patients at a time. This has been involved rolling out training and use of high flow oxygen therapy, use of inotropes and prostaglandin in a ward environment.

**Paediatric and Neonatal Intensive Care Unit**

Cardiac Critical Care is managed by the teams in both the Neonatal and Paediatric Intensive Care Units.  The Paediatric Cardiac Service works closely with both NICU and PICU on a daily basis.  Dr Mark Davidson is the Cardiac Lead for PICU and Clinical Director of the Scottish Paediatric Cardiac Service.

Interactions between the wider cardiac faculty and both PICU and NICU take place at clinical levels as well as being interfaced at both governance and managerial levels.  Both the NICU and PICU teams have extensive experience in the management of patients with cardiac conditions and patients are transitioned as clinically appropriate to maximise utility of the critical care capacity on the campus.

Nurse staffing in critical care has improved of late and this has led to a more efficient use of the cardiac surgical theatre team and a reduced waiting time for cardiac surgical patients. Within critical care we continue to complete in-house cardiac competency programmes for nurses who have completed the relevant education requirements and have at least a year of critical care experience. These nursing pressures have impacted on the critical care nurse education programme which has been unable to run the Glasgow Caledonian University accredited cardiac nursing module over the last three years. We plan to run these nursing courses again from 2022.

Critical care has formed a cardiac focus group along with colleagues from the cardiac ward, pre-admission, NICU and cardiac theatres, to develop key areas with the aim of enhancing the care delivered. This multi-disciplinary group has further refined the cardiac surgical patient’s pathway which is available on the Royal Hospital for Children guidelines app. This process has led to the development of physiology and patient specific pathways including the right ventricular outflow tract pathway and fast track programme which have led to enhanced care. Further work is now underway to refine and review the cardiac catheter patient pathway.

**Clinical Psychology**

Cardiology has no funded NSD sessions which is a significant gap and means the service is limited in what it can offer, particularly to non GGC patients.  Specialist Children’s Services currently provide 0.4wte from generic funding but this means the service is not protected and could be impacted upon by fluctuating levels of psychological need in other specialties within the RHC Glasgow.

The Paediatric Psychology service received 45 referrals​ between April 2021-Mar 2022. This represents a reduction in annual referrals (typically around 80+ per year) which is likely to be as a result of the ongoing impact of COVID and temporary subsequent reduction in some elective surgeries.  As the NHS remobilises with a return towards pre pandemic ways of delivering clinical care, we have seen an increase in referrals to psychology and would anticipate that this will continue to increase. We may also see a period of a potential surge in referrals as previously unmet or unrecognised psychological need is detected.   The service is currently continuing to meet national HEAT standards for referral to treatment time for evidence based psychological therapies (currently set at 18 weeks RTT) but this will be impacted as referral rates increase back to pre-pandemic levels (or potentially higher).

In addition to one to one psychological assessment and intervention, we have continued to offer:

* A weekly parent support group offered to all cardiac inpatient families is currently being relaunched as a face to face session after COVID restrictions stopped this from being an option. Previously a virtual format was explored but did not run due to no take up.
* A monthly reflective practice group for the cardiac nurse specialist team and available time on a Friday morning for staff to consult with the psychologist about patients has been offered.  Both of these extend the reach of the psychology service by enabling psychological advice to be provided in order that staff can manage low level psychological difficulties on the wards. This minimises the need for a referral for one to one psychological therapy. Due to reduced Cardiac Nurse Specialist time the monthly reflective practice group has not been possible but we are planning dates to start again.
* Attendance at the Cardiology Transition Day for young people and families who are transitioning to adult services. Support and advice is offered relating to adjusting to the changes associated with moving to an adult service.
* Consultation and advice on key developments within the cardiology service. For example, articulating the psychological needs of infants who have been on ECMO therapy in order to contribute to the establishment of a neurodevelopmental pathway.
* Research in conjunction with the Doctoral Clinical Psychology course.  A research project is currently underway exploring the impact of surgery and hospitalisation on infant mental health.  It is hoped that this research project will provide valuable insight and will allow the cardiac service to think about possible service developments which will improve patient care for infants and their families.

**Dietetic Support**

Paediatric cardiology dietetic support within GGC is provided by a single dietician, funded to 0.3 WTE, whose role is to assess and optimise the nutritional status of infants and children with Congenital Heart Disease. This includes those admitted to the cardiology ward where acute nutritional intervention is provided and in the community, both pre and post cardiac intervention. A key part of this role is the intensive dietetic review provided to infants (shunt dependent or with Hypoplastic Left Heart Syndrome - HLHS) who follow the cardiac home monitoring programme throughout Scotland. There are on average 80 patients on the acute caseload. The Cardiac Dietician is the main contact for advice for paediatric dieticians, health visitors and community nurses working with paediatric cardiology patients across Scotland. The responsibilities of this essential post also include research and audit of any nutritional intervention in children with Congenital Heart Disease both locally and nationally. This has included implementation of a validated nutrition screening to be used for all infants admitted to the cardiology ward.

The experienced post holder has developed protocols for the nutritional management of cardiac infants & children including the nutritional section for the Hypoplastic Left Heart Syndrome home monitoring programme. They also have an active role in training paediatric dieticians and has developed tutorials for dietitians beginning to work in cardiology.

Changes in the demands on the cardiac dietetic service has seen a significant increase in the need for advanced dietetic input within the cardiac service with referrals increasing by 242% and patients who need ongoing dietetic support post-discharge increasing by 227%. This workload is a real challenge given the limitations imposed by the 0.3 WTE funding of this essential part of the cardiac service.

**Data Management**

The post delivers mandatory reporting of surgical, catheter and fetal activity and outcomes to the hospital management team, NSD as well as providing internally validated data to PHS to participate in the Scottish National Audit Programme (SNAP). Further demands on this post include participation in the Peer Review run by the Quality Surveillance Program and NHS England. It is vital that the data that is produced by SPCS remains at the highest quality. Standards for congenital heart disease state that there should be 1 WTE data manager allocated to the service and this is not currently being met.

**Secretarial Support**

Previously, 4.4 WTE Medical Secretaries supported the Cardiac Service team but one post has been vacated and there is now 3.48 WTE. Patients that are treated by SPCS have life-long, life-limiting diseases and due to this the nature of the workload generated by the SPCS is very demanding. Both the volume and complexity of the administrative burden has continued to increase over recent years. Since 2013 the number of cardiologists has increased from four to eight. This was identified as an area of risk and work is ongoing to ensure the service is adequately supported.

