Scottish Adult Congenital Cardiac Strategy

2022 to 2025

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2	08 June 2022	i. Summary boxes for each priority ii. Add Priority 4 – EP service	A McGuire

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Contents

INTRODUCTION

The Scottish Adult Congenital Cardiac Service (SACCS) is the National specialist service commissioned by the National Services Division of NHS Scotland at the Golden Jubilee National Hospital to deliver care to adults with congenital heart disease. The service is provided for adults who are resident in Scotland with complex congenital heart disease. Congenital heart disease can be diagnosed antenatally, during childhood or be undetected into adult life.

The demographics of congenital heart disease are changing due to increasing survival of children into adult life. There are increasing numbers of adults with congenital heart disease with the English prevalence in 2018 estimated at more than 4 per 1000 adults. The number of patients with complex disease is increasing with 10% of the adult congenital heart disease population now falling within the complex group. It is recognised that there will be continued growth in the adult congenital population both numerically in terms of patient numbers and also in terms of lesion complexity and comorbidities. This is a celebration of paediatric cardiac services. It does however require significant planning to ensure ongoing care to the adult years.

The purpose of this strategy is to describe the immediate priorities for the service over the next 3 years. This time period has been selected as there are specific challenges facing the service as we recover from the pandemic and preceding that, gaps in the service provision due to limited resource and long term medical vacancies. The service is now in a strong position following successful recruitment in 2020 to develop world class adult congenital services for the population of Scotland which are contemporary and fit for the future.

A major service review has been commissioned by NSD and one of the key priorities for ensuring the service is resilient to meeting the needs of the growing ACHD population will be to redefine the specialist service that SACCS is commissioned to provide. It is recommended that a network approach is adopted, similar to the approach in England, with more care provided locally, and maintaining SACCS to deliver the specialised care to the more complex patients.

The purpose of the strategy is to define the priorities for the period 2022-25. The strategy is supported by more detailed documents which are attached as appendices:

Appendix 1 – Overview of the SACCS in 2021

Appendix 2 - Congenital Cardiac Standards – Gap analysis August 2021

Appendix 3 – Education Strategy

Appendix 4 – Research Strategy

Appendix 5 - The Annual Report 2020-2021 provides a contemporary assessment of the performance of the service.

SACCS PRIORITIES FOR THE NEXT 3 YEARS

Following the UK wide peer review process of 2019, substantial progress has been made in recruitment to the consultant cardiologist team. This opportunity has been somewhat attenuated by the global pandemic of COVID 19. We therefore seek to describe the priorities for the service in the short to medium term that will address the impact of the pandemic whilst renewing the delivery of care throughout Scotland.

Whilst acknowledging that there are many areas requiring development within SACCS, the team will focus on the following for areas to deliver measurable improvement by 2024.

1. **contemporary outpatient model for the National specialist service**
2. **patient management system achieving resilient booking process and incorporating a database**
3. **advanced imaging capacity**
4. **EP Capacity**
5. **inpatient capacity**
6. **workforce**
7. **Contribute to the Major Review, recommending a redefining of the national service and introducing a network model of care**

Priority 1: Contemporary Outpatient Model for National Specialist Service

We have an increasing cohort of adults with moderate and complex conditions who require ongoing specialist care that considers indication and timing of interventions including pharmacology, catheter intervention, electrophysiological intervention, and surgery which may include cardiac transplantation or indeed multiorgan transplantation or long term mechanical circulatory support.

The challenge faced by all specialist ACHD services is coordination of assessment. The usual model is of centralised assessment in the specialist centre sometimes requiring multiple visits to complete one assessment process. We recognise that this is not a patient centred approach, particularly given the geography of Scotland, as some patients will have significant travel for often multiple appointments in the specialist centre. In line with the realistic medicine movement of NHS Scotland we seek to refresh our outpatient model.

A modern outpatient assessment model will be patient centred, delivering streamlined care pathways, models of shared care with local and regional centres supported by an integrated patient management system, ensuring timely access to specialist care and seamless local follow up as clinically appropriate. Currently the

Service Level Agreement includes 1400 assessment slots per year, with some slots supported by imaging. The future requirements will be determined by the assessment model including consideration of what can be delivered locally. Given the growth in the ACHD population, it is anticipated that there will be a capacity gap.

In order to determine what this would look like, further work is required including:

- Patient engagement and survey
- Description of alternative clinic models
- Pilot centre testing of alternative models with PDSA feedback loops.
- Activity projections to ensure the model is sustainable and fit for the future

We have already gained the support of the GJNH executive management team. Performance and planning have committed to the improvement work and have developed a proposal for a comprehensive patient engagement project to ensure every service user will have the opportunity to share their views and experience through a variety of media including face to face meetings, telephone and MS Teams. In parallel, we are collecting data regarding the patient pathways to inform more quantitative modelling to ensure optimisation of resources.

