NHS
Golden Jubilee

Scottish Adult Congenital Cardiac Service (SACCS)

Annual Report

2023/24

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Executive summary

The Scottish Adult Congenital Cardiac Service (SACCS) was designated in 2007 to delivery high quality specialist care to adults with congenital heart disease in Scotland. In conjunction with the paediatric cardiac service at the Royal Hospital for Children, the adult service aims to provide seamless life-long care for patients with moderate and complex adult congenital heart disease. The 2 key components of the service are:

- specialist surveillance and prevention; and
- active intervention (including medical, catheter based and surgical care).

Based at the Golden Jubilee University National Hospital in Clydebank, the SACCS is managed by NHS Golden Jubilee. It is co-located with the other cardiovascular national services (Scottish Pulmonary Vascular Unit and the Scottish National Advanced Heart Failure Service) and with the other adult cardiac services including electrophysiology (EP) and percutaneous coronary intervention.

The demographics of congenital heart disease are changing in a predictable way. Increased survival into adulthood and a move of morbidity and mortality from early life to adult life leads to an expected growth in patient numbers and complexity. This necessitates an efficient and robust centre of excellence.

Last year (2023/24) was an important year for the SACCS. This year there has been stability in the clinical team, new clinical leadership and the completion of the National Services Division (NSD) Major Review. Activity across the Service Level Agreement (SLA) has been strong – in particular the delivery of specialist outpatient visits and congenital cardiac MRI. There remains, however, several challenges in the service in terms of delivering high quality care to Scottish adult congenital heart disease (ACHD) patients and there is a pressing need to review the SLA as patient's needs change. Last year also brought a renewed emphasis on patient-centred care with successful Transition and Patient Education Events and we plan to further develop this aspect of the service.

The NSD Major Review released this year acknowledged the Service designation should remain 'National'. The report also described the SACCS as a 'high-quality service with a cohesive, experienced, and multidisciplinary team'. The report highlighted several key areas around data and benchmarking; financial sustainability and the possibility of a networked approach. Although currently out with the remit of the SACCS and Golden Jubilee Teams, we are enthusiastic about embracing a well-funded and well-led Scottish Network for ACHD. An ongoing dialogue with NSD and the territorial health boards is welcomed.

In 2022 we delivered a Business case to NHS National Services Scotland. The Major Review concluded in its recommendations that a 'bottom up 'costing exercise be undertaken to inform a new Business case to be submitted this year. The ability to maintain an excellent service will depend on the success of the new Business Case.

[redacted]

Dr Lorna Swan

Clinical Lead Scottish Adult Congenital Cardiac Service
Golden Jubilee University National Hospital

PA: [redacted]

1. Service delivery

Congenital heart disease remains the commonest birth anomaly and encompasses a range of conditions from minor to highly complex. Those with moderate and complex lesions will require specialist life-long care. The majority of these patients are adults; the minority neonates and children.

For many patients the long-term implications of having congenital heart disease include reoperation, heart failure and rhythm disturbances and patients require regular specialist assessment and treatment. Specialist care is known to be associated with reduced mortality and improved outcomes (1).

The exact prevalence of adult congenital heart disease (ACHD) in Scotland is unclear. However accepted estimates suggest there are at least 3000 adults with moderate to complex disease who would benefit from regular contact with the SACCS and an additional 7000 requiring single or occasional review. The majority of referrals to the SACCS come via the Transition and Transfer pathway from paediatric cardiology care. There are, however, many historic patients with ACHD who have fallen out of regular review. These patients often present when symptomatic or when they present with new non-cardiac issues such as pregnancy. Patients who are also new to Scotland, either from the rest of the UK or from overseas, also present for assessment, triage and ongoing care.

Although there is no robust database for ACHD patients in Scotland the SACCS is aware that there is in excess of 5000 patients. World-wide statistics would suggest a prevalence of ACHD of 300 per 100,000 population (2).

There are 2 main components to ACHD:

1. Pro-active surveillance/prevention
2. Active treatment (this includes medication, surgery and intervention)

There is no formal network for ACHD in Scotland. The SACCS team do, however, work in partnership with local ACHD clinics. These clinics are present in most of the Health Boards in Scotland and are run by cardiologists with an interest in ACHD. The majority of these local cardiologists do not have formal training in ACHD but do have experience caring for this population. Many patients are under the regular care of the local team with only intermittent specialist review by the SACCS team. Those with complex ACHD have their care predominantly at the Golden Jubilee.

The core activity of the SACCS is the multidisciplinary assessment of patients. Specialist investigations such as cardiac MRI, CT, specialist echo, cardiopulmonary exercise testing and cardiac catheterisation are all utilised to assess patients. This may be as a prequel to cardiac surgery, specialist heart failure care, or other interventions. Serial assessment is often required to detect early change and trigger further treatment.

Access to local ACHD varies between NHS Boards, and for that reason, the threshold for referral to the SACCS team also varies. This works in 2 directions: if local care is less robust a higher proportion of patients may be required to attend NHS Golden Jubilee for additional testing. Another issue is that problems many not be detected in patients that should be triggering referral if local care is less robust.

Diagram of SACCS service

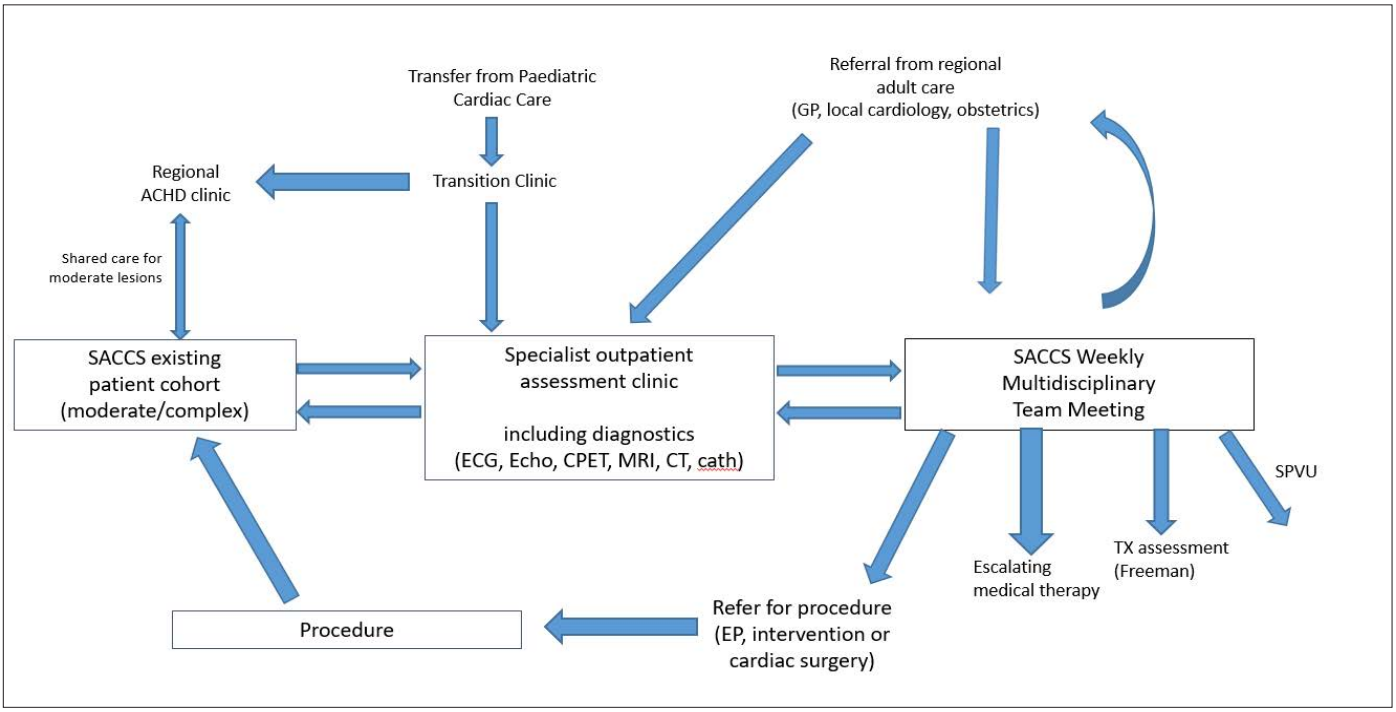


Figure 1: SACCS Care Pathways

Core Team

Consultant Medical Staff

Name	Interests	WTE
Dr Lorna Swan	Clinical Lead Cardiac obstetrics Transition	[redacted]
Dr Niki Walker	Intervention Cardiac obstetrics	
Dr Amanda Hunter	Cardiac Imaging – Echo	
Dr Hamish Walker	Cardiac Imaging – MRI	
Dr Gruschen Veldtman	Diagnostic cardiac catheterisation Research	
Dr Christopher Rush	Cardiac Imaging – MRI SPVU	
Professor Mark Danton	Cardiac Surgeon / Surgical Lead Research	RHC
Mr Andrew McLean	Cardiac Surgeon	RHC
Mr Edward Peng	Cardiac Surgeon	RHC

Cardiac Radiologists

Dr John Dreisbach provides Cardiac CT support for the SACCS. This includes presenting imaging at the weekly Multidisciplinary Team Meeting (MDT).

ACHD Electrophysiology

Dr Gareth Padfield and Professor Derek Connelly and their colleagues provide an electrophysiology (EP) and device service for the SACCS patients. They also participate in the monthly SACCS EP MDT meeting.

Anaesthetic Staff

Dr Bozzetti and Dr Moise are regularly involved in the perioperative care of SACCS patients and attend the weekly MDT meeting. In addition, Dr Church and other colleagues regularly anaesthetise for the SACCS patients.

Psychological Medicine team

Name	Role
Dr Deirdre Hollie	Psychologist
Dr John Sharp	Psychologist

SACCS nurse specialists

Name	Interests	WTE
[redacted]	Transition/Cardiac Obstetrics	[redacted]
	Cardiac Obstetrics/Pulmonary hypertension	
	Intervention/Surgical Pathway	
	Pulmonary hypertension/Transition	
	Surgical Pathway/Intervention	
	Total =	

Management team

Name	Role
Kate Robb	Head of Nursing
Shona MacLeod	Clinical Nurse Manager
Ms Lynne Ayton	Director of Operations, Heart and Lung Division
Professor Hany Eteiba	Associate Medical Director
Dr Mitchell Lindsay	Clinical Director Cardiology and NSD services
Ms Alex McGuire	Deputy Director HLD
Mr Martin Dawes	Clinical Service Manager, Cardiology/SACCS
Ms Amanda Forbes	Clinical Service Manager, Cardiac Surgery

Administration team

Name
[redacted]
[redacted]
[redacted] (Booking Coordinator)
[redacted] (Data Manager)
Band 3 FTE (vacant at present)

Other staff integral to the service

Our SACCS patients require expert care for all aspects of their care pathway. This spans from specialist cardiac physiologists who perform echocardiograms/specialist pacing/EP investigations to specialist inpatient ward nursing staff.

NHS Golden Jubilee has 19 ICU level 3 beds and 16 surgical HDU level 2 beds. These are managed by a dedicated team of cardiac anaesthetists, intensivists and specialist nursing staff. Unlike the majority of ICU units, our facility has experience and expertise in caring for ACHD patients. This includes for non-cardiac surgery in those with more complex disease.

Their expertise also extends to advanced heart failure, mechanical support, advanced cardio-obstetric care and expertise in dealing with patients with learning difficulties. There is also a highly experienced cardiac theatre team and catheter lab team. The inpatient wards 3East, NSD and NSD2 all have expertise in caring for ACHD patients. In 2024, NSD2 opened to provide additional inpatient capacity for the ACHD, transplant and Pulmonary arterial hypertension (PAH) patients.

SACCS outreach network

NHS Scotland has, through the National Services Division (NSD), commissioned NHS Golden Jubilee to manage the SACCS. In addition to the care delivered at the Golden Jubilee there are a series of local ACHD clinics. Although not part of a formal network, these clinics work closely with the SACCS team. The SACCS team visit the majority of these local clinics to undertake joint clinics.

Region	Hospital	Link clinician
West	West Glasgow ACH, Glasgow	Dr Andrew McCulloch
West	Forth Valley Royal Hospital, Larbert	Dr Stephen Glen / Dr Fiona Shearer
West	Crosshouse Hospital, Kilmarnock	Dr Gavin Nicol
West	Dumfries and Galloway Royal Hospital	No local ACHD clinic
West	Wishaw General Hospital	Dr Caroline White / Dr Graeme Tait
SEAT	Royal Infirmary of Edinburgh	Dr Patrick Gibson
SEAT	Borders General Hospital	Dr Pinky Yadav
SEAT	Perth Royal Infirmary	Dr Peter Currie
SEAT	Ninewells Hospital, Dundee	Dr Peter Currie
SEAT	Queen Margaret Hospital, Dunfermline	Dr Lynn Millar / Dr Kirsten Kruszewski
North	Aberdeen Royal Infirmary	Dr Adelle Dawson / Dr Vera Lennie
North	Raigmore Hospital, Inverness	Dr Peter Clarkson

2. Activity Levels

A. Outpatient specialist care

Clinical visits

Comprehensive assessment, clinical surveillance and outpatient care are the foundation of the SACCS care pathways. Expert review incorporating high quality complex imaging and physiological testing are required before any escalation of medical therapy or intervention.