**Multi-Disciplinary Team**

The Cardiac Service is further supported by the wider clinical multi-disciplinary team. This includes a team of 7 cardiac anaesthetists who support cardiac surgical theatre. Support for the catheter laboratory is provided by both the cardiac paediatric anaesthetic team and a small number of the general paediatric anaesthetists. The cardiac surgical program is also supported by a team of perfusionists that rotate between the adult and paediatric congenital heart programs.

All Medical Staff participate in job planning and reviews on an annual basis. All nursing and admin/clerical staff participate in Knowledge and Skills Framework (KSF) programme.

# 7. Audit & Clinical Research / publications

SPCS has job planned and allocated Clinical Leads for Research from both cardiology and cardiac surgery (Dr K MacLeod and Mr M Danton).

Research is an essential pre-requisite of the paediatric congenital heart program and this unit actively participates in national ad multi-centre trials to further clinical research into congenital heart disease and its management. Gaining insight into the key questions and mechanisms requires a multi-level or translational approach where the changes that are measured clinically are simultaneously analysed at a basic or population level.

**Projects**

**Complications after Heart Surgery in Children**

This UK wide NIHR (National Institute of Health and Care Research) funded multi-centre study is looking specifically at the incidence and the impact of post-operative morbidities in children undergoing cardiac surgery in the UK. The Royal Hospital for Children in one of five centres participating in this study. In close collaboration with the National Institute of Cardiovascular Outcomes Research (NICOR) and using the PRAiS model (Partial Risk Adjustment in Surgery) the study seeks to identify the development of post-operative morbidities and evaluate resultant impact on patients, families and the NHS. Recruitment to the incidence and impact arm of the study began in October 2015. The study has recruited just under 3500 patients post- cardiac surgery across the 5 centres. Analysis of the incidence of morbidity is currently on-going in collaboration with University College, London. The impact data analysis, which is to follow, will focus on the impact of morbidity on ‘quality of life’ and to some extent, the financial impact to both the families of these children and the NHS. Dr Warren Rodrigues, Paediatric Intensivist is the PI (???) with Mr Andrew McLean is the co-investigator.

**The Impact of the COVID-19 pandemic on the Outcome Scottish Congenital Heart Population**Grant funding of £20,000 was awarded by Medical Research Scotland for our study ‘Influence of the COVID-19 pandemic on the Scottish Congenital Heart Population’   
Danton M, Cleland J, McConnachie A.  
This work will be performed in collaboration with Robertson centre of Biostatistics.

**Epidemiology and Outcomes of Proximal Aortopathy in Scotland**Gradinariu G, McConnachie A., Danton M.

**Comparison of Face-to-Face versus Remote Videoconferencing in Paediatric Congenital Cardiac Multidisciplinary Meetings.**   
McGinley M, Danton M, Bushnell I.

**Intrathoracic epicardial pacing in children**Ferguson R, McLean A, McLeod K

**Multi-centre Trials**

Individual institution clinical trials are compromised by cohort size. Multi-centre studies can attempt to address this issue.

**Ongoing**

* European Paediatric Hypertrophic Cardiomyopathy registry. The aim of this registry is to understand and improve the diagnosis and management Hypertrophic cardiomyopathy in children.
* EDITS - The aim of the Early Development in Tuberous Sclerosis (Edits) Study is to better understand how the development of babies with TSC differs to typically developing babies, and how sudden changes in seizure severity and treatment affect development. RHC are part of the UK study recruiting patients with rhabdomyomas and tuberous sclerosis. [www.edits-study.org](http://www.edits-study.org/).
* Dravet study investigating the use of fenfluramine in Dravet epilepsy – Fenfluramine has been associated with valve abnormalities and pulmonary hypertension. The cardiology team are involved in this study, monitoring echos in children participating in the study.
* FAST trial. The Fetal Atrial Flutter and Supraventricular Tachycardia (FAST) Therapy Trial is a prospective international multicenter trial to determine the efficacy and safety of standard trans-placental medication for fetal tachyarrhythmias in healthy singleton pregnancies prior to 37 weeks.
* Prenatal Right Aortic Arch and Double Aortic Arch Study (PRAADA 1). This is a multicentre, retrospective, national study of prenatally diagnosed right aortic arch and double arch: Incidence; associations and outcomes. A collaboration by the National Fetal Cardiology Working Group.
* Di George Study – retrospective multinational study. Main site, Columbia, NYC, & CHOP
* Prospective Clinical Assessment Study in Children With Achondroplasia - The PROPEL trial. This is a long-term, multi-center, observational study in children 2.5 to 10 years with achondroplasia (ACH). The objective is to evaluate growth, ACH-related medical complications, and treatments of study participants.
* Royal Hospital for Children Glasgow is part of the UK paediatric hypertrophic cardiomyopathy consortium investigating risk factors and outcomes of patients with hypertrophic cardiomyopathy. This Collaboration has resulted in a number multicentre publications (see below).
* Contribution to a multicentre study coordinated by the British Paediatric Cardiac Association looking at the clinical course and outcomes of children with congenital heart disease who have tested positive for COVID-19
* Contribution to a UK registry of children with Brugada and related syndromes.