We recognise that central to this process is defining the purpose of bringing a patient to the Golden Jubilee National Hospital for SACCS review. In addition, increasing care local to home for the patient will require increased support from the SACCS consultant cardiologists in local clinics, but this will address concerns raised by our patient groups by increasing the time invested in the local centres with education and support. We acknowledge that the model will need to be flexible, recognising the different and variable care models across local and regional health care systems in Scotland. This makes the challenge more complex, however it is achievable with robust protocols and patient pathways. The preferred model will require significant engagement with referring clinicians and Health Boards to agree safe and appropriate pathways of care and to ensure resources are aligned to the model of care.

An in-depth discussion of the current challenges and future goals for outpatient assessment can be found in appendix 1: Outpatient Assessment.

In order to achieve a contemporary model for outpatient care we require a patient management tool that is robust, resilient and accessible.

Summary of Resource Impact

i. This is dependent on the recommendation from the patient engagement and exercise, and the Review of Service which is planned.
ii. Expected to require investment in referring boards to develop the infrastructure and support to deliver care closer to the patients'

Priority 2: Patient Management System/Database/Booking system

There are a number of strands to delivering a robust solution to the data challenges -

i. **National database and development of digital solutions to populate the database**
ii. **Fit for Purpose Patient Management System**
iii. **Effective audit / benchmarking database**
iv. **Patient Portal**

i. National database

All services require data and therefore data services to deliver care. As a national service based in one health board within Scotland's 14 health boards the challenge of readily accessible data has been a long-standing problem. The need for a database recording patients with congenital heart disease from birth through to death was recognised by the National Services Division of NHS Scotland in 2017. Work was completed to described the requirements. This work stalled in 2019 and has not progressed. There is not a complete record of patients with congenital heart disease in the paediatric sector.

The digital strategy for NHS Scotland continues to evolve but is clear in rejecting plans for standalone unsupported databases.

SACCS requires data that describes, as a minimum, who our patients are by CHI number, where our patients live, and what condition they have. This database is a requirement of the standards as described by NHS Scotland.

We have an opportunity to work with the Information Services Division of National Services Scotland. As an interim solution, they have offered to develop a PowerApp for SACCS and SOCN (Scottish Obstetric Cardiac Network) that is a web-based application hosted by National Services Scotland that would allow us to upload known CHI numbers and seek our local cardiology colleagues to share their known cases also. Dr Veldtman has developed a natural language processing programming tool together with artificial intelligence that could then be used to interrogate letters to identify clinical conditions and populate a database with condition and health board. Thus with these two approaches we could improve and document our known patient population. We could then consider an annual upload of cases entering adult hood from the Scottish Paediatric cardiac service who have congenital cardiac conditions. The PowerApps project is led by Claire Lawrie at NSS, and we are actively working to progress to the next steps of the project with a descriptor of key fields.

ii. Fit for Purpose Patient Management System

An additional requirement of the standards is the ability to plan long term follow up for our patient cohort. The current patient management tool at the Golden Jubilee National Hospital is Trakcare. The current working version at GJNH is from 2012. It is recognised that for the entire organisation this historic version is limiting and an upgrade is planned imminently. It is anticipated that the updated version will allow a more efficient booking process for the administrative team.

It is imperative that the national ACHD service is supported by a robust patient management system to support an integrated assessment pathway with multiple synchronous investigations, long term follow up, and shared care with local and regional Cardiology services across Scotland.

iii. Effective audit / Benchmarking Tool

The third issue with regards to data for SACCS is the current work stream led by Public Health Scotland to describe and deliver an alternative to NICOR as a clinical audit process for cardiology and cardiac surgical work including that within the congenital heart disease arena. SACCS has a data manager who collects and collates the clinical data previously uploaded to the NICOR dataset. We anticipate working with Public Health Scotland in this important work that considers quality assurance for clinical care and will hopefully include contemporary data sharing solutions that minimise error.

To progress this work, we would suggest learning from other areas of healthcare with similar issues. We anticipate that some of the complex cancer services are also functioning at regional or national level scheduling repeat investigations at specific time intervals– i.e. routine imaging follow-up for breast cancer. Equally this work is likely to be able to translate to other areas such as evolving aortopathy services, heart failure services and valve surveillance processes.

iv. Patient Portal

The service previously piloted a version of Patient Portal. The potential benefits of this to support patients with a long term condition is widely recognised and used in other areas, including renal and cancer services. The pilot demonstrated limited benefits with the current system available, however this work should be progressed, exploring alternative suppliers to gain maximum benefit.

An additional opportunity would be to work with Intersystems who deliver the Trakcare product. This large international company has a number of additional products that could offer significant utility to our patient group without additional spreadsheets or tools. For example, the HealthShare product includes a patient portal feature and also a cohorts feature which would allow the definition of specific pathways for identified patient groups such as some of our more complex and higher risk patients with single ventricular physiologies. It may be possible for GJNH to be considered a reference centre for Intersystems products and share in the benefit of product development. This opportunity is under review with the new Director of eHealth at GJNH and is likely to depend on the wider work across the West of Scotland in the adoption of TrakCare.