The outpatient setting is where the majority of patient-centred care is delivered. This includes patient and family education, psychological support, advance care planning and caring for those with learning difficulties. Although data on the escalation of medical therapies for arrhythmia, heart failure and pulmonary hypertension are difficult to collect these are vital components of ACHD care.

New patients

For many new referrals, the outpatient assessment process will be their first introduction to the SACCS. The Golden Jubilee Conference Hotel facilitates visits for those travelling from a distance.

A typical first visit will include a clinical consultation with the SACCS consultant, a lifestyle and education session with a Clinical Nurse Specialist, ECG, echo and blood tests. Other investigations will be added as required such as exercise testing, MRI or 6-minute walk test (6MWT).

On occasions those with very complex needs will be admitted to the National Services Division Ward for this first assessment.

Many of these patients will then be discussed at the MDT meeting or be allocated to interval review.

Core SACCS cohort

The majority of outpatient visits will be for those under ongoing surveillance. Serial assessment is required to prevent future complications and assess optimal timing of treatment. This patient group also requires a high level of counselling regarding living with a life-long disorder.

Patients with more minor ACHD will be discharged back to local care. Those with moderate lesions will have shared care with the regional service. Those with complex disorders will have the majority of their care at the Golden Jubilee. The interval between reviews will vary greatly from once every 6 months to once every 5 years.

Specialist clinics

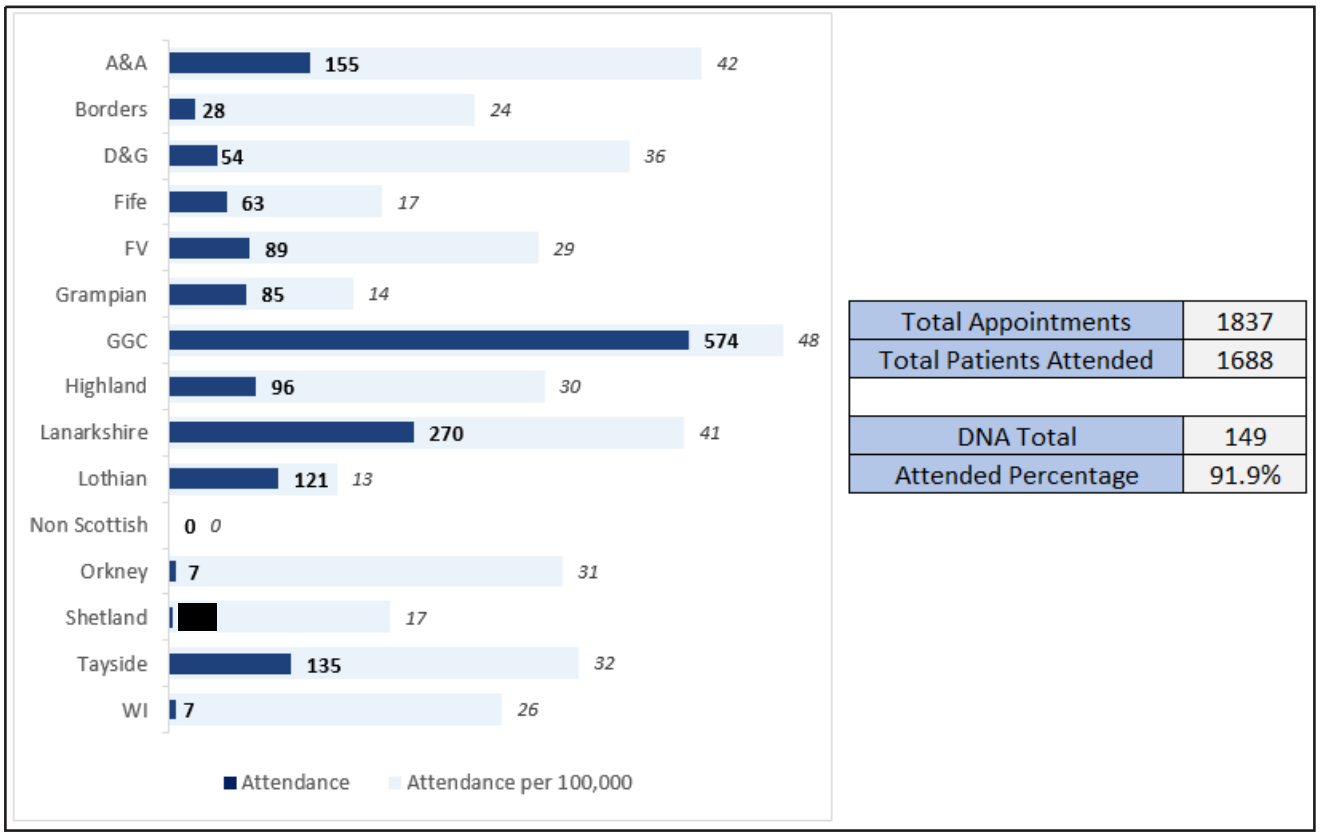
A series of specialist clinics are also offered. These are tailored to specific clinical cohort and include:

- Transition Clinics for young patient transferring from paediatric care;
- Pulmonary Hypertension clinic for SACCS patients. This service also follows those on pulmonary vasodilator therapies;
- Pre-pregnancy counselling clinic;
- Cardio-obstetric clinic for pregnant women with heart disease;
- Intervention clinics - pre and post catheter lab intervention; and
- Surgical clinics – pre and post cardiac surgery.

Several of these clinics use the Near Me platform for remote visits. Again, this improves equity of access for those living outside the West of Scotland.

Outreach clinics

Post pandemic the outreach clinics have been re-established. In many regions there are high quality joint clinics with the local providers. Many of these successful clinics are keen to expand but are, at present, limited by the availability of consultant time – for both the SACCS cardiologist and the local cardiologist. In other regions outreach is less successful and this mirrors challenges with the local cardiology provision, e.g. Dumfries and Galloway.



Total Appointments	1837
Total Patients Attended	1688
DNA Total	149
Attended Percentage	91.9%

Figure 2: SACCS Clinic Attendance by Health Board of Residence against Attendance per 100,000 of 2021 General Populations. This graph does not allow for the variations in prevalence of ACHD in Scotland. Outreach appointments are not included in these data.

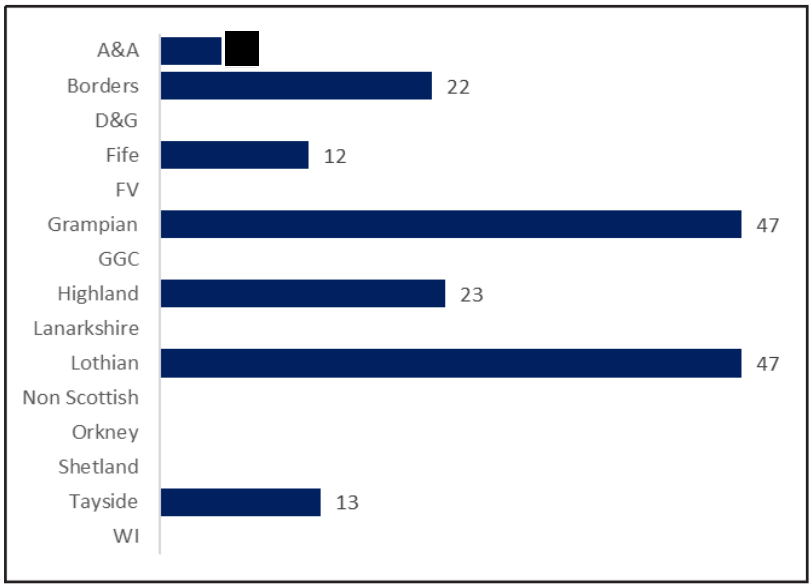


Figure 3: Outreach Clinic Attendance by Health Board of Clinic

Drug Therapy	Total number of patients
ERA (Bosentan or Ambrisentan) monotherapy	[redacted]
PDE-5 Inhibitors (Sildenafil or Tadalafil) monotherapy	24
Combination therapy: ERA and PDE Inhibitors	21
Total	[redacted]

Figure 4: SACCS Patients on Pulmonary Hypertension Therapy by Drug Group at 2023-2024 Year-End

B. Multidisciplinary Team clinical review

The conclusion of many of the complex assessments is referral for MDT review. The weekly 3-hour meeting is hosted as a hybrid meeting of the full SACCS team including anaesthetic staff and psychology input. The hybrid format maximises attendance and offers local Cardiologists and trainees to participate in discussions.

Regional cardiologists can also directly refer patients to the SACCS MDT meeting for expert review. The MDT will recommend the next steps for the patient, including further investigation, face-to-face review with the SACCS team, catheter intervention, cardiac surgery or advanced medical therapies. These discussions are often long, complex and nuanced, particularly when discussing patients at high risk of adverse outcomes. These meetings integrate high quality imaging and formal presentations of all aspects of the patient's history and are an excellent opportunity for learning for visiting registrars or regional consultants.

In 2023/24 the SACCS MDT meeting discussed 384 cases (excluding Morbidity and Mortality cases). Of the 384 cases, 270 were routine outpatients; 80 soon referrals and 34 were urgent or inpatients. This is slightly down from 2022/23 reflecting the increasing proportion of the meeting now allocated to Surgical Scheduling. The patient's Health Board and MDT outcomes are shown below.

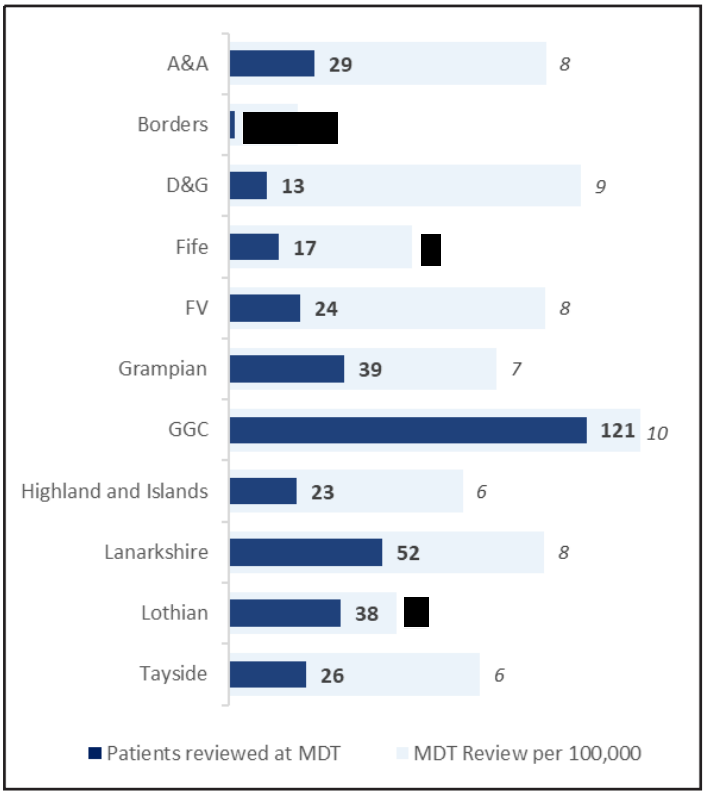


Figure 5: MDT Review: Health Board of residence against review per 100,000 of 2021 general populations

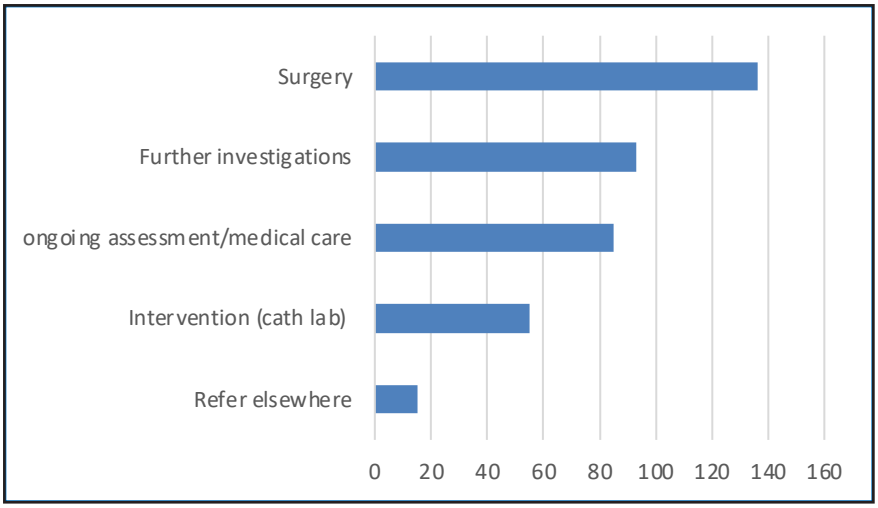


Figure 6: MDT Review: Outcomes

Note: Further investigation is usually MRI or cardiac catheter. Refer elsewhere includes [redacted] patients to SPVU and [redacted] to NHS England providers.

C. Echo

Echocardiography (transthoracic, transoesophageal and stress echo) is the primary imaging modality in ACHD and requires specific expertise and imaging as those with severe lesions are complex cases. Every clinical appointment and decision is underpinned by echo and these are often high-stakes investigations – i.e. the result of the test may have a very significant contribution towards making complex decisions and patient outcome.