**Completed**

* Ventricular Fibromas in Children, Arrhythmia Risk and Outcomes: A Multicenter Study, accepted for publication the Journal ‘HeartRhythm’ June 2018. JHRM-D-18-00470R1
* Hypertrophic Cardiomyopathy - part of an international consortium looking at risk factors for sudden death in children with hypertrophic cardiomyopathy. A paper has now been published.
* Hypertrophic Cardiomyopathy - part in a UK multicentre study to evaluate the programming of internal cardiac defibrillators in children and adolescents with hypertrophic cardiomyopathy. The paper has now been submitted for publication.
* The EFFORTLESS trial is a registry documenting follow up and outcomes following implantation of a fully subcutaneous defibrillator. A subcutaneous defibrillator is an implantable device that can record the heart rhythm and deliver DC ‘shock’ if the rhythm has become dangerously fast and life-threatening.
* Perinatal Management and Outcomes of 22q11 Deletion Syndrome  
  ‘Recent technological advances and improvements in SNP-based NIPT have allowed for the accurate prenatal detection of microdeletions, including most prominently the recurrent 22q11.2 deletions associated with 22q11.2DS.  However, it remains controversial as to whether this testing should be incorporated into routine prenatal care.  There is a paucity of published data regarding the natural history of children prenatally diagnosed with 22q11.2DS.  It is thus unclear how this prenatal information impacts parental decision-making and management among patients both with and without congenital heart disease.  In addition, such neonates and infants have not been compared to a contemporaneous group of postnatally diagnosed patients to demonstrate the impact of prenatal diagnosis on medical care and early survival.  We expect our collaborative investigation to provide data on these critical questions.’  
  The lead sites were: Columbia University Medical Center, Morgan Stanley Children’s Hospital of New York-Presbyterian &Children’s Hospital of Philadelphia, Perelman School of Medicine at the University of Pennsylvania.
* Catheterization RISk Score for Pediatrics (CRISP)Congenital cardiac centres in the UK currently have no validated and uniform means of predicting morbidity during cardiac catheterisation. Whilst some data collection is achieved through NICOR, this primarily aims to describe mortality figures rather than categorise and assign risk to specific cases. In the USA significant work has been undertaken in constructing scoring systems to predict risk in congenital catheterisation. The CRISP score (Catheterisation RISk score for Paediatrics) is the most widely utilised and has been modelled on retrospective data gathered from several thousand catheterisations. Whilst one centre in the UK has routinely submitted data to the C3PO database from which CRISP sores are generated, the scores and use of CRSIP primarily reflects North American practice; applicability to practice in the NHS has not been tested.  
  RHCG has recently collaborated with three other centres in the UK and one in Ireland in a pilot trial designed to assess the applicability of the CRISP score to congenital catheterisation in the NHS. The trial has been co-ordinated through the Evelina Children’s Hospital, with data collection at each centre and analysis undertaken by an academic research FY2. Each centre submitted 300 consecutive anonymised catheterisations dated up to the end of July 2016 (sample size 1500). The incidence of adverse events predicted by the CRISP scores (CRISP score 1-5, 5 being the highest risk) were compared with the observed incidence and severity of complications. The incidence of adverse events predicted within each CRISP score category was statistically very close to the observed incidence, validating the use of CRISP score as an accurate predictor of catheterisation risk in NHS paediatric practice. The CRISP score underestimated the risk of adverse events in adult congenital practice for higher risk patients, consistent with the tool being designed for use in children. The results from this research are being prepared for publication.

**Audit**

Audit can be characterised as an internal measure of quality control - something that is of importance to the specific program, but not of wider beyond unit, relevance, in contra-distinction to peer review/published research.

**Completed**

* **ECG Checklist and Red Flags (Wood J, Mcleod KA)**

An ECG checklist using red flags was developed to assist ECG reporting in the paediatric emergency department. The ECG checklist improved confidence in ECG reporting, reduced the workload for paediatric cardiology trainees and reduced the time for patients with ECG abnormalities to be seen in the paediatric cardiology outpatient department. This was presented at the BCCA and published in the Archives of Diseases in Childhood. Other paediatric centres have adopted the checklist, including Royal Hospital for Children and Young people in Edinburgh, Tayside Children’s Hospital at Ninewells, Dundee and Forth Valley Royal Hospital, Larbert. In addition, we have agreed to requests to use the checklist in paediatric emergency departments in London and Bristol.

* **3D Mapping (Ali, A (medical student), Mcleod KA)**

Following acquisition of a 3D mapping (non-fluoroscopy) system for catheter electrophysiology and ablation procedures in 2018, we undertook an audit to determine fluoroscopic screening times before and after implementation of the 3D mapping. The audit demonstrated a statistically significant reduction in fluoroscopy screening times (and therefore radiation exposure). There was a trend towards improved results with the 3D mapping, which did not reach statistical significance. There was no difference in complication rates. However, the use of the 3D mapping was significantly more expensive.

**Current**

* **Conscious sedation for children undergoing electrophysiology procedures (Kennedy L, Leoni S, McLeod KA)**

Conscious sedation rather than general anaesthetic has been used for selected patients undergoing catheter electrophysiology procedures. The aim of the audit is to assess its efficacy, safety and acceptability for the patients.

* **Re-intervention in the peri-operative cardiac patient (Smith B, Bader V, Brincat E)**
* **Peri-operative necrotising enterocolitus in the cardiac patient (McLeod I, Simpson J, Jacovides M, Davidson M et al)**
* **Cardiac ECLS use triggers and indicators (Begg C, Brincat E, Danton M, King A, Davidson M)**
* **Surgical site infection aetiology and risk reduction (Salami M, Hoque K, Davidson M, Spence N, Bell L, Gardiner C, Peng E)**
* **Risk reduction for peri-operative cardiac neurological insults (Perry N, Pegler R, McLeod I, Nelson D, Forrest K, Matta N, Latta S, Knight K, Hunter L)**

**Additional Studies**

* Natural History study in pediatric patients with MYBPC3 mutation associated cardiomyopathy. Commercial study, PI K McLeod

**Research Publications**

Consultants have been authors in the following recent publications these can be found on <http://www.ncbi.nlm.nih.gov/pubmed>