Both Dr Hunter and Dr Veldtman have expertise in echo and have a total of 3 PA /week towards supporting the echo department. In addition, there are 4 cardiac physiologists with experience in ACHD. However, a sizable proportion of echos need review by consultant staff.

The numbers of SACCS echos continues to grow as the service develops. Echo capacity is 1 of the major imitations to increasing outpatient clinic capacity and impaction on the waiting list.

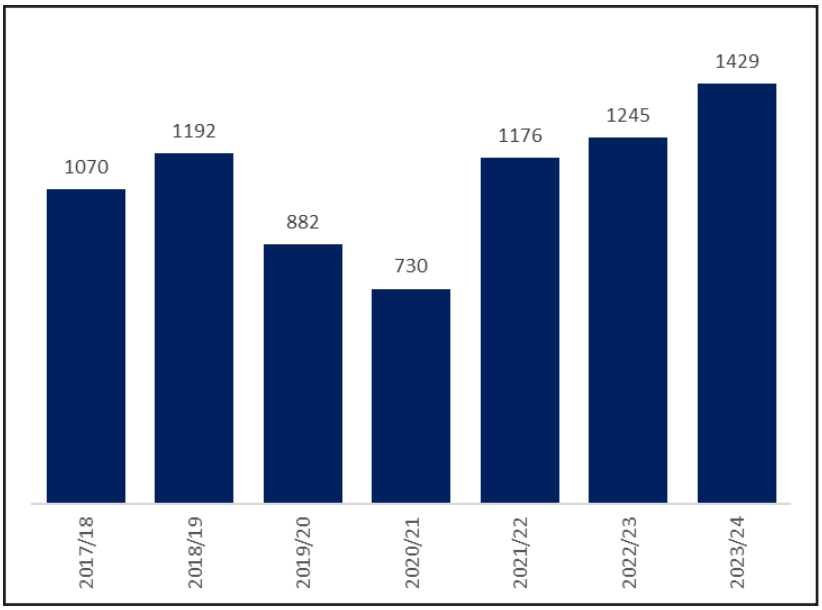


Figure 7: Echo activity over previous 7 years

Note: This activity does not include peri-operative imaging; emergency inpatient echo and echo in the ICUs. Activity in 19/20 and 20/21 reflected the impact of the COVID-19 pandemic.

D. MRI

Cardiac MRI has revolutionised our understanding of congenital heart disease. It is vital in the understanding of aortic disease, right heart lesions and in those with complex physiology. Each scan is a sophisticated assessment of anatomy, physiology and change over time. Serial imaging is required for many lesions.

Edinburgh and Aberdeen provide MRI scanning for a sub-set of patients with ACHD. However, NHS Golden Jubilee is the only centre in Scotland that can scan the most complex ACHD patients. See section on Effectiveness for issues regarding the need to repeat MRI scans performed in the local centres (section 3.4)

Additional support for MRI and the appointment of a further consultant with ACHD MRI expertise has enabled the service to increase our MRI activity and reduce our waiting list.

In 2023/24, 636 scans were performed which represents a significant (44%) growth from 2022/23. This was delivered by an increase in scanning and reporting sessions, which included the implementation of concurrent lists in order to optimise consultant scan supervision time. Necessary to the delivery of this was the displacement of regional (non SACCS) activity provided by the Radiology department into weekend sessions and a short hire period of a mobile MRI scanner. Without the additional funding and service redesign it would not have been possible to provide the increase in SACCS MRI activity.

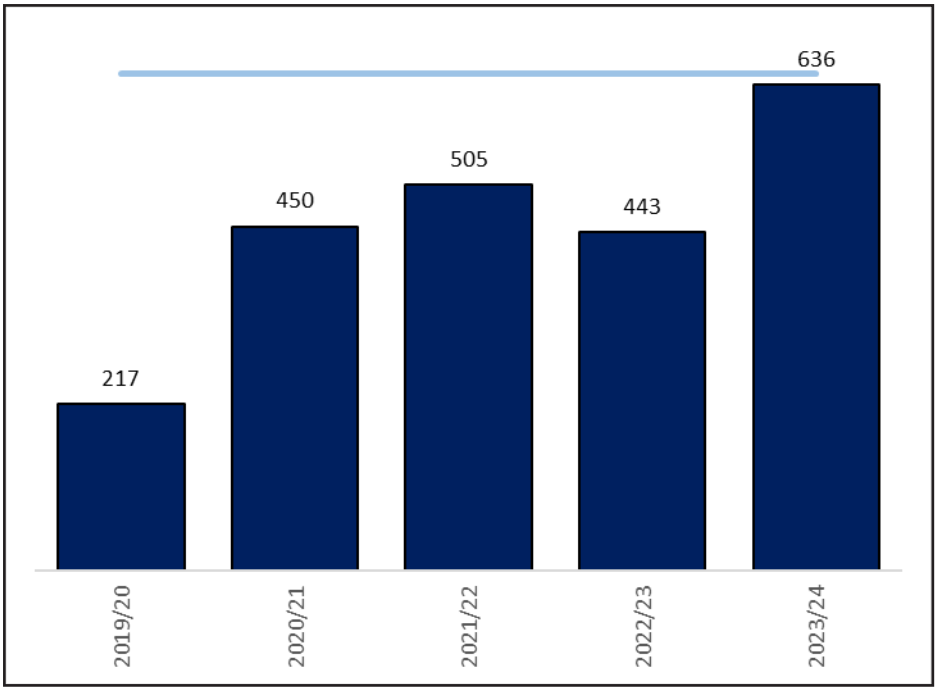


Figure 8: MRI Activity against the SLA

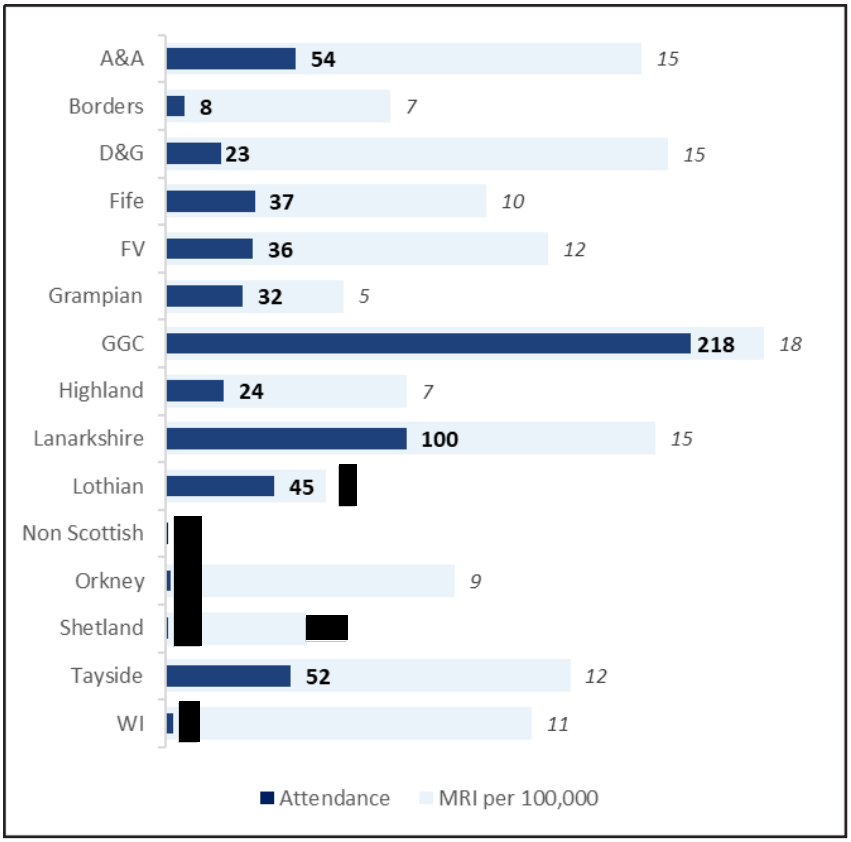


Figure 9: MRI Activity by Health Board of residence against MRI per 100,000 of 2021 general populations Data not corrected for prevalence of disease in each health board. Lothian and Grampian both provide an MRI service for noncomplex ACHD patients.

E. Cardiac CT

Cardiac CT is being utilised in the care of ACHD patients. The remit is wide but includes those unable to have MRI scans and specific indications – such as coronary anatomy in ACHD and those requiring high resolution imaging (for example aortic root or coarctation pre-intervention imaging). In addition, emergency out of hours CT is often required for post-operative complications or for new admission (such as endocarditis or dissection). At present the SACCS has no funding allocated for CT imaging. This is an area of urgent review.

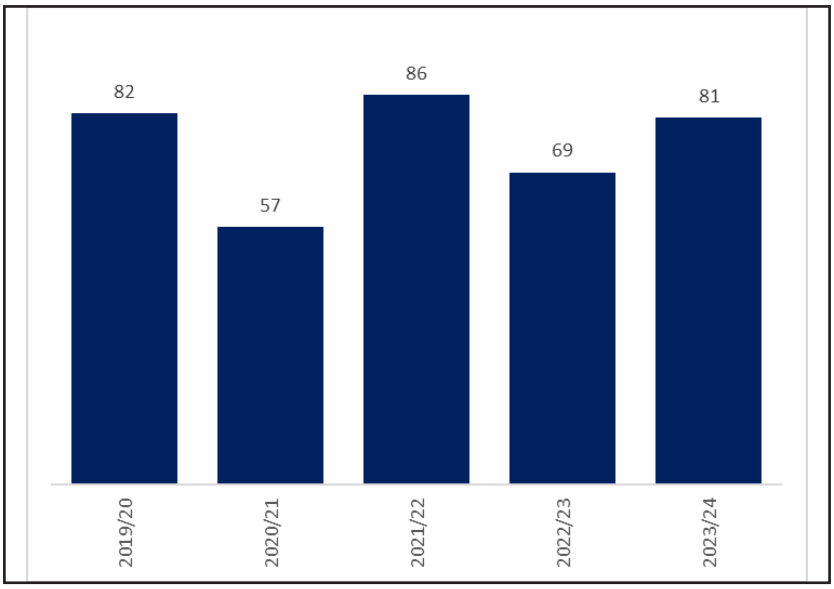


Figure 10: CT activity over previous 5 years

F. Exercise data

Cardiopulmonary exercise testing (CPET) is the prime physiological test used in ACHD. There are multiple CPET parameters that give prognostic information about patients. CPET is also routinely used to determine the timing of intervention. The CPET lab at NHS Golden Jubilee is run by respiratory physiology staff from NHS Greater Glasgow & Clyde. There is, therefore, a fixed level of activity that can go through the lab despite increasing demand. This has led to a degree of rationing of this resource and an inappropriately high threshold for requesting this investigation.

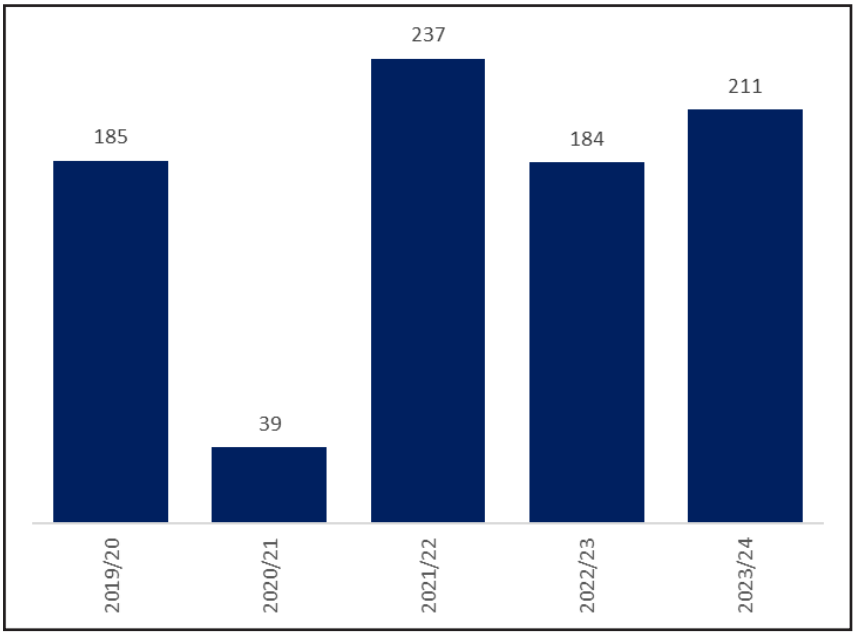


Figure 11: CPET activity over previous 5 years

G. Inpatient case

The majority of SACCS inpatient activity relates to intervention and cardiac surgery. However, the number of medical admissions is growing due to the increasing complexity of this patient group and to the increase in heart failure. In 2024, additional inpatient beds (NSD2) were opened to allow for the increased SACCS and Scottish National Advanced Heart Failure Service (SNAHFS) activity. This has allowed for more timely transfer of patients who are acutely unwell. The Golden Jubilee Conference Hotel remains an excellent resource for patient-centred care especially for patients travelling some distance for their treatment.

A sizable subset of inpatient care is related to patients with learning difficulties. Our NSD ward, 3 East (surgical ward), ICU and HDU all have expertise in caring for patients with learning difficulties. The ability for family members to stay in the patient's room overnight or in the hotel is a major advantage.

		Catheter	Surgical	Admission with no procedures	TOTAL
Inpatients	CCU	16	[redacted]	[redacted]	21
	HDU	9	266	[redacted]	280
	NSD	88	106	105	299
	ICU	32	293	17	342
	Ward	114	764	129	1007
	Total	**259**	**1430**	**260**	**1949**
Day cases	CDU	53	0	15	68
	SDU	0	[redacted]	[redacted]	[redacted]
	NSD	0	0	16	16
	Ward	0	0	[redacted]	[redacted]
	Total	**53**	[redacted]	**35**	**89**
Total		**312**	**1431**	**295**	**2038**

Figure 12: Bed day utilisation of procedural patients by procedure type

Inpatients are any patients that have stayed overnight regardless of the original intention – inpatient bed days are counted as of midnight each day. Day cases are patients that were admitted and discharged from hospital on the same day – day case bed days are counted as 1 day per day case.

H. Diagnostic catheterisation

A total of 59 diagnostic catheters were performed in 2023/24. A growing number of these assessments relate to the complex patient group who require catheterisation with provocation testing such as exercise or fluid challenge. The ability to do these investigations has greatly improved our understanding of complex physiology in these patients.

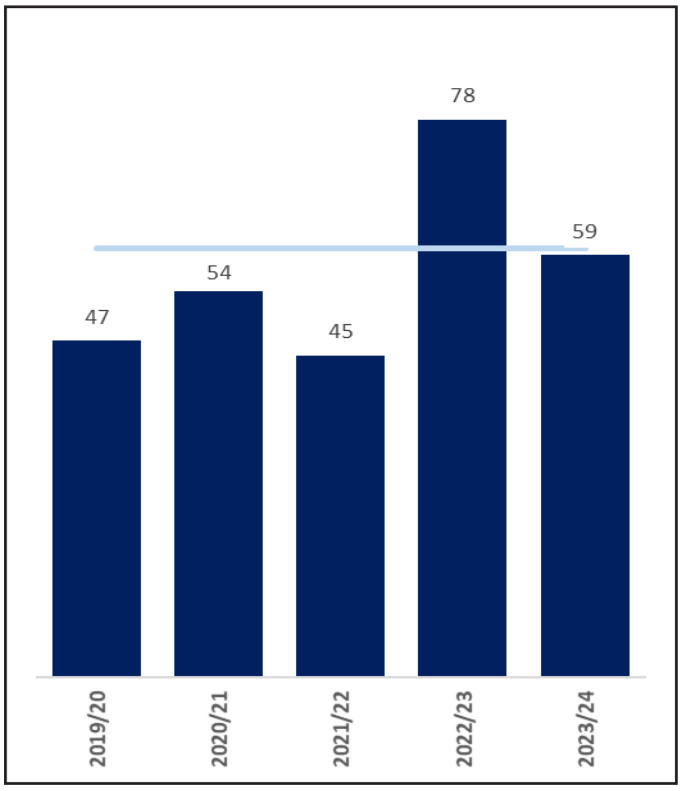


Figure 13: Diagnostic catheter activity against the SLA

I. Catheter intervention

The catheter intervention service provides a range of procedures including atrial septal defect (ASD) closure, coarctation stenting and percutaneous valves. The numbers of interventions per year has remained relatively static over recent times and has always been less than the original SLA. The reasons for this are unclear, but there has been no robust bench-marking with comparable services. All interventional cases are discussed at MDT meetings in the same way as surgical cases.

The interventional service is delivered by Dr Niki Walker and Dr Ben Smith (from the Royal Hospital for Children). The proportion of complex cases is increasing as newer intervention techniques become available. On occasions hybrid cases are performed, combining the skills of the surgical and catheter lab teams. An example would be surgical access to the heart and then a transcatheter intervention.

Over the last few years, the types of devices we use has expanded. This includes the use of the Gore Cardioform device. The teams' experience with this device has recently been published. In addition, new trans-catheter valves such as the Venus P valve are now available for patients with right ventricular outflow tracts too large for current technologies. These patients would previously have needed a surgical valve replacement and will lead to a small increase in our complex intervention numbers.

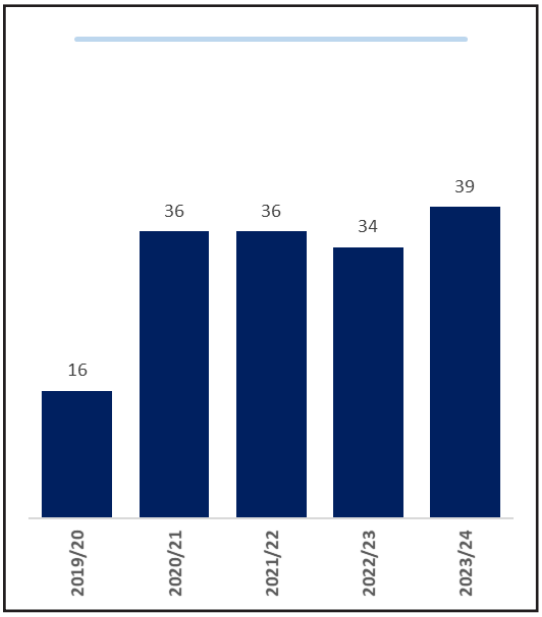


Figure 14: Interventional catheter activity against the SLA

Electrophysiology and device intervention

The incidence of arrhythmia in ACHD increases dramatically with age. This includes tachyarrhythmia requiring medication and/or ablation and bradycardias requiring pacing. Cardiac resynchronization therapy (CRT) and cardiac defibrillators are also a key component of the care of those with heart failure or prior ventricular arrhythmia.

All patients requiring complex EP or device treatment are discussed at a specific SACCS EP MDT meeting. The electrophysiology team has a high level of expertise in complex ablations in ACHD patients. These cases are challenging and often require 2 specialist operators with complex mapping systems and anaesthetic support. This requires careful pre-assessment and scheduling. One of the rate-limiting components of the SACCS EP service is anaesthetic support.

Waiting times for EP procedures have not recovered post-pandemic. The pressure on the service, for SACCS patients and non-SACCS patients, remains high. There are currently 12 procedures funded per annum within the SLA, and therefore, a business case has been submitted to increase the number to 36.

Occasionally complex electrophysiology cases are referred to units outside of Scotland. These referrals access expertise in Magnetic Navigation ablation technology which is available at the Royal Brompton Hospital. In 2023/24 no such procedures were performed.

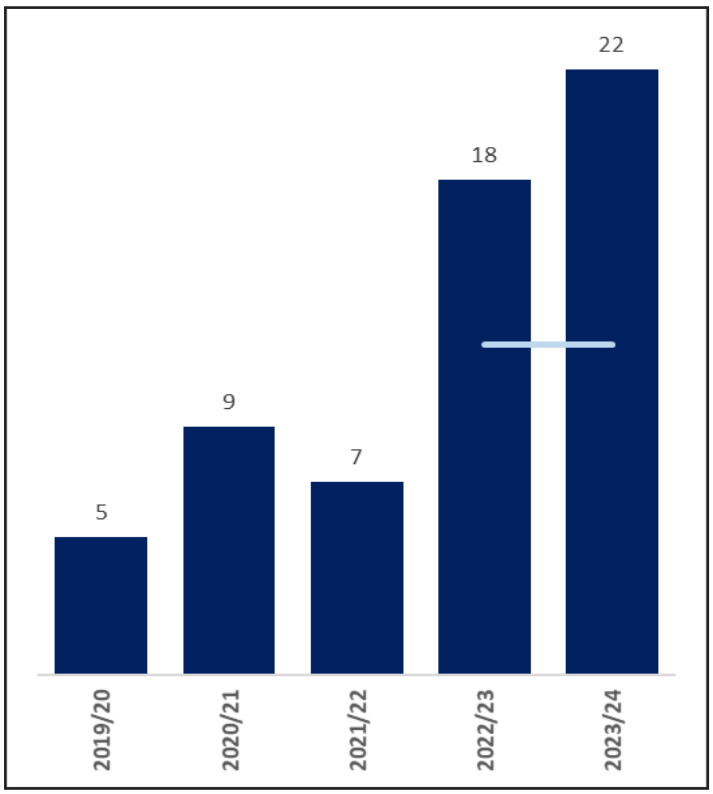


Figure 15: EP activity against the SLA introduced 2022/23

J. Congenital cardiac surgery

NHS Golden Jubilee is the national designated centre for adult congenital heart surgery in Scotland where all ACHD surgery is performed. This includes the whole spectrum of ACHD surgery with increasing numbers of reintervention. The SACCS service currently shares the 3 full-time cardiac surgeons with the children's hospital. There are 3 surgical lists per week operating mainly on elective patients. Urgent or emergency patients are usually fitted into 1 of these 3 lists, however on occasion, emergency operations are performed on any day due to their pressing clinical status.

The SACCS surgeons operate on all congenital heart disease. In addition, their expertise is used to undertake non-ACHD operations including hypertrophic obstructive cardiomyopathy, carcinoid heart disease, complex aortic root surgery and complex endocarditis surgery (often with a non-ACHD surgeon).

Due to the increasing numbers of complex redo operations, dual consultant operator surgery is becoming more common. Dual consultant operator procedures now account for 15% of cases and has implications for scheduling and surgical throughput. Lack of a junior surgical staff (fellow) at NHS Golden Jubilee also impacts of surgical efficiency. To support good governance, the Major Review recommended that there is review of the surgical workforce to support cross site working.

Small numbers of patients are referred, after MDT review, outside Scotland to other surgical centres for highly specialised surgery. These numbers are small and not expected to increase. There was 1 such referral this year.