* **Outcomes of adults with repaired tetralogy of Fallot from the national Scottish Cohort**Dobson RJ, Ramparsad N, Walker NL, McConnachie A, and Danton MHD (2021). Cardiology in the Young 31: 1306–1314. doi: 10.1017/S1047951121000238
* **Right ventricular remodelling in hypoplastic left heart syndrome following Fontan completion**Danton MHD. Eur J Cardiothorac Surg 2022;61:43–4.
* **Tangled up in blue: the complexities of pulmonary artery augmentation.**Danton MHD. Eur J Cardiothorac Surg 2021;60:1102–3.
* [**Fluid-structure interaction in a fully coupled three-dimensional mitral-atrium-pulmonary model.**](https://pubmed.ncbi.nlm.nih.gov/33770307/)   
  Feng L, Gao H, Qi N, Danton M, Hill NA, Luo X.Feng L, et al. Among authors: danton m. Biomech Model Mechanobiol. 2021 Mar 26. doi: 10.1007/s10237-021-01444-6. Online ahead of print.Biomech Model Mechanobiol. 2021. PMID: 33770307
* **A Prospective Randomized Blinded Trial of Remote Ischemic Preconditioning in Children Undergoing Cardiac Surgery.**Verdesoto M, Spenceley N, Ilina M, Danton MHD. Seminars in Thoracic and Cardiovascular Surgery 2020 Vol 32 Issue 2
* **Blood flow simulations in the pulmonary bification in relation to adults patients with repaired Tetralogy of Fallot.**Boumpouli M, Danton MHD, Gourley T, Kazakid A. Medical Engineering and Physics 2020, 85, 123-138
* **COVIDSurg Collaborative, GlobalSurg Collaborative. SARS-CoV-2 vaccination modelling for safe surgery to save lives: data from an international prospective cohort study.**Br J Surg. 2021 Sep 27;108(9):1056-1063
* **COVIDSurg Collaborative; GlobalSurg Collaborative. Timing of surgery following SARS-CoV-2 infection: an international prospective cohort study.**Anaesthesia. 2021;76(6):748-758.
* **A Chandiramani, V Bader, E Finlay, S Lilley, A McLean, Ed Peng. The role of abnormal subaortic morphometry as a substrate for left ventricular outflow tract obstruction following atrioventricular septal defect repair.**Eur J Cardiothorac Surg.  [published online ahead of print, 2021 Sep 22]. Eur J Cardiothorac Surg. 2021 (Original article)
* **COVIDSurg Collaborative; GlobalSurg Collaborative. Effects of pre-operative isolation on postoperative pulmonary complications after elective surgery: an international prospective cohort study.**Anaesthesia. 2021;76(11):1454-1464.
* **COVIDSurg Collaborative; GlobalSurg Collaborative. SARS-CoV-2 infection and venous thromboembolism after surgery: an international prospective cohort study.**Anaesthesia. 2022 Jan;77(1):28-39
* **Harry Stewart Hutchinson Prize for Best Original Research Paper Year 2022**University of Glasgow: A Chandiramani, V Bader, E Finlay, S Lilley, A McLean, E Peng. Eur J Cardiothorac Surg. 2022 Feb 18;61(3):545-552.
* [**The role of the electrocardiographic phenotype in risk stratification for sudden cardiac death in childhood hypertrophic cardiomyopathy.**](https://pubmed.ncbi.nlm.nih.gov/33772274/) Norrish G, Topriceanu C, Qu C, Field E, Walsh H, Ziółkowska L, Olivotto I, Passantino S, Favilli S, Anastasakis A, Vlagkouli V, Weintraub R, King I, Biagini E, Ragni L, Prendiville T, Duignan S, McLeod K, Ilina M, Fernández A, Bökenkamp R, Baban A, Drago F, Kubuš P, Daubeney PEF, Chivers S, Sarquella-Brugada G, Cesar S, Marrone C, Medrano C, Alvarez Garcia-Roves R, Uzun O, Gran F, Castro FJ, Gimeno JR, Barriales-Villa R, Rueda F, Adwani S, Searle J, Bharucha T, Siles A, Usano A, Rasmussen TB, Jones CB, Kubo T, Mogensen J, Reinhardt Z, Cervi E, Elliott PM, Omar RZ, Kaski JP.Norrish G, et al. Among authors: mcleod k. Eur J Prev Cardiol. 2021 Mar 27:zwab046. doi: 10.1093/eurjpc/zwab046. Online ahead of print.Eur J Prev Cardiol. 2021. PMID: 33772274
* [**Acute Cardiovascular Manifestations in 286 Children With Multisystem Inflammatory Syndrome Associated With COVID-19 Infection in Europe.**](https://pubmed.ncbi.nlm.nih.gov/33166189/)   
  Valverde I, Singh Y, Sanchez-de-Toledo J, Theocharis P, Chikermane A, Di Filippo S, Kuciñska B, Mannarino S, Tamariz-Martel A, Gutierrez-Larraya F, Soda G, Vandekerckhove K, Gonzalez-Barlatay F, McMahon CJ, Marcora S, Napoleone CP, Duong P, Tuo G, Deri A, Nepali G, Ilina M, Ciliberti P, Miller O; AEPC COVID-19 Rapid Response Team\*.Valverde I, et al. Among authors: ilina m. Circulation. 2021 Jan 5;143(1):21-32. doi: 10.1161/CIRCULATIONAHA.120.050065. Epub 2020 Nov 9.Circulation. 2021. PMID: 33166189
* **Friedreich's ataxia-associated childhood hypertrophic cardiomyopathy: a national cohort study**[Gabrielle Norrish](https://pubmed.ncbi.nlm.nih.gov/?term=Norrish+G&cauthor_id=34610949), [Thomas Rance](https://pubmed.ncbi.nlm.nih.gov/?term=Rance+T&cauthor_id=34610949), [Elena Montanes](https://pubmed.ncbi.nlm.nih.gov/?term=Montanes+E&cauthor_id=34610949), [Ella Field](https://pubmed.ncbi.nlm.nih.gov/?term=Field+E&cauthor_id=34610949), [Elspeth Brown](https://pubmed.ncbi.nlm.nih.gov/?term=Brown+E&cauthor_id=34610949), [Vinay Bhole](https://pubmed.ncbi.nlm.nih.gov/?term=Bhole+V&cauthor_id=34610949), [Graham Stuart](https://pubmed.ncbi.nlm.nih.gov/?term=Stuart+G&cauthor_id=34610949), [Orhan Uzun](https://pubmed.ncbi.nlm.nih.gov/?term=Uzun+O&cauthor_id=34610949), [Karen A McLeod](https://pubmed.ncbi.nlm.nih.gov/?term=McLeod+KA&cauthor_id=34610949), [Maria Ilina](https://pubmed.ncbi.nlm.nih.gov/?term=Ilina+M&cauthor_id=34610949), [Satish Adwani](https://pubmed.ncbi.nlm.nih.gov/?term=Adwani+S&cauthor_id=34610949), [Piers Daubeney](https://pubmed.ncbi.nlm.nih.gov/?term=Daubeney+P&cauthor_id=34610949), [Grazia Delle Donne](https://pubmed.ncbi.nlm.nih.gov/?term=Delle+Donne+G&cauthor_id=34610949), [Katie Linter](https://pubmed.ncbi.nlm.nih.gov/?term=Linter+K&cauthor_id=34610949), [Caroline B Jones](https://pubmed.ncbi.nlm.nih.gov/?term=Jones+CB&cauthor_id=34610949), [Tara Bharucha](https://pubmed.ncbi.nlm.nih.gov/?term=Bharucha+T&cauthor_id=34610949), [Elena Cervi](https://pubmed.ncbi.nlm.nih.gov/?term=Cervi+E&cauthor_id=34610949), [Juan Pablo Kaski](https://pubmed.ncbi.nlm.nih.gov/?term=Kaski+JP&cauthor_id=34610949)  
  PMID: **34610949** DOI: [10.1136/archdischild-2021-322455](https://doi.org/10.1136/archdischild-2021-322455)
* **Clinical presentation and long-term outcomes of infantile hypertrophic cardiomyopathy: a European multicentre study**[Gabrielle Norrish](https://pubmed.ncbi.nlm.nih.gov/?term=Norrish+G&cauthor_id=34486247), [Gali Kolt](https://pubmed.ncbi.nlm.nih.gov/?term=Kolt+G&cauthor_id=34486247), [Elena Cervi](https://pubmed.ncbi.nlm.nih.gov/?term=Cervi+E&cauthor_id=34486247), [Ella Field](https://pubmed.ncbi.nlm.nih.gov/?term=Field+E&cauthor_id=34486247), [Kathleen Dady](https://pubmed.ncbi.nlm.nih.gov/?term=Dady+K&cauthor_id=34486247), [Lidia Ziółkowska](https://pubmed.ncbi.nlm.nih.gov/?term=Zi%C3%B3%C5%82kowska+L&cauthor_id=34486247), [Iacopo Olivotto](https://pubmed.ncbi.nlm.nih.gov/?term=Olivotto+I&cauthor_id=34486247), [Silvia Favilli](https://pubmed.ncbi.nlm.nih.gov/?term=Favilli+S&cauthor_id=34486247), [Silvia Passantino](https://pubmed.ncbi.nlm.nih.gov/?term=Passantino+S&cauthor_id=34486247), [Giuseppe Limongelli](https://pubmed.ncbi.nlm.nih.gov/?term=Limongelli+G&cauthor_id=34486247), [Martina Caiazza](https://pubmed.ncbi.nlm.nih.gov/?term=Caiazza+M&cauthor_id=34486247), [Marta Rubino](https://pubmed.ncbi.nlm.nih.gov/?term=Rubino+M&cauthor_id=34486247), [Anwar Baban](https://pubmed.ncbi.nlm.nih.gov/?term=Baban+A&cauthor_id=34486247), [Fabrizio Drago](https://pubmed.ncbi.nlm.nih.gov/?term=Drago+F&cauthor_id=34486247), [Karen Mcleod](https://pubmed.ncbi.nlm.nih.gov/?term=Mcleod+K&cauthor_id=34486247), [Maria Ilina](https://pubmed.ncbi.nlm.nih.gov/?term=Ilina+M&cauthor_id=34486247), [Ruth McGowan](https://pubmed.ncbi.nlm.nih.gov/?term=McGowan+R&cauthor_id=34486247), [Graham Stuart](https://pubmed.ncbi.nlm.nih.gov/?term=Stuart+G&cauthor_id=34486247), [Vinay Bhole](https://pubmed.ncbi.nlm.nih.gov/?term=Bhole+V&cauthor_id=34486247), [Orhan Uzun](https://pubmed.ncbi.nlm.nih.gov/?term=Uzun+O&cauthor_id=34486247), [Amos Wong](https://pubmed.ncbi.nlm.nih.gov/?term=Wong+A&cauthor_id=34486247), [Laz Lazarou](https://pubmed.ncbi.nlm.nih.gov/?term=Lazarou+L&cauthor_id=34486247), [Elspeth Brown](https://pubmed.ncbi.nlm.nih.gov/?term=Brown+E&cauthor_id=34486247), [Piers E F Daubeney](https://pubmed.ncbi.nlm.nih.gov/?term=Daubeney+PEF&cauthor_id=34486247), [Amrit Lota](https://pubmed.ncbi.nlm.nih.gov/?term=Lota+A&cauthor_id=34486247), [Grazia Delle Donne](https://pubmed.ncbi.nlm.nih.gov/?term=Delle+Donne+G&cauthor_id=34486247), [Katie Linter](https://pubmed.ncbi.nlm.nih.gov/?term=Linter+K&cauthor_id=34486247), [Sujeev Mathur](https://pubmed.ncbi.nlm.nih.gov/?term=Mathur+S&cauthor_id=34486247), [Tara Bharucha](https://pubmed.ncbi.nlm.nih.gov/?term=Bharucha+T&cauthor_id=34486247), [Satish Adwani](https://pubmed.ncbi.nlm.nih.gov/?term=Adwani+S&cauthor_id=34486247), [Jon Searle](https://pubmed.ncbi.nlm.nih.gov/?term=Searle+J&cauthor_id=34486247), [Anca Popoiu](https://pubmed.ncbi.nlm.nih.gov/?term=Popoiu+A&cauthor_id=34486247), [Caroline B Jones](https://pubmed.ncbi.nlm.nih.gov/?term=Jones+CB&cauthor_id=34486247), [Zdenka Reinhardt](https://pubmed.ncbi.nlm.nih.gov/?term=Reinhardt+Z&cauthor_id=34486247), [Juan Pablo Kaski](https://pubmed.ncbi.nlm.nih.gov/?term=Kaski+JP&cauthor_id=34486247)  
  PMID: **34486247** PMCID: [PMC8712843](http://www.ncbi.nlm.nih.gov/pmc/articles/pmc8712843/) DOI: [10.1002/ehf2.13573](https://doi.org/10.1002/ehf2.13573)
* **Relationship Between Maximal Left Ventricular Wall Thickness and Sudden Cardiac Death in Childhood Onset Hypertrophic Cardiomyopathy**[Gabrielle Norrish](https://pubmed.ncbi.nlm.nih.gov/?term=Norrish+G&cauthor_id=35491873), [Tao Ding](https://pubmed.ncbi.nlm.nih.gov/?term=Ding+T&cauthor_id=35491873), [Ella Field](https://pubmed.ncbi.nlm.nih.gov/?term=Field+E&cauthor_id=35491873), [Elena Cervi](https://pubmed.ncbi.nlm.nih.gov/?term=Cervi+E&cauthor_id=35491873), [Lidia Ziółkowska](https://pubmed.ncbi.nlm.nih.gov/?term=Zi%C3%B3%C5%82kowska+L&cauthor_id=35491873), [Iacopo Olivotto](https://pubmed.ncbi.nlm.nih.gov/?term=Olivotto+I&cauthor_id=35491873), [Diala Khraiche](https://pubmed.ncbi.nlm.nih.gov/?term=Khraiche+D&cauthor_id=35491873), [Giuseppe Limongelli](https://pubmed.ncbi.nlm.nih.gov/?term=Limongelli+G&cauthor_id=35491873), [Aris Anastasakis](https://pubmed.ncbi.nlm.nih.gov/?term=Anastasakis+A&cauthor_id=35491873), [Robert Weintraub](https://pubmed.ncbi.nlm.nih.gov/?term=Weintraub+R&cauthor_id=35491873), [Elena Biagini](https://pubmed.ncbi.nlm.nih.gov/?term=Biagini+E&cauthor_id=35491873), [Luca Ragni](https://pubmed.ncbi.nlm.nih.gov/?term=Ragni+L&cauthor_id=35491873), [Terrence Prendiville](https://pubmed.ncbi.nlm.nih.gov/?term=Prendiville+T&cauthor_id=35491873), [Sophie Duignan](https://pubmed.ncbi.nlm.nih.gov/?term=Duignan+S&cauthor_id=35491873), [Karen McLeod](https://pubmed.ncbi.nlm.nih.gov/?term=McLeod+K&cauthor_id=35491873), [Maria Ilina](https://pubmed.ncbi.nlm.nih.gov/?term=Ilina+M&cauthor_id=35491873), [Adrian Fernandez](https://pubmed.ncbi.nlm.nih.gov/?term=Fernandez+A&cauthor_id=35491873), [Chiara Marrone](https://pubmed.ncbi.nlm.nih.gov/?term=Marrone+C&cauthor_id=35491873), [Regina Bökenkamp](https://pubmed.ncbi.nlm.nih.gov/?term=B%C3%B6kenkamp+R&cauthor_id=35491873), [Anwar Baban](https://pubmed.ncbi.nlm.nih.gov/?term=Baban+A&cauthor_id=35491873), [Peter