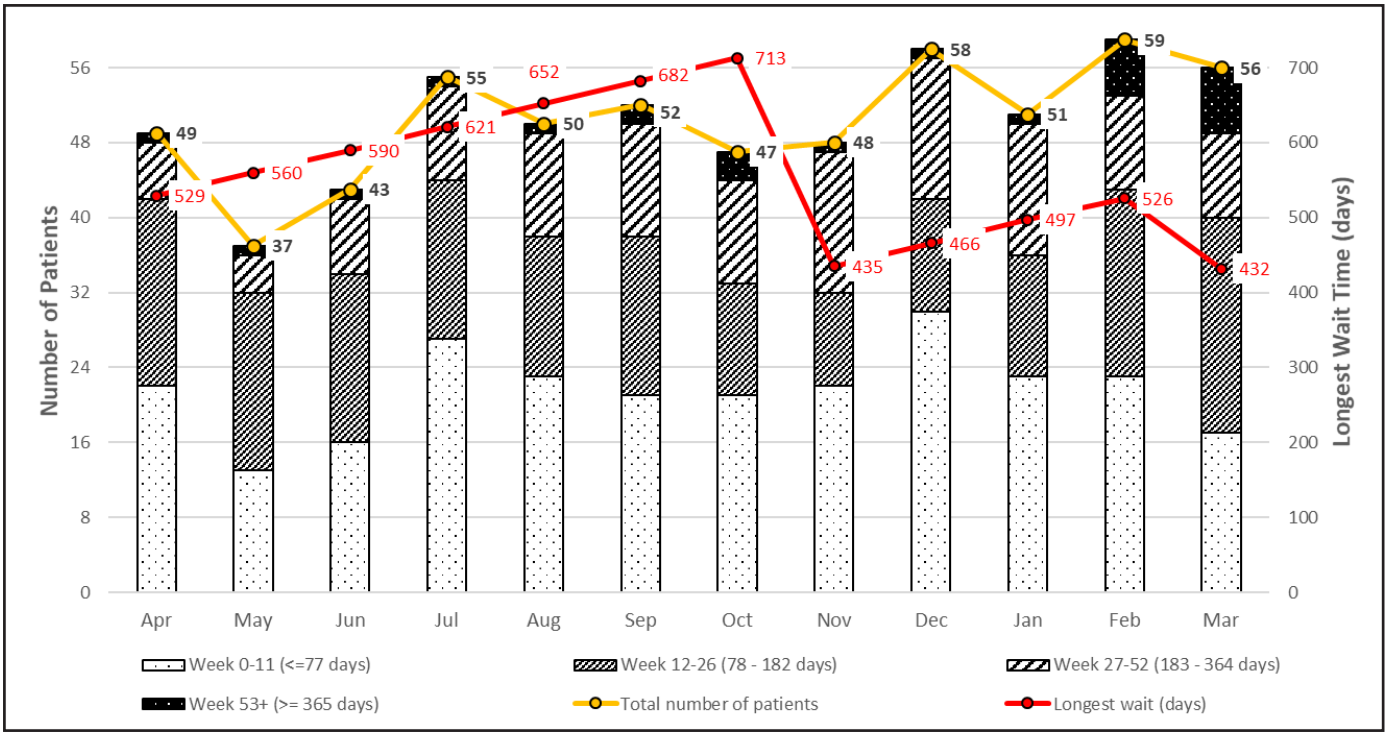


Figure 16: Surgical waiting list by time patients on the list have been waiting

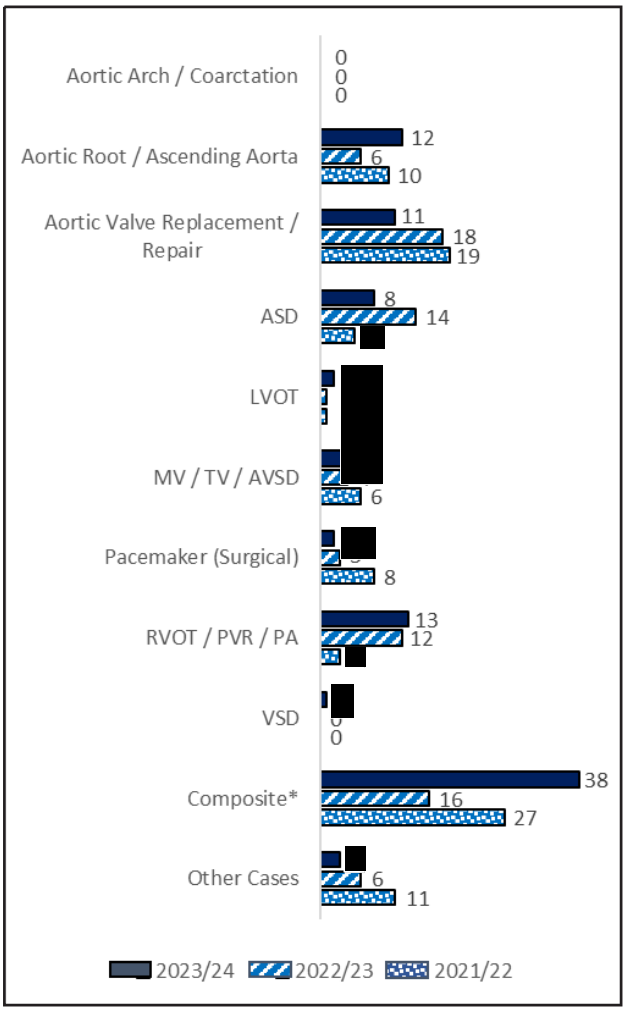


Figure 17: Surgical activity by type over previous 3 years

*A composite category has been added to more accurately demonstrate single operations in which more than one main procedure is performed. Previous years have been re-categorised for comparison.

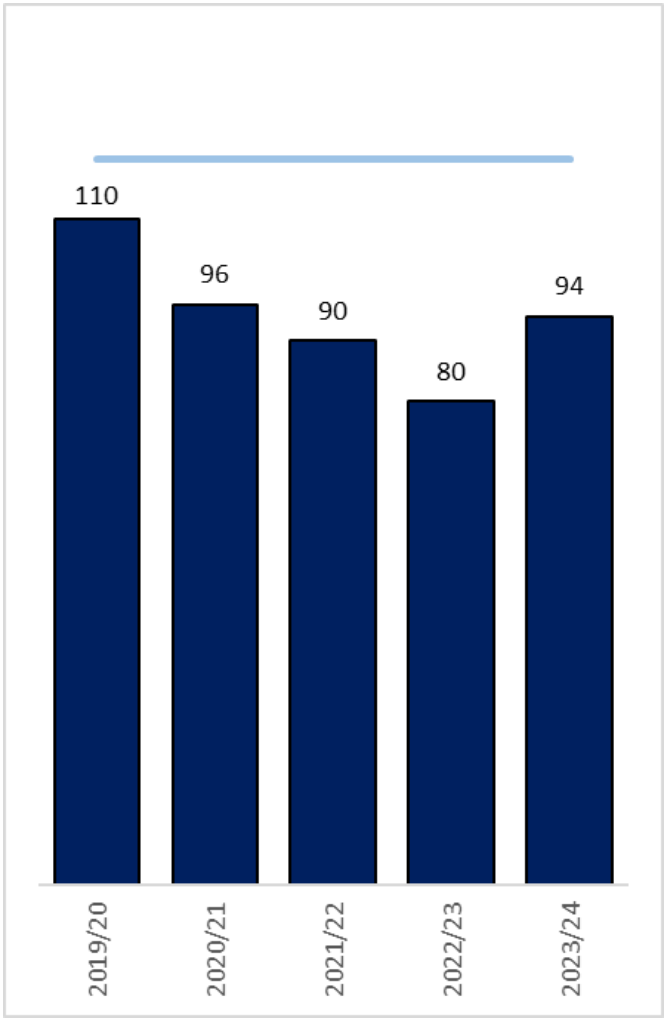


Figure 18: Surgical activity against the SLA

Non-cardiac surgery at NHS Golden Jubilee

A number of non-cardiac surgical operations on ACHD patients are scheduled at the Golden Jubilee. The reason for this is to ensure expert peri-operative anaesthetic and ICU care. These cases are complex to schedule as they include clinical teams who are not based at the Golden Jubilee. Over 2023/24 there were 6 such procedures including dental, gynaecology and general surgical procedures.

K. Transplantation

All transplant referrals from Scottish ACHD patients continue to go to the Freeman Hospital. In 2023/24, 6 patients were under the care of the Freeman transplant team – [redacted] patients were transplanted (both alive); [redacted] are on the active list ([redacted] on the urgent list) and [redacted] died [redacted] in the Freeman.

Access to inpatient urgent listing at the Freeman is challenging due to their bed availability. One proposal has included these patients remaining as inpatients at the Golden Jubilee. However, without additional expertise here this would greatly disadvantage patients.

Dr Niki Walker and Dr Katrijn Jansen (Freeman) hold regular transplant clinics at the Golden Jubilee to review those on the active list and to assess new referrals.

L. Psychology

In 2021 the SACCS service employed a full-time psychologist, Dr Deirdre Holly. Dr Holly has had a very significant impact on the care we can provide for SACCS patients. The bulk of Dr Holly's activity has been 1:1 sessions. These are mainly to treat health anxiety, needle phobia, PTSD and issues about planning for high-risk surgery/interventions. In addition, she has undertaken a series of patient events including learning cafes and education sessions. A total of 339 SACCS Psychology appointments were attended by patients in 2023/24.

O. Pregnancy and heart disease service

The cardiac obstetric service continues to provide specialist care to pregnant women with heart disease.

There are 3 main components of this service:

- preconception counselling (based at NHS Golden Jubilee);
- specialist antenatal care and delivery planning (based at the Queen Elizabeth University Hospital (QEUH) maternity unit); and
- an emergency delivery service at NHS Golden Jubilee for the most high-risk of cardiac patients.

The combined team includes cardiologists from SACCS (Dr Niki Walker and Dr Lorna Swan), specialist obstetricians, high risk obstetric anaesthetic staff and SACCS clinical nurse specialists (David Rodgers and Sandra Jansz) with expertise in pregnancy and heart disease. The antenatal cardiac assessment is facilitated by onsite echo facilities within the clinic staffed by an experienced echo physiologist from the Golden Jubilee together with utilisation of other inpatient and outpatient cardiology services at the QEUH. The cardiac obstetric multidisciplinary team meeting after each clinic helps crystallise the clinical plan and is an excellent educational opportunity for cardiology, obstetric and anaesthetic trainees.

The location of delivery continues to be based on the risk profile of each individual patient and this is reviewed throughout the patients' pregnancy. The contribution of the MDT is vital in this decision-making process. The expertise in the management of these high-risk patients at the QEUH allows the majority of complex patients to be delivered in the obstetric centre there. In 2023/24, there were [redacted] emergency deliveries at the Golden Jubilee – [redacted] with severe heart failure and [redacted] with acute aortic dissection. All mothers and babies survived.

The cardiac obstetric clinic based at the QEUH facilitates local, regional, and national levels of care for women across Scotland. The majority of women attending are from the west of Scotland reflecting the population in this area. There are no comparable services in other Scottish health board regions. In addition, the QEUH clinic facilitates access to national expertise in cardiac obstetrics for women with high-risk heart disease in pregnancy including access to the national cardiac services based at NHS Golden Jubilee

Collaborating with other centres providing cardiac obstetric care is essential to share experience and produce information on outcomes in this patient population. The SACCS have worked with cardiac obstetric centres across the UK to contribute to data on outcomes of pregnancy in patients with heart disease. The information published has led to contemporary information being available to better counsel woman of their risk in pregnancy and also instruct delivery of care for these patients during pregnancy. In addition, members of the cardiac obstetric team are internationally regarded as experts in the field. They contribute to education, development and publication of guidance to support the provision of care for women with heart disease of reproductive age in preconception counselling and pregnancy care.

Summary of Activity levels

	2023/24 SLA	2023/24	2022/23	2021/22
Surgical procedures	120	94	80	90
Diagnostic catheter procedures (23/24 re-categorised figures*)	60	59	81 (78)	54 (corrected**: 47) (re-categorised: 45)
Interventional catheter procedures (23/24 re-categorised figures*)	60	39	31 (34)	45 (corrected**: 34) (re-categorised: 36)
MRI Scans	650	636	443	505
EP procedures (diagnostic, interventional)***	12	22 ([redacted], 21)	18 ([redacted], 15)	
Consultant appointments (number of clinics)	1400 (160)	1435 (174)	1367 (189)	1723 (264)
Obstetrics appointments (number of clinics)	172 (22)	196 (21)	196 (21)	191 (22)
Transition appointments (number of clinics)	64 (12)	48	59	73
Patients on therapy for PH	45	47	43	53

Figure 19: Summary of SACCS activity levels against SLAs

*Retrospective re-categorisation of unsuccessful catheter interventions
**2021/22 catheter figures corrected to remove pacemaker and EP procedures
***2022/23 was the first year EP procedures were reported to an SLA

* The following definitions have been agreed to more accurately group these procedures, and previous year's figures have been re-categorised:

- attempt made, device / stent / coil introduced to the patient's body = interventional catheter
- no attempt made, no device / stent / coil introduced to the patient's body, i.e. anatomy found to be unsuitable to proceed to intervention = diagnostic catheter

3. Performance and clinical outcomes

3.1 Equitable

Figure 20 (below) describes the NHS Board areas of those attending the SACCS service. This includes those attending clinic, those being discussed at MDT and those undergoing catheter-based intervention and surgery. A large number of patients came from the west of Scotland NHS Boards as before. It is known that the demographics of ACHD patients in Scotland is skewed towards the central belt (Appendix 1). In addition, confounding factors may include a higher proportion of patients being seen locally in outreach clinics (for example Edinburgh) and variations in referrals (for example Dumfries and Galloway).

The use of video and telephone clinics (for example the pre-pregnancy and transition clinics) are improving access for those living some distance from the Golden Jubilee.

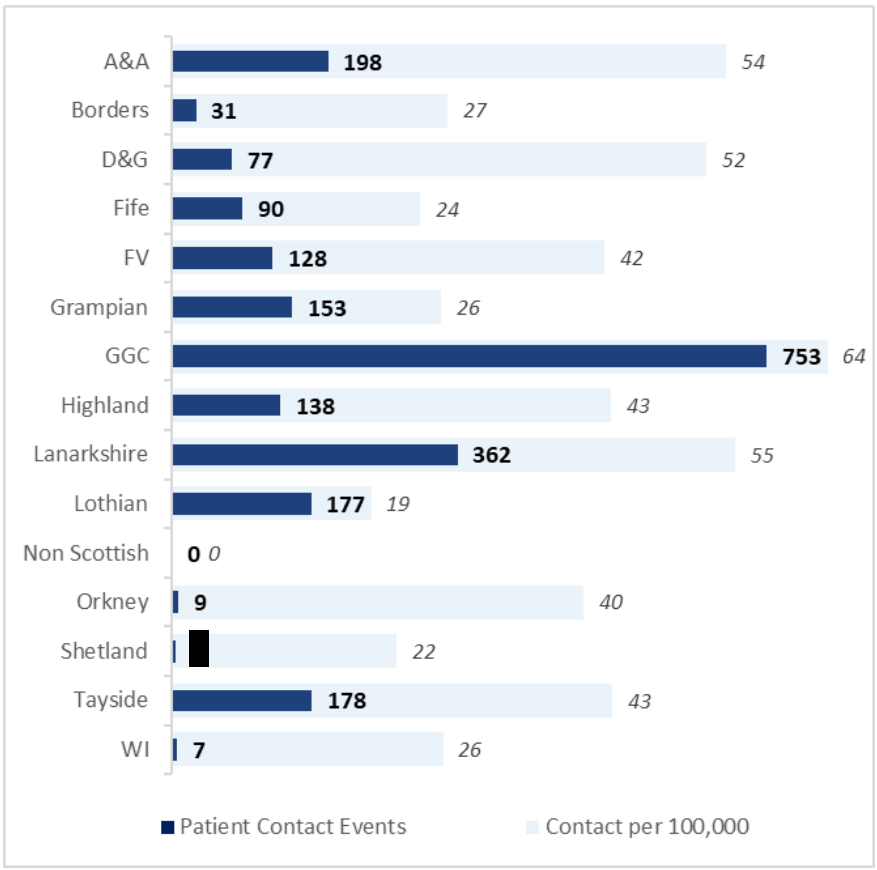


Figure 20: All SACCS patient contact by Health Board of residence against contact per 100,000 of 2021 general populations. This data is not corrected for prevalence of ACHD in each Health Board.