Kubus](https://pubmed.ncbi.nlm.nih.gov/?term=Kubus+P&cauthor_id=35491873), [Piers E F Daubeney](https://pubmed.ncbi.nlm.nih.gov/?term=Daubeney+PEF&cauthor_id=35491873), [Georgia Sarquella-Brugada](https://pubmed.ncbi.nlm.nih.gov/?term=Sarquella-Brugada+G&cauthor_id=35491873), [Sergi Cesar](https://pubmed.ncbi.nlm.nih.gov/?term=Cesar+S&cauthor_id=35491873), [Sabine Klaassen](https://pubmed.ncbi.nlm.nih.gov/?term=Klaassen+S&cauthor_id=35491873), [Tiina H Ojala](https://pubmed.ncbi.nlm.nih.gov/?term=Ojala+TH&cauthor_id=35491873), [Vinay Bhole](https://pubmed.ncbi.nlm.nih.gov/?term=Bhole+V&cauthor_id=35491873), [Constancio Medrano](https://pubmed.ncbi.nlm.nih.gov/?term=Medrano+C&cauthor_id=35491873), [Orhan Uzun](https://pubmed.ncbi.nlm.nih.gov/?term=Uzun+O&cauthor_id=35491873), [Elspeth Brown](https://pubmed.ncbi.nlm.nih.gov/?term=Brown+E&cauthor_id=35491873), [Ferran Gran](https://pubmed.ncbi.nlm.nih.gov/?term=Gran+F&cauthor_id=35491873), [Gianfranco Sinagra](https://pubmed.ncbi.nlm.nih.gov/?term=Sinagra+G&cauthor_id=35491873), [Francisco J Castro](https://pubmed.ncbi.nlm.nih.gov/?term=Castro+FJ&cauthor_id=35491873), [Graham Stuart](https://pubmed.ncbi.nlm.nih.gov/?term=Stuart+G&cauthor_id=35491873), [Gabriele Vignati](https://pubmed.ncbi.nlm.nih.gov/?term=Vignati+G&cauthor_id=35491873), [Hirokuni Yamazawa](https://pubmed.ncbi.nlm.nih.gov/?term=Yamazawa+H&cauthor_id=35491873), [Roberto Barriales-Villa](https://pubmed.ncbi.nlm.nih.gov/?term=Barriales-Villa+R&cauthor_id=35491873), [Luis Garcia-Guereta](https://pubmed.ncbi.nlm.nih.gov/?term=Garcia-Guereta+L&cauthor_id=35491873), [Satish Adwani](https://pubmed.ncbi.nlm.nih.gov/?term=Adwani+S&cauthor_id=35491873), [Katie Linter](https://pubmed.ncbi.nlm.nih.gov/?term=Linter+K&cauthor_id=35491873), [Tara Bharucha](https://pubmed.ncbi.nlm.nih.gov/?term=Bharucha+T&cauthor_id=35491873), [Pablo Garcia-Pavia](https://pubmed.ncbi.nlm.nih.gov/?term=Garcia-Pavia+P&cauthor_id=35491873), [Ana Siles](https://pubmed.ncbi.nlm.nih.gov/?term=Siles+A&cauthor_id=35491873), [Torsten B Rasmussen](https://pubmed.ncbi.nlm.nih.gov/?term=Rasmussen+TB&cauthor_id=35491873), [Margherita Calcagnino](https://pubmed.ncbi.nlm.nih.gov/?term=Calcagnino+M&cauthor_id=35491873), [Caroline B Jones](https://pubmed.ncbi.nlm.nih.gov/?term=Jones+CB&cauthor_id=35491873), [Hans De Wilde](https://pubmed.ncbi.nlm.nih.gov/?term=De+Wilde+H&cauthor_id=35491873), [Toru Kubo](https://pubmed.ncbi.nlm.nih.gov/?term=Kubo+T&cauthor_id=35491873), [Tiziana Felice](https://pubmed.ncbi.nlm.nih.gov/?term=Felice+T&cauthor_id=35491873), [Anca Popoiu](https://pubmed.ncbi.nlm.nih.gov/?term=Popoiu+A&cauthor_id=35491873), [Jens Mogensen](https://pubmed.ncbi.nlm.nih.gov/?term=Mogensen+J&cauthor_id=35491873), [Sujeev Mathur](https://pubmed.ncbi.nlm.nih.gov/?term=Mathur+S&cauthor_id=35491873), [Fernando Centeno](https://pubmed.ncbi.nlm.nih.gov/?term=Centeno+F&cauthor_id=35491873), [Zdenka Reinhardt](https://pubmed.ncbi.nlm.nih.gov/?term=Reinhardt+Z&cauthor_id=35491873), [Sylvie Schouvey](https://pubmed.ncbi.nlm.nih.gov/?term=Schouvey+S&cauthor_id=35491873), [Costas O'Mahony](https://pubmed.ncbi.nlm.nih.gov/?term=O%27Mahony+C&cauthor_id=35491873), [Rumana Z Omar](https://pubmed.ncbi.nlm.nih.gov/?term=Omar+RZ&cauthor_id=35491873), [Perry M Elliott](https://pubmed.ncbi.nlm.nih.gov/?term=Elliott+PM&cauthor_id=35491873), [Juan Pablo Kaski](https://pubmed.ncbi.nlm.nih.gov/?term=Kaski+JP&cauthor_id=35491873), [ERN GUARD-HEART\*](https://pubmed.ncbi.nlm.nih.gov/?term=ERN+GUARD-HEART%2A%5BCorporate+Author%5D)  
  PMID: **35491873** DOI: [10.1161/CIRCEP.121.010075](https://doi.org/10.1161/circep.121.010075)
* **Neonatologist-performed echocardiography: a pilot programme for delivering training and maintaining accreditation**  
  Heuchan AM, Montasser M, Patel N, Hunter LE  
  Infant 2020 Nov;16(6):244-248
* **Effects and side effects of maternal administration of indomethacin for fetal tricuspid valve dysplasia**  
  Hunter L, Vigneswaran TV, Pasupathy D, Callaghan N, Tenenbaum J, Zidere V, Simpson JM  
  Ultrasound Obstet Gynecol. 2020 Sep 17. doi: 10.1002/uog.23122
* **Vitamin D Deficiency Cardiomyopathy in Scotland: A Retrospective Review of the Last Decade**McDevitt H, Ferguson R, Hunter L.  
  Arch Dis Child 2020 Sep;105(9):853-856
* **Validating a risk assessment tool in United Kingdom and Irish paediatric cardiac catheterisation practice**[Barry O'Callaghan](https://pubmed.ncbi.nlm.nih.gov/?term=O%27Callaghan+B&cauthor_id=34645531), [Emma Shepherd](https://pubmed.ncbi.nlm.nih.gov/?term=Shepherd+E&cauthor_id=34645531), [Demetris Taliotis](https://pubmed.ncbi.nlm.nih.gov/?term=Taliotis+D&cauthor_id=34645531), [James Bentham](https://pubmed.ncbi.nlm.nih.gov/?term=Bentham+J&cauthor_id=34645531), [Damien Kenny](https://pubmed.ncbi.nlm.nih.gov/?term=Kenny+D&cauthor_id=34645531), [Benjamin Smith](https://pubmed.ncbi.nlm.nih.gov/?term=Smith+B&cauthor_id=34645531), [Salvador Rodriguez Franco](https://pubmed.ncbi.nlm.nih.gov/?term=Franco+SR&cauthor_id=34645531), [Gareth J Morgan](https://pubmed.ncbi.nlm.nih.gov/?term=Morgan+GJ&cauthor_id=34645531)PMID: 34645531 DOI: [10.1017/S1047951121004170](https://doi.org/10.1017/s1047951121004170)
* [**Novel PRKAG2 Variant Manifesting with a Cardiac Arrest in a Child.**](https://www.pubfacts.com/detail/31720784/Novel-PRKAG2-Variant-Manifesting-with-a-Cardiac-Arrest-in-a-Child)   
  Spentzou G, Hares D, McLeod KA.   
  Pediatr Cardiol 2020 Apr 12;41(4):843-845.
* **PPA2-associated sudden cardiac death: extending the clinical and allelic spectrum in 20 new families.**Genetics in Medicine 2021 23:2415-2425 (multinational multicentre study, amongst authors, McLeod KA)

**Abstract Presentations**

* Factors associated with Unplanned Reinterventions and their relation to Early Mortality following pediatric cardiac surgery – results from a prospective multicenter study. S.Stocia, A.McLean et al. Presented at the American Association of Thoracic Surgery, May 2020.
* Disproportionate Subaortic-Aortic Annular Area as a Substrate for Left Ventricular Outflow Tract Obstruction following Atrioventricular Septal Defect Repair: a Mechanism that is Dictated by Time and Morphology. European Association for Cardiothoracic Surgery Annual Meeting Oct 2020.  A Chandiramani, V Bader, E Finlay, S Lilley, A McLean, Mark H Danton, Ed Peng. Glasgow Paediatric Research Day Nov 2020 - Runner Up Prize Winner
* Disproportionate sub-aortic annular area as a substrate for left ventricular outflow tract obstruction following atrioventricular septal defect repair: a mechanism that is dictated by time and morphology. A Chandiramani, V Bader, E Finlay, S Lilley, A McLean, Mark H Danton, Ed Peng.
* Scimitar Syndrome. Panagiotopoulou O, Knight B, Peng E, Walayat M, McLeod K. Presentation AEPC 2022.

**Scientific Presentations**

* G Gradinariu, W Gabir, V Bader, Ed Peng. Minimal Access Surgery in Paediatric and Adult Congenital Heart Operation. Society of Cardiothoracic of GB and Ireland Annual Meeting 2021, 9-11 May 2021
* V Bader-A Chandiramani, P Noonan, B Knight, M H Danton, E Peng. The utility of 3D model in facilitating repair for complex transposition of great arteries. Society for Cardiothoracic Surgery in Great Britain and Ireland Annual Meeting 2021,  9-11 May 2021
* A Chandiramani, V Bader, E Finlay, S Lilley, A McLean, Mark H Danton, Ed Peng. Disproportionate sub-aortic annular area as a substrate for left ventricular outflow tract obstruction following atrioventricular septal defect repair: a mechanism that is dictated by time and morphology.   Society for Cardiothoracic Surgery in Great Britain and Ireland Annual Meeting 9-11 May 2021
* McDonald J, Finlay E., Peng E, Danton MH. Initial experience of the Ozaki Procedure in a Paediatric and Young Adult Population in Glasgow.  Society for Cardiothoracic Surgery in Great Britain and Ireland Annual Meeting 2021 9-11 May 2021
* Bader V, Peng E. Repair of obstructed supracardiac TAPVD and rare compression of left main bronchus between pulmonary venous confluence and aorta   Society for Cardiothoracic Surgery in Great Britain and Ireland Annual Meeting Belfast May 2022
* Kesieme E, Danton MH, Bader V, McLean A, Knight B, Smith B, Noonan P, Peng E. Outcome of patients following presentation with Tetralogy of Fallot, Pulmonary Atresia with ductal dependent, confluent pulmonary arteries. Society for Cardiothoracic Surgery in Great Britain and Ireland Annual Meeting Belfast May 2022
* Chandiramani A, Bader V, Finlay V, Lilley S, Young D, Peng E.  The Impact of Surgical Repair on Left Ventricular Outflow Tract in Atrioventricular Septal Defect with Common Atrioventricular Valve Orifice. American Association of Thoracic Surgery Annual Meeting, Boston, May 2022
* Bader V, Peng E. Extreme LVOT: Case scenarios / surgical options. Society for Cardiothoracic Surgery in Great Britain and Ireland Annual Meeting Belfast May 2022.