3.2 Efficient

The SACCS team has worked over recent years to optimise the efficiency of our service. For example, we have worked with our colleagues at local hospitals to ensure delivery of local ACHD clinics. This has allowed us to discharge to local care patients with milder disease. In addition, we can utilise a shared care model for those with moderate disease. This reduces the numbers of visits to the national service based at NHS Golden Jubilee. As part of this we have developed clear guidance regarding escalation pathways should new clinical findings arise.

The MDT meeting is now highly efficient with easy access for any external referrer. The MDT waiting list is actively managed to prioritise case discussion depending on their clinical risk. The SACCS team have also undertaken several rounds of population triage to target limited investigation capacity (such as CPET and MRI) to those who need it the most. This has positively impacted on waiting lists. In addition, the use of video and telephone clinics has reduced the need to travel to Clydebank for many patients.

Did not attend (DNA) appointments

Patients not attending for appointments remains an issue for the NHS. Pro-active booking teams reduce this inefficiency by telephoning patients for confirmation of their intention to attend. However, at times of reduced staffing in the booking team (due to sickness absence) means that this is not always possible. During these periods DNA levels rise. It is also known that in ACHD patients are more likely to attend clinic if it is bundled with other investigations in a day case “one stop” assessment visit. With additional resources in MRI this is becoming a possibility.

One clinic that has had challenges regarding DNA rates is the teenage Transition Clinic. There are several reasons for this but primarily the population being targeted felt that this was an optional additional clinic. Patients were offered a visit rather than a specific appointment being sent. This approach has been changed to a more standard clinic visit approach.

	2023-24	2022-23	2021-22
New Patient Clinic DNA	10.3%	6.2%	6.3%
Returning Patient Clinic DNA	7.4%	4.2%	5.5%
MRI DNA	4.3%	5.1%	9.5%
Echo DNA	7.9%	5.0%	7.5%
CT DNA	1.2%	10.4%	8.1%
CPET DNA	10.2%	8.9%	9.7%

Figure 21. DNA rates for clinic appointments and investigations

Same Day Surgical Cancellations

The percentage of same day cancellations remains high. In 2023/24 there were 18 patients cancelled on the day of surgery (16% of total cardiac surgery activity). Of these cancellations, the 3 most common reasons were cancellations due to priority or emergency cases, staff not available, or patient being medically unfit for surgery. As the numbers of urgent operations, such as heart transplants, has increased so had the number of late cancellations. This is inefficient in terms of resource utilisation but also causes psychological morbidity for patients and families. Ring fencing ACHD activity would help reduce this issue but may be challenging.

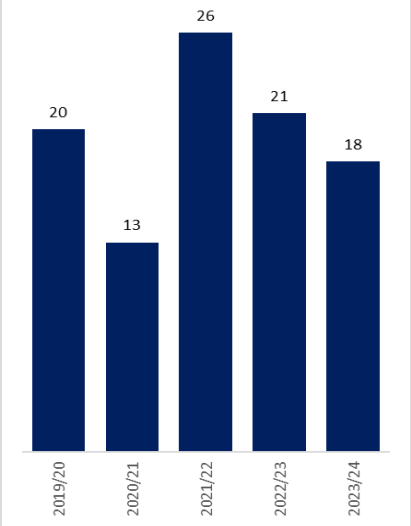


Figure 22: Total number of same-day surgical cancellation

3.3 Timely

At present there are 3 areas of particular concern with regards to timely delivery of care:

A. The waiting times for follow-up clinic visits
B. The waiting times for EP procedures (ablation)
C. The surgical waiting list

A. The waiting time for clinic review

As at 31 March 2024, 19 new patients were on the outpatient waiting list. The definition of a new patient is challenging in ACHD as all referrals from the paediatric service are not counted as new patients, although they have never been seen in adult care. This transition pathway is the primary source of new referrals. Other new referrals include patients with new diagnosis, and patients with a diagnosed congenital heart disease moving into Scotland.

There has been an increase in patients waiting more than 6 months beyond the planned clinic review date. As previously highlighted, there is still a catch-up phenomenon from historic issues. Increased diagnostic capacity has been highlighted as a priority in previous business case submissions to NSD.

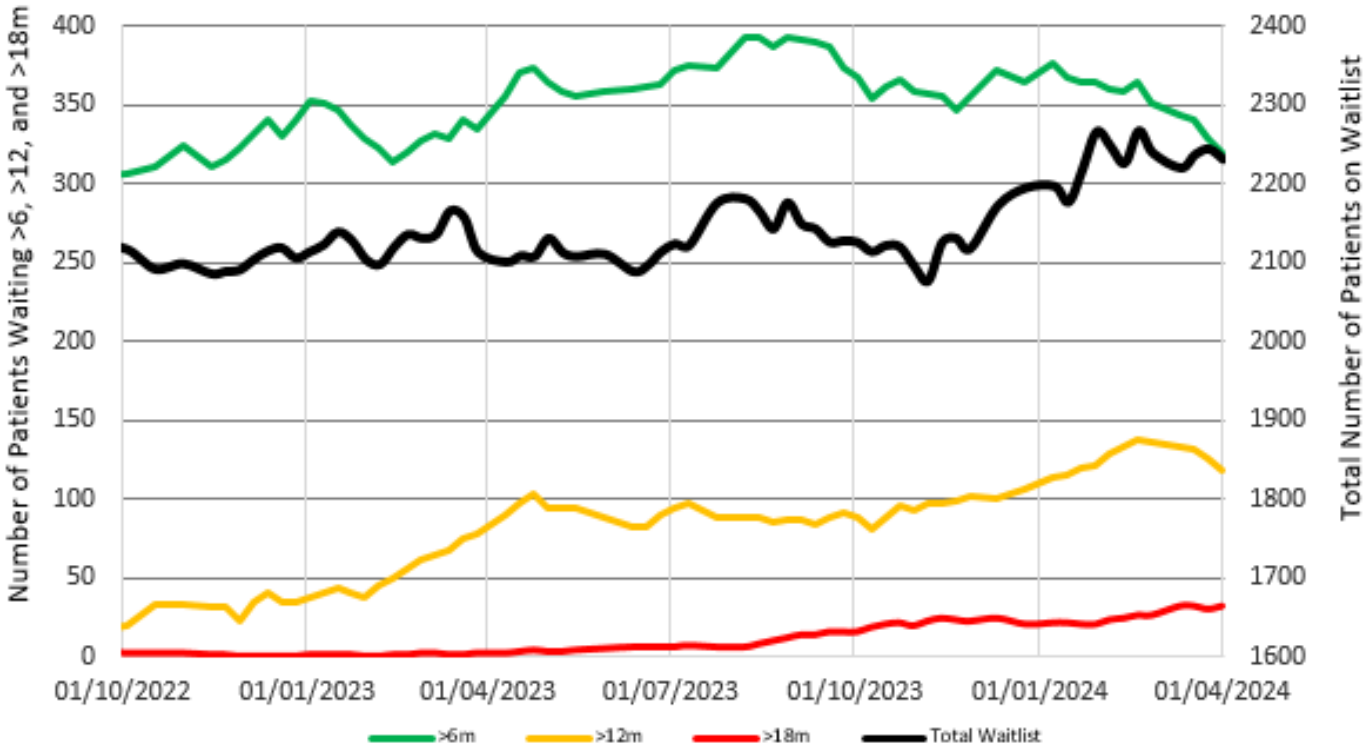


Figure 23: Total return outpatient waiting list against patients waiting >6 months past their recall date

B. The waiting times for EP procedures (ablation)

The greatest concern around catheter lab waits, is the patients waiting for an ablation as many of these procedures are complex requiring anaesthetic cover, and 2 EP operators. All the patients are discussed at the EP SACCS MDT and are vetted as “1 per day” or “2 per day” cases depending on the complexity, to facilitate scheduling and to fully utilise the general anaesthetic lists. Simple cases are often referred locally.

NSD has approved recurring funding to deliver 12 all day lists initially. It is recognised that the nature of ACHD EP is that repeat procedures are common, not because of procedural failure, but because the nature of the complex anatomies promotes the generation of new pathways. Therefore, it is anticipated that, in line with other ACHD units, there will be an increasing volume of EP cases in the ACHD population. Delays to access specialist EP service results in multiple further admissions to local emergency services and deterioration in clinical status.

Total number of patients	**25**
Median waiting time (days)	**141**
Longest waiting time (days)	**576**

Figure 24: EP waiting list as of 2023-24 year end

C. The surgical waiting list

The surgical waiting list is a clinical risk. At present the waiting time for routine non-urgent surgery is in excess of 1 year. Long waiting time impacts on efficiency (for example tests needing repeated as out of date), increase patient anxiety and increase the likelihood of complications. There have been no deaths on the waiting list.

Limitations to surgical throughput include surgeon availability (only 3 surgeons working cross site and the need for annual leave, dual operator procedures), anaesthetic staff availability (for example if called in overnight for an urgent transplant then unavailable) and ICU bed availability. Surgical cancellations remain high. Concerns about protecting the SACCS surgical lists have been escalated to senior management level at NHS Golden Jubilee.

Total number of patients	**56**
Median waiting time (days)	**125**
Longest waiting time (days)	**432**

Figure 25: Surgical waiting list as of 2023-24 year end

Cancellations

Cancellations are a feature of cardiac surgery, which can be difficult for the service to manage when balancing patient needs and expectations alongside challenges in resources.

The surgeons each have significant clinical caseloads in the Royal Hospital for Children and this limits their flexibility to cover any lists at short notice. The move to spread operating lists across 3 days rather than 2 has been of benefit in reducing cancellations and sharing the impact of cancellation on individual surgeons. The management team is working closely with the surgeons to identify how to reduce cancellations and maximise the surgical capacity.

There are no designated surgical fellows assigned to the ACHD surgical team. Given the complex nature of the surgery, and the cross-site commitments of the surgeon, a designated senior clinical fellow to the ACHD service has previously been identified as a development to support this service. Developing a cross-site supported surgical model remains a priority for the team.

Summary of limiting factors regarding Timely and efficient care

Component of care	Description of current service	Limiting capacity / efficiency
Outpatient clinic review	Reaching SLA. Current waiting times are >6months behind scheduled appointment.	Geographical space for consultation rooms Echo capacity.
Echo	Few stand-alone appointments. Appointments linked to clinical visits.	Trained echo staff. Geographical space for echo department.
MRI	Reaching SLA.	Requirement for additional recurrent funding to support this activity.
Cardiac surgery	Long waiting list.	Surgeon availability. Anaesthetic support. ICU beds.
Intervention	Current waiting list acceptable.	Longer waiting times for cases requiring anaesthetic support.
EP and devices	Long waiting list.	Funding for additional SACCS lists. Anaesthetic support.

3.4 Effectiveness

MDT meeting

The SACCS MDT takes place on a weekly basis on a Friday morning. The minimum attendance to achieve quorum is a cardiologist, an interventional cardiologist (who may be the same person) and a surgeon. In addition, we encourage attendance from as wide a range of the team as possible including the specialist nurses, psychologist and Clinical Fellows. Cardiac anaesthetists and cardiac intensivists frequently attend. The MDT is linked by MS Teams to local cardiologists who wish to attend. Dr Lorna Swan maintains the list of the patients awaiting discussion and circulates the list on a weekly basis. She also documents the attendees. Outcomes are documented on a spreadsheet database and clinical letters are written on all cases.

In 2023/24, there were 49 MDT meetings. No meetings were cancelled due to lack of attendance and all discussed cases were entered into the database.

Effectiveness of MRI service

The SACCS MRI team are often asked to repeat imaging performed locally due to poor image quality or lack of appropriate imaging. The MRI team here perform approximately 600 scans per annum. Less than 1% of these scans needed repeated due to the clinical question not being answered during the first scan. This is largely achieved as a result of the specialist training and skills of the radiographers and the direct supervision of the SACCS MRI Cardiology Consultants.

Post-op inpatient care

Each post-operative patient is reviewed every day by a SACCS Cardiology Consultant. This is in addition to review by the patient's surgeon. This results in an optimal length of stay with no delays related to senior decision making. In addition, readmission rates are low.

3.5 Safe

All unexplained complications or poor outcomes are discussed in the SACCS Morbidity and Mortality (M&M) meeting. This now forms part of the Friday morning MDT meeting. A written report for this meeting is then fed into the hospital risk and incident system, DATIX, and our serious adverse event review (SAER) process. Once a year the learning from the M&M meetings is summarised and disseminated via the governance team. In addition, all data is submitted to Public Health Scotland and this data forms the basis of their annual audit report.