**Book Reviews**

* Simpson JM, Hunter LE. Chapter 32 Fetal Echocardiography. Echocardiography in Pediatric and Adult Congenital Heart Disease (3rd Edition) Eidem et al 2020. (Textbook for the Mayo Clinic)

**University of Glasgow BSc Dissertation Supervisor 2020-2022**

* Stewart C. Impact of Mitral Valve Replacement on Left Ventricular Function
* Hadjisoteriou A. Cardiopulmonary exercise testing in children with repaired Tetralogy of Fallot

**National Policy/Guidelines**

* Cardiac care of young people with dystrophinopathy and females carrying DMD-gene variations (Represented: Karen McLeod and Maria Ilina)
* Myocarditis and pericarditis after COVID-19 vaccination: clinical management guidance for healthcare professionals (Represented: Maria Ilina)
* Management of SVT in peripheral units in Scotland (represented Karen McLeod)

**Invited Talks**

* How I Teach It - Modified Blalock-Taussig-Thomas Shunt. 30th Annual meeting of the Association of Thoracic and Cardiovascular Surgeons of Asia, Bangkok, Thailand, November 6-7, 2021 (E Peng)
* How I Teach It - Fontan operation. 30th Annual meeting of the Association of Thoracic and Cardiovascular Surgeons of Asia, Bangkok, Thailand, November 6-7, 2021  (E Peng)
* The Evolutions of Surgery for Congenital Heart Disease, St Andrews Surgical Society, 25 Nov 2021 (E Peng)
* The Evolution of Cardiac Surgery, University of Edinburgh Cardiology and  Cardiothoracic Surgery Conference, 12 Feb 2022(E Peng)
* May 2019 – invited speaker at Heart Rhythm, Boston, USA – debate on transvenous v subcutaneous ICDs (Mcleod, KA)
* September 2019 – lecturer on paediatric arrhythmia course for AEPC
* 2020 – invited speaker to AEPC annual meeting Gottenburg (McLeod KA) – presented on line conference May 2021 ICD indications and programming in paediatric heart muscle disease
* Heart Rhythm Congress, UK Oct 2021 (McLeod KA) (on-line conference due to COVID)
* RAS: Why pacemakers and drugs are rarely advised?
* Heart Rhythm Congress, UK Oct 2021 (McLeod KA) (on-line conference due to COVID)
* Table Tilt test, has it gone out of fashion or still a valid tool?
* Heart Rhythm Congress, UK Oct 2020 (McLeod KA) (on-line conference due to COVID)
* Pacemaker syndrome in children: diagnosis and treatment (Dr Karen McLeod)
* The subcutaneous ICD in children: current status and future prospects, BCCA, 2 Nov 2021 (K McLeod)
* Multicentre research project on outcomes from ballooning of pulmonary arterial bands, BCCA, 2 Nov 2021 (P Fernandes)
* Case presentation about a now 20 year old patient who had one of the first ever hybrid procedures in the UK, BCCA, 2 Nov 2021 (P Fernandes)
* Medial microcalcification in thoracic aortopathy: a window into disease severity, BCCA, 2 Nov 2021 (A Fletcher) (winning first prize for best trainee research presentation)

# Looking ahead

The delivery of equitable Paediatric Cardiac Services to the population of Scotland is geographically challenging due to the population dispersal. The population of 5.4 million will only support one centre for provision of Paediatric Cardiac surgical and catheter intervention. Following a reconfiguration exercise in 2000 this centre is based in Glasgow. Although cardiac surgery and catheter intervention are nationally commissioned services through NSD the provision of cardiology services remains the domain of regional health boards which are supported through a series of Service Level Agreements (SLA) with either NHS GGC or NHS Lothian. We are currently reviewing several of the SLA’s as they are out of line with the current service provision.

**SPCS Paediatric Congenital Cardiac Conference June 2022**

This event will be held in the Teaching and Learning Centre, The Queen Elizabeth University Hospital Campus with presentations to include topics on:

* **Transition of cardiac patients from paediatric to adult care**
* **Congenital cardiac audit**
* **Hypoplastic left heart syndrome**

**Cardiologist posts**

To manage increasingly complex patients managed by the paediatric Cardiac Service there is a recognised need for expansion of the Cardiology workforce. In particular we continue to look to expand our service so that all sub-specialist areas are covered. SPCS is hopeful to be able to appoint a second fetal cardiologists now the cross-sectional imaging post has been filled.

**Cardiac surgical posts**

We are currently in the process of assessing a 4 surgeon model for the next financial year to assess whether we can increase surgical through put, development and efficiencies on both the RHC and GJNH sites. This is being funded by GGC health board.

**Cardiac ANP & Nurse specialists**

It is essential we develop the Cardiac ANP and Nurse Specialist team in line with UK wide standards. Work is required to refine the funding stream for the ANP team and ensure adequate staffing of the Cardiac ANP team in line with the funded capacity.

**Cardiac psychology**

Work is underway to review and define the real patient need from the psychology team (currently 0.4WTE) and how we can ensure our patients and families are supported in line with agreed standards across the United Kingdom.

**Cardiac dietetics**

Work has been completed showing the large gap between the funded dietetic input to the cardiac service and what is being provided. It is essential this service is protected and developed for all patients support by the national SPCS team.

**Cardiac physiotherapy**

The physiotherapy team are currently rolling out enhanced early mobilisation guidance and support for cardiac patients and their families in line with the PICU #MoVE programme. The next step is to focus on “pre-hab” for the adolescent patient group to ensure they come to their cardiac surgery or catheter intervention in the best possible physical and psychological condition to reduce their time in hospital and enhance their post-operative recovery.

**National Standards for Paediatric Congenital Heart Disease**

In January 2018 the National Standards for Paediatric Congenital Heart Disease were released by NSD. There are many of these standards that have already been achieved by the SPCS but there are several areas where development continues. One particular area for focus is the transition of patients form the paediatric to adult services. Integral to the establishment of a well-structured and well-maintained network is the national delivery of the paediatric cardiology service. The current model is delivered from a local health board level through service level agreements Lothian and GGC health boards. There is a very real risk this may lead to inconsistencies in how care is delivered to congenital heart disease patients throughout Scotland.

During the recent COVID pandemic there has been regular contact between SPCS and all of the UK paediatric heart centres. In each centre there is a full-time network manager who has allocated administration support. There is also funding for a senior nurse to oversee the network as well as allocated programmed activities for a cardiologist to act as the network clinical director. This is the model that SPCS should be following to allow active development of the network. Added benefits can be seen in the development of a national network of support by paediatric cardiac nurse specialists. We have the most advanced cardiac physiology department in the UK and this can be utilised to develop a national physiology network to improve skills in regional health boards. Most importantly is the development of a consistent program of transition across Scotland.

Finally, a scoping project to develop a nationally accessible congenital cardiac database has been undertaken involving both SPCS and SACCS. Over the next year there will be further work on this project. A nationally accessible database is vital to ensure that best care is delivered for congenital heart disease patients as close to home as possible.

# Appendices

## Appendix 1

## Appendix 2

## Appendix 3



**Appendix 4 - Paediatric Surgery and Interventional Cardiology Twelve Month Financial Report**