	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	**Total**
Procedure related complete atrioventricular block requiring permanent pacemaker system	▮	▮		▮	▮		▮		▮			▮	**10**
Unplanned reoperation/ reintervention within 30 days of procedure (excludes bleeding)		▮		▮			▮			▮	▮		**6**
Cardiac arrest following procedure		▮								▮			▮
Requirement for mechanical circulatory support									▮	▮			▮
Surgical site infection requiring surgical intervention													**0**
Post-procedural prolonged pleural drainage (over 10 days)													**0**
Post-procedural requirement for tracheostomy													**0**
Phrenic nerve injury requiring plication of diaphragm													**0**
Acute kidney injury requiring dialysis									▮	▮			▮
New neurological impairment (global or focal) present at discharge	▮						▮						▮
Post-procedural necrotising enterocolitis – established requiring treatment													**0**
Acute neurological event during or within 30 days after cardiovascular procedure	▮	▮					▮						▮
Other significant procedure related complications									▮				▮
Total	▮	▮	**0**	▮	▮	**0**	▮	**0**	▮	▮	▮	▮	**33**

Figure 26: Surgical complications in 2023-2024

	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	**Total**
Surgical mortalities		▮							▮	▮			▮

Figure 27: Surgical mortalities in 2023/24

	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	**Total**
Failed attempt to implant coil-device during transcatheter intervention					1	1			1	1			4
Embolisation of catheter introduced device													**0**
Embolisation (dislodgement) of catheter introduced coil													**0**
Embolisation of stent													**0**
Rupture of conduit or vessel following stent implantation													**0**
Stent left expanded in unplanned site after migration or embolisation					1								1
Erosion of or into cardiac structure by implanted transcatheter device													**0**
Coronary arterial compression following transluminal device implantation													**0**
Mechanical haemolysis due to transcatheter implanted device or coil requiring transfusion													**0**
Unplanned reoperation/ reintervention within 30 days of procedure (excludes bleeding)					1								1
Local complication at access site of cardiac catheterisation requiring transfusion													**0**
Local complication at access site of cardiac catheterisation requiring thrombolysis													**0**
Local complication at access site of cardiac catheterisation requiring surgical intervention													**0**
Post-procedural necrotising enterocolitis – established requiring treatment													**0**
Requirement for bail out transcatheter procedure following procedural complication													**0**
Requirement for bail out surgical procedure following procedural complication										1			1
Cardiac arrest following procedure													**0**
Acute neurological event during or within 30 days after cardiovascular procedure													**0**
New neurological impairment (global or focal) present at discharge													**0**
Other significant cardiac catheterisation complication					1								1
Total	**0**	**0**	**0**	**0**	3	1	**0**	**0**	2	3	**0**	**0**	**9**

Figure 28: Catheter complications in year 2023-2024

Individual complications are reported, meaning multiple of the reported complications in figure 26 and 28 could have been within the same patient. Complications of surgical mortality patients are also reported in figure 27. Only the above complications are reported in line with audit guidelines.

National Public Domain Outcomes Data – NICOR NCHDA and SCAP

The outcomes for congenital cardiac surgery and cardiological interventions are scrutinised more closely than any other area of clinical practice. The service previously submitted outcome data to the National Congenital Heart Disease Audit (NCHDA) which allowed for UK wide benchmarking against defined statistical limits, including mortality rates. NHS Scotland withdrew from NCHDA in 2021 and was replaced by the Scottish Cardiac Audit Programme (SCAP) hosted by Public Health Scotland. The withdrawal from NICOR removed the externally validated assurance and benchmarking of the safety and quality of ACHD surgical and cardiological intervention services in Scotland. Efforts have been made to mitigate the risks of the NICOR withdrawal and restore benchmarking via comparison of PHS and NICOR published data however it remains a topic of significant concern.

3.6 Person-centred

The SACCS team have a patient centred approach. Examples of this are the holistic role of the nursing team, the psychological care events (Learning cafes), the easy access to expert care (SACCS email) and the quality improvement project caring out by the Performance Team. The SACCS team also have official patient volunteers to assist in this person-centred approach for both our inpatients and outpatients.

In addition, the team has developed several patient centred events – these include the transition day for teenagers moving from paediatric cardiology care and the Patient Education Evening for all of our patients.

Of those attending the Transition Day, 94% said they would recommend the event.

The below table includes several direct patient comments.

Patient Education Evening 2024
My mum and I thought it was great information and the SACCS team were great always there when I need them
Excellent efforts by SACCS team.
Thank you once again for all your hard work and for taking care of us all.
I thought the evening was really good, it was great to see the staff involved. I would definitely attend more events should they become available.
I would say the topics covered I already knew about but it was nice to meet new people.
I would firstly like to thank the SACCS team for all their hard work in putting together the conference.
Yesterday evening was a total game changer for me as up until then I felt like there was very little peer support at all.

The SACCS team also have close links to the various patient charity groups and have fundraised on their behalf. The SACCS team hope to host the Somerville Heart Foundation Annual Conference next year.

4. Quality and service improvement

The SACCS service has undergone major transformational change in the last 5 years. There is now a robust team with a strong complement of specialist cardiologists, specialist nurses, cardiac surgeons and psychologists. This team has made major advances in service delivery and patient focused care. However, despite this there still remains a historical legacy of under provision of expert care in Scotland and the numbers of referral and the size of the active SACCS population had not reached steady state. From international data there is the expectation that an ACHD service will grow by 10% per annum at least for the next 2 decades over and above any catch up.

Assessment against Adult Specialist Service Congenital Cardiac Standards

The SACCS service fulfils the majority of the national congenital heart disease standards. There have been, in particular, improvements in the access to psychology and palliative care services. However, there are several of the standards that are not met. These include standards related to the wider health service such as the provision of patient-held records and access to community adult services. Standards specific to SACCS that are not fulfilled relate predominantly to intervention numbers, to the surgical waiting list and to the need for a congenital heart disease database.

Patient Engagement Project: Improving the Scottish Adult Congenital Cardiac Service

In 2022/23 the Golden Jubilee Quality, Performance, Planning and Programmes team (QPPP) embarked on an extensive engagement exercise with service users who had interacted with the Scottish Adult Congenital Cardiac Service (SACCS) over the prior 3 years. This project was commenced at the instigation of the SACCS team. The main objective was to ascertain what aspects of the patient pathway could be redesigned to deliver an enhanced person-centred model of care around the needs and preferences of service users.

In a series of surveys, questionnaires and interviews 172 service users were asked to give feedback on the service. This feedback validated many of the aspects of the current service model including access to specialist care, telephone support and family centred care. The issues raised by this project included challenges around the hospital appointment system, procedural cancellations, communication of MDT outcomes and the need to improve the hospital website. Another suggestion was for further peer-to-peer support. In 2023 and 2024 the SACCS team have been addressing several of these issues including a patient education event for peer-to-peer support and a new post-MDT pathway for surgical patients.

NSS Review Report Scottish Adult Congenital Cardiac Service (SACCS), 2023

In late 2023/24 NSS released the report of their ‘major’ review of the SACCS Service. Overall, the service was described as a ‘high -quality service with a cohesive, experienced, and multidisciplinary team’. The report stated that ‘The service has continued to run well and received positive feedback from patients and clinicians, praising the service staff and quality of MDT assessments, amongst other positive feedback’.

The report raised several key issues for future consideration/collaboration:

Issue	Comments/outcome
Benchmark Data	As discussed, there is agreement that the move from NICOR to PHS has been challenging regarding bench-marking for congenital heart disease procedures. There is agreement for the SACCS team and NSD to continue to work on a solution.

Finance	This is a major challenge for the provision of care for Scottish patient with congenital heart disease. The SACCS team and the Golden Jubilee executive challenge the concept of a fixed envelope of funding. A business case had been submitted (see Section 8 Looking ahead).
Data Collection	The pressing need for a robust database is agreed. The Discovery platform will hopefully provide a solution in 2024/25.
Assessments – new to return model	The ability to have a higher new patient to return model is limited by the type of care ACHD patients require. Expert care in this setting is known to be associated with improved mortality. For moderate and complex patients this care can only be carried out by the SACCS team.
Clinic DNA Rates	It is agreed that reducing DNA rates is a priority.
Reporting	The SACCS will continue to report agreed indicators annually.
Risk – non co-location between paediatric and adult care	There are clear mitigation plans in place regarding non co-location. These are related to cardiac surgeon and intervention staffing.
Continuous Improvement regarding stakeholder feedback	This is the basis of ingoing improvement (see section above).
Cardiac MRI	A funded sustainable cardiac MRI strategic plan is required. This should include an attempt to share MRI protocols for simple ACHD lesions and to fund complex imaging at the Golden Jubilee.
Patient Outreach	To continue to provide equity of access to regional outreach clinics across Scotland
Interconnected Network Approach	Consider an interconnected/network approach within congenital cardiac care in Scotland to support the distribution of best practice and ways of working with local / regional services.
Electronic Patient Record	The service is enthusiastic to embrace such a project once established.
Transition	Cross site working and Transition events are now done in collaboration with the paediatric service.
Intervention numbers	The SACCS would support bench-marking to establish if the current SLA is appropriate.
Reporting/Updating the SLA	The SACCS will collaborate to update the service level agreement and performance measures.

Education

Since our last report there has been a major change in the provision of medical training in ACHD in the west of Scotland. The West of Scotland specialist trainees in cardiology now spend a period of 10 weeks with the SACCS team. This will lead to a step change in improving the knowledge and understanding of issues in ACHD patients. This modular approach should be rolled out to other Deaneries.

The 12th Scottish Adult Congenital Heart Disease Conference was held in November 2023 at the Golden Jubilee Conference Hotel. This was a hybrid event to facilitate access across the country. As usual the feedback was of a high scoring event.

5. Governance and regulation

5.1 Clinical Governance

The SACCS team have a robust clinical governance process and the governance lead is Dr Amanda Hunter. The SACCS team hold bimonthly clinical governance sessions covering all aspects of care. This group reviews multiple aspects of care including the Risk Register and the outcomes from any DATIX investigations. The findings and actions of these meetings are then reported to the Clinical Governance Risk Management Group (CGRMG) on a quarterly basis.

5.2 Risks and Issues

The current entries on the SACCS Risk register are:

Title	Description	Progress	Status
Shortage of admin resource	Admin shortage leads to delays re clinical letters; increased DNA (booking team cannot phone to confirm appointments; delays in booking appointments.	Additional Band 3 post has been advertised but challenging to fill.	Medium
Diagnostic capacity	Significant backlogs awaiting investigations.	Some improvement in MRI capacity.	High
Discontinuation of submission of data to NICOR	No ability to benchmark congenital data via the PHS audit.	Ongoing attempts to improve interaction with NICOR data.	Very high
Lack of IT database for SACCS	Major clinical risk in terms of service planning, losing patients to follow-up; inability to track patient care.		High
Quality issues with Winscribe dictation system	Dictation occasionally going missing.	Ongoing audit / investigation.	Very high
Requesting tests from territorial boards system	Challenge of being unable to follow-up on investigations performed/requested by the local team.	Ongoing risk.	High
SACCS surgical staffing	Need for good surgical support in theatre.	Lack of middle grade staff Only 3 surgeons working across site.	High

5.3 Adverse events

Any adverse event is captured through the Datix system. In 2023/2024 there were 4 significant adverse events reported via Datix relating to SACCS and processed via the significant adverse events review (SAER) process.

5.4 Complaints and compliments

The SACCS service receive numerous compliments via social media, thank you cards and letter directly to the ward and there were also 2 compliments logged in the Datix system. In addition, patient events and Transition Days generate many compliments. The SACCS nursing team are currently finalists in the RCN Nursing Team of the Year. Patient feedback from our Performance Patient Survey demonstrated high ratings for patient feedback.

5.5 Equality

NHS Golden Jubilee's Diversity and Inclusion Strategy 2021-2025 features an ambitious set of deliverables and associated outcomes to further strengthen its position as a leader in the field of equality, diversity, and inclusion. The 4-year strategy and 2023 midpoint report are available to review on the hospital website.

The strategy has 3 key themes:

Theme A: Diversify Talent
Theme B: Wellbeing and cohesion
Theme C: Inclusive Service design

Staff networks and forums

NHS Golden Jubilee recognise the benefits that staff networks can bring towards fostering an inclusive workplace culture. Over the past 24 months we have embarked on an ambitious journey to establish a family of networks to represent the 9 protected characteristics and Fairer Scotland duty.

Staff network	Protected Characteristic	Executive lead
Ethnic minority	Race	**Medical Director** Mark MacGregor
Ability	Disability	**Director of Strategy, Planning and Performance** Carol Anderson
LGBT+	Sexual orientation Gender reassignment (trans status)	**Director of Nursing** Anne Marie Cavanagh
Young Person's	Age Socio-economic status	**Director of Finance** Michael Breen
Armed Forces	Intersectional	**Director of Strategic Communications and Stakeholder Relations** Sandie Scott
Spiritual Care	Religion and belief Marriage and civil partnership	**Director of HR** Laura Smith
Women's	Sex Maternity and Pregnancy	**Director of Operations** Carolynne O'Connor

The SACCS team mirrors these values. In addition, it has an additional focus on caring for those with physical, psychological, emotional and intellectual disabilities.

6. Financial reporting and workforce

2023/24 SACCS Financial report

	2023/24 Profile	2023/24 Profile	Actual March 24	Actual March 24
Staff costs	**w.t.e**	**£**	**w.t.e**	**£**
Consultant Cardiologist	[redacted]	[redacted]	[redacted]	[redacted]
Consultant Radiologist				
Consultant Cardiac Surgeon				
Consultant Anaesthetist				
Consultant Anaesthetist (EP Lists)				
Cardiac Physiologist				
Cardiac Physiologist (Increase Echo BC Outcome)				
SACCS Fellow				
Radiographer (upgrade B7-8a)				
Radiographer (Band 6)				
Medical	**8.75**		**9.36**	
Psychology Band 8c	[redacted]		[redacted]	
Psychology Band 8a				
Liaison Manager Band 7				
Clinical Nurse Specialist Band 7				
Transition Nurse Band 7				
Ward Nursing			8.58	
CICU Nursing			[redacted]	
Nursing	**10.70**		**16.06**	
Data Manager	[redacted]		[redacted]	
Secretary (Band 4)				
Admin (Band 3)				
Admin / clerical				
Total staff costs	**24.45**		**30.18**	
Ward			0.00	
Theatre			0.00	
Cath Lab (EP Lists)			0.00	
MRI Sessions			0.00	
MRI Sessions (BC Outcome)			0.00	
GA Sessions			0.00	
Pharmacy supplies				
Ward Supplies			0.00	
Sub Total				

Devices			0.00
Named Drug Costs			0.00
Sub Total			
Biochemistry			0.00
Bacteriology			0.00
Haematology			0.00
Other			0.00
Labs			
Catering			0.00
Portering			0.00
Linen			0.00
Cleaning			0.00
Other Costs			0.00
General services			
Maintenance			0.00
Capital Charges			0.00
Overheads			
Other			
SACCS Conference			0.00
Total costs	**24.45**		**30.18**

7. Audit and clinical research / publications

Together with the Royal Hospital for Children, the SACCS team submit data to the PHS Scottish Cardiac Audit Programme. This is a systemic review of all of our procedures and interventions.

Other examples of audit from 2023/24 were reviews of the complexity of patients in our service – there were 2 components of this – 1 outpatient care and 1 MRI. Both demonstrated that the majority of patients in the service are moderate or highly complex. This is unlike several other large international services who see a higher proportion of simple lesions and do not employ shared care models.

The SACCS team remain very active in terms of publications and research. These vary from local projects to international projects. Several members of the SACCS team are also involved in writing national and international guidelines in ACHD and in pregnancy. A list of 2023/24 publications is included in Appendix 2

Dr Gruschen Veldtman is the research lead for the cardiology component. He has protected time in his job plan to coordinate research for the service. Professor Mark Danton leads on the academic surgical side. Appendix 3 lists ongoing or recent Research projects from the SACCS team.

8. Looking ahead

A sustainable service

The predictable growth in ACHD services and the known increase in late complications and morbidity of an aging population mean that a sustainable and safe service cannot be delivered within the current funding envelope. This was the basis of a Business Case submitted in 2022. The previous funding agreement dated back to 2013. The intention of that business case was to meet the funding gap of our current service and permit important service developments. These will be aligned to the strategic priorities of the service and the recommendations of the major review. These service developments will be proportionate and in keeping with the needs of the ACHD population and the national ACHD standards.

The summer 2022 SACCS / Golden Jubilee Business Case highlighted the following priorities:

1. Sustainable workforce model
2. Advanced imaging and diagnostic capacity
3. Electrophysiology (EP) capacity
4. Inpatient capacity
5. Contemporary outpatient model
6. Patient management system (bookings and database)

The SACCS will submit an updated Business Case in 2024 to reflect the ongoing changes within the service and within the specialty of ACHD.

Network Approach

One of the major recommendations from the NSD Review was to revisit the wish for a Scottish Adult Congenital Heart Network. At present the responsibilities for care of ACHD patients out with the SACCS is with the territorial boards as is the ability to take forward a formal network. However, we would embrace our role to inform, support and influence this work. Resourced and well-led networks have been modelled in ACHD care in England and the learning from those experiences would help form a bespoke Scottish solution. One of the major advantages for a networked approach would be to focus complex assessment and care at the Golden Jubilee and to devolve other aspects of care to high quality, supported local teams.

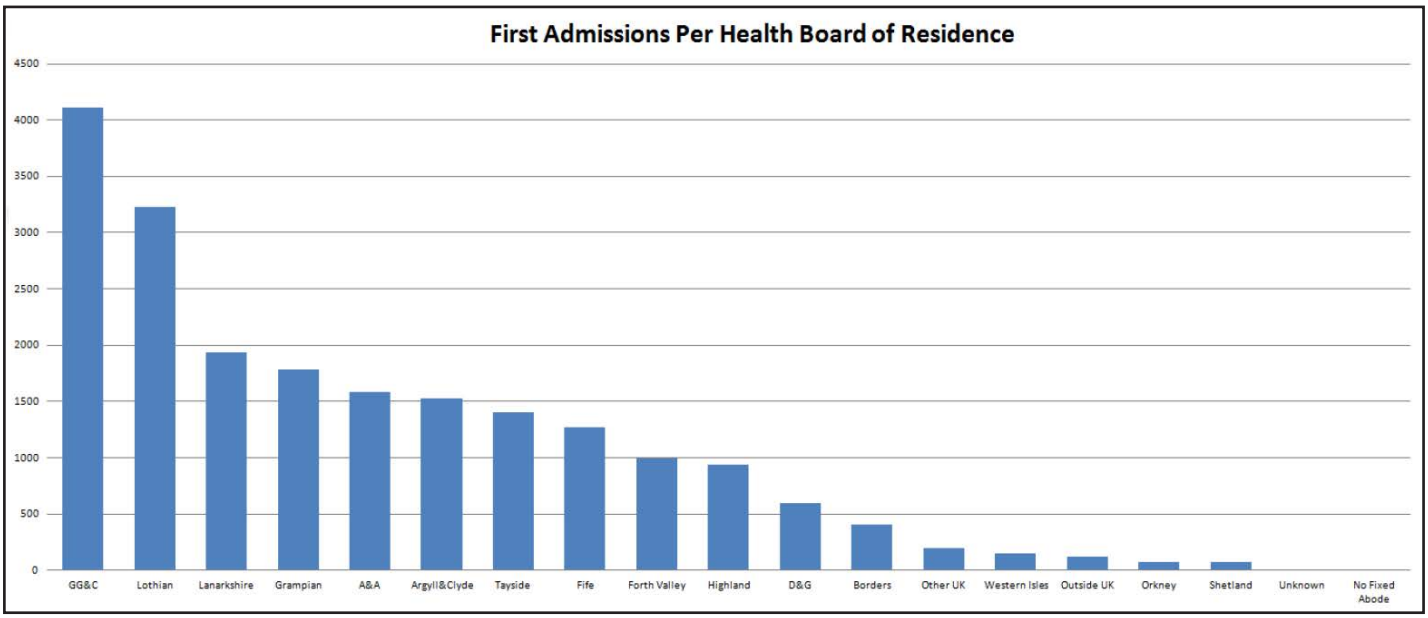
Horizon Scanning

The field of ACHD continues to evoke several important clinical themes that are likely to impact on the provision of services over the next decade. These include:

- The increase in ACHD related heart failure and the need for specialist congenital heart disease heart failure programmes;
- The increased burden of arrhythmia requiring expansion in ablation and device therapies; and
- The increasing complexity of ACHD cardiac surgery requiring additional surgical, MDT and imaging (such as 3D reconstruction) expertise.

NHS Golden Jubilee and the SACCS team are in an excellent position to meet these challenges with appropriate partnership with NSD and the Scottish Government.

Appendix 1: Geographical distribution of adult patients with CHD in Scotland



Utilising from ISD data 1990-2015 discharges from Scottish hospital with an ICD or OPCS code related to congenital heart disease

Appendix 2: SACCS Team Publications 2023/24

- Socioeconomic deprivation and illness trajectory in the Scottish population after COVID-19 hospitalization. Morrow AJ et al. Commun Med (Lond). 2024 Feb 28;4(1):32. doi: 10.1038/s43856-024-00455-5. PMID: 38418616
- Anxiety and Depression in Adults With Congenital Heart Disease. Kovacs AH et al. J Am Coll Cardiol. 2024 Jan 23;83(3):430-441. doi:10.1016/j.jacc.2023.10.043. PMID: 38233017
- Post-COVID-19 illness and associations with sex and gender. Mangion K et al. BMC Cardiovasc Disord. 2023 Aug 8;23(1):389. doi: 10.1186/s12872-023-03412-7. PMID: 37553628
- Isosorbide DiNitrate Effect on Hemodynamic Profile, Liver Stiffness, and Exercise Tolerance in Fontan Circulation (The NEET Clinical Trial). Bigelow AM et al. Pediatr Cardiol. 2023 Apr 21:1-9. doi: 10.1007/s00246-023-03156-3. PMID: 37084132
- Cardiovascular Complications of Down Syndrome: Scoping Review and Expert Consensus. Dimopoulos K et al. Circulation. 2023 Jan 31;147(5):425-441. doi: 10.1161. Epub 2023 Jan 30. PMID: 36716257
- Adjudicated myocarditis and multisystem illness trajectory in healthcare workers post-COVID-19. Sykes R et al. Open Heart. 2023 Feb;10(1):e002192. doi: 10.1136. PMID: 36822817
- Thromboprophylaxis in Patients With Fontan Circulation. Van den Eynde J et al. J Am Coll Cardiol. 2023 Jan 31;81(4):374-389. PMID: 36697138
- Occult Diastolic Dysfunction and Adverse Clinical Outcomes in Adolescents and Young Adults With Fontan Circulation. Peck D et al. J Am Heart Assoc. 2023 Jan 3;12(1):e026508. doi:10.1161/JAHA.122.026508. PMID: 36565206
- The prognostic role of liver volumetry in Fontan patients. Najashi Ka et al. Cardiol Young. 2023 Oct;33(10):1834-1839. doi: 10.1017/S1047951122002992. PMID: 36258282
- Patient-reported outcomes in the aging population of adults with congenital heart disease: results from APPROACH-IS. Moons P et al. Eur J Cardiovasc Nurs. 2023 May 25;22(4):339-344. PMID: 35901014
- A novel device for atrial septal defect occlusion (GORE CARDIOFORM). Hribernik I et al. EuroIntervention. 2023 Nov 17;19(9):782-788. doi: 10.4244/EIJ-D-23-00378.PMID: 37609882
- Direct current cardioversion in pregnancy: a multicentre study. Cauldwell M et al. BJOG. 2023 Sep;130(10):1269-1274. doi: 10.1111/1471-0528.17457. Epub 2023 Apr 11.PMID: 37039253
- British Society for Haematology guideline for anticoagulant management of pregnant individuals with mechanical heart valves. Lester W et al. Br J Haematol. 2023 Aug;202(3):465-478. doi: 10.1111/bjh.18781. Epub 2023 Apr 1.PMID: 37487690
- Response to Knight and Nelson-Piercy 'Clarity of guidelines concerning the care of pregnant women is lost by the use of de-sexed language'. Lester W et al. Br J Haematol. 2023 Jul;202(2):438-439. doi: 10.1111/bjh.18858. Epub 2023 May 23.PMID: 37221821
- Sexual Health and Well-Being in Adults With Congenital Heart Disease: A International Society of Adult Congenital Heart Disease Statement. Swan L et al. JACC: Advances,Volume 2, Issue 10,2023. 100716.
- Effect of Sodium-Glucose Cotransporter 2 Inhibitors in Adults With Congenital Heart Disease. Neijenhuis RML et al. J Am Coll Cardiol. 2024 Mar 12:S0735-1097(24)00385-1. doi: 10.1016/j.jacc.2024.02.017. PMID: 38530688
- Zoom and its Discontents: Group Decision Making in Pediatric Cardiology in the Time of COVID (and Beyond) : Aurthors. Danton MHD et al. J Med Syst. 2023 May 5;47(1):59. doi: 10.1007/s10916-023-01944-1.PMID: 37145204
- Modification of the Warden Procedure for Surgical Repair of Partial Anomalous Pulmonary Venous Connection. Danton MHD et al. World J Pediatr Congenit Heart Surg. 2023 Jul;14(4):497-499. doi: 10.1177/21501351231168830. Epub 2023 May 15.PMID: 37186786
- The impact of surgical repair on left ventricular outflow tract in atrioventricular septal defect with common atrioventricular valve orifice. Chandiramani A et al. JTCVS Open. 2023 Jan 19;14:385-395. doi: 10.1016/j.xjon.2022.11.023. eCollection 2023 Jun.PMID: 37425447

Appendix 3: Examples of Ongoing Research Activity from SACCS Team

Ongoing Project Title	Lead investigators	Comments
Cardiopulmonary exercise testing in children and young adults with repaired tetralogy of Fallot	Mark Danton	In Press
Computational modelling of RV in repaired TOF and the impact of pulmonary valve replacement	Mark Danton Niki Walker	BHF Funded project
COVID-19 outcomes on the Scottish congenital heart population	Mark Danton Niki Walker	MRS Funded
Surgical management of proximal aortopathy in Scotland	Mark Danton	
ESC Pregnancy and heart disease guideline	Lorna Swan	
ACHD Registry – AI driven risk	Gruschen Veldtman	Collaboration with University of Glasgow
Optimal Timing of PVR in Tetralogy of Fallot	Gruschen Veldtman	
Integrated Flow Reserve in CV diseases	Gruschen Veldtman	Ongoing mechanistic clinical study
Integrated Flow Reserve in CV diseases: Cardiorenal and cardio hepatic effects of SGLT2i	Gruschen Veldtman	
Research Endpoints in ACHD (REACH)	Gruschen Veldtman	International collaboration
Aortic Aneurysm in Conotruncal Abnormalities	Gruschen Veldtman	
Nationwide outcomes of PVR: transcatheter and surgical in CHD (NICOR)	Gruschen Veldtman	National Study

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