Summary of Resource Impact

i. Development of Patient Management System
ii. National Database – led by NSD
iii. National Audit – ongoing commitment to submit data for benchmarking purposes
iv. Development of a patient portal

Priority 3: Advanced Imaging Capacity

The central aspect of SACCS is intervention service including surgery and catheter intervention along with well-timed pharmacological intervention. The timing of any intervention requires careful consideration of the patient’s symptoms interpolated with data from functional assessment and from high quality imaging. As the patient cohort increases in number it is important to reconsider the timing and modality of assessment. We have written lesion specific protocols to share with our local cardiology colleagues in addition to the published protocols for echocardiography in congenital heart disease. From priority 1 we will increase our support in the local clinics and echo labs.

Our previous strategy anticipated an upskilling of local radiology services to increase the case mix that could be repatriated to local teams for ongoing surveillance. It has become clear that this is not the anticipated direction for local radiology services. We would therefore propose a review of our imaging capacity at the Golden Jubilee National Hospital. Our patients need to be able to access high quality imaging at the correct time supported by high quality reporting. This is the definition of the specialist service: a service that cannot be provided out with the commissioned service. This includes most cardiac MRI and cardiac CT in congenital heart disease. Complex transthoracic echo, exercise stress echo, and transoesophageal echo are also specialist imaging assessments important in the sequential assessment of the adult with congenital heart disease, necessary as both supplementary to advanced cross-sectional imaging, but as an alternative in some cases. Investing in upscaling complex echocardiography services is thus an important strategic pillar to the increase in advanced imaging capacity.

The current challenge in advanced imaging is defining the capacity requirement which is linked to the incomplete data available. Parallel work in reviewing protocols specifically for MRI and CT is ongoing. This work seeks to define scan protocols for primary scans and sequential follow-up imaging. There is opportunity for improved efficiency in reporting with access to contemporary reporting software and reporting hardware.

The imaging service requires reorganisation in the requesting pathway, waiting list management and booking process. Within the reconfiguration there is opportunity to facilitate prioritisation of cases. This will work alongside priority 2 the patient management system.

GJNH is currently developing a strategy for cardiac imaging services to identify the national and regional priorities for imaging and to describe how the GJNH can deliver the specialist imaging and support training to complement local and regional services. The imaging requirements across the modalities to deliver a contemporary national ACHD service will feed into this overarching strategy and will help to define which specialist services should be delivered, i.e. MRI and CT, and also describe innovative technologies including 3D printing which is increasingly being adopted as a diagnostic tool for congenital heart disease. Again in line with the growing ACHD population and the increasing complexity, it is anticipated that the demand for specialist imaging will grow, whether this is delivered locally or in a specialist centre.

Summary of Resource Impact

i. Increase in MRI scanning and reporting capacity to 1000 scans per annum
ii. Increase the CT capacity and provide resilience around the reporting
iii. CPET – Review SLA with GGC to increase capacity
iv. Echo – Review demand and capacity – will be informed by the outpatient review recommendations re model of service

Priority 4. EP Capacity

There is currently a limited service for the complex congenital patients requiring an Electrophysiology (EP) procedure. Given the complexity, it is beneficial for the patients to be discussed at an MDT and a plan agreed between the EP and the SACCS clinical teams, with congenital expertise available during the procedure.

The GJNH is ideally placed to deliver this service, as the host of the SACCS, and with an established regional EP service, with EP clinicians with congenital expertise. Other Scottish centres are unwilling to perform EP Procedures on Adult Congenital Heart Disease (ACHD) patients due to lack of expertise, no MDT process and no ACHD surgeon or Cardiologist on site for urgent advice or procedures should there be complication. To date, limited national EP provision has been funded as part of the SACCS service, however the current funded service of one list per month is insufficient to meet the demand.

Establishing a robust national ACHD EP service will significantly improve the pathway for this cohort of patients, improving access – both geographical and reduced waiting times.

Summary of Resource Impact

i. 1 staffed cath lab – 12 full days per annum
ii. Anaesthetic cover
iii. Medical cover – dual operator
iv. Ward nursing

Priority 5. Inpatient Service

The inpatient service for SACCS comprises the *surgical* pathway, the *cath lab* pathway including diagnostic, interventional, electrophysiological and pacing, and the *medical* pathway. Our current demand on inpatient beds exceeds the capacity allocated. The majority of the disparity is in the medical pathway and reflects increasing referrals of patients with complex ACHD and decompensated heart failure, arrhythmia, pulmonary hypertension and endocarditis.

The majority of these patients have been admitted to a local hospital and stabilised. The local ACHD team refer the patients to the SACCS for complex assessment and management. The increasing numbers reflect the changing population cared for by SACCS.

An additional inpatient requirement is for patients with complex ACHD who require non-cardiac surgery but with the support of our cardiac anaesthetic and critical care teams in association with the SACCS team. The type of surgeries include cholecystectomy in Fontan circulation, oesophageal stenting in Eisenmenger syndrome, dental work in our learning disabled population with complex cardiac conditions and orthopaedic surgery in advanced ACHD. Included in the non-cardiac surgeries are a cohort of our Fontan patients who develop hypervascular liver lesions that can progress to hepatocellular carcinoma. They require liver biopsy as radiologic features as not definitive in a Fontan physiology, +/- microwave ablation. This is a specialist procedure that requires anaesthetic and critical support. The SACCS service supports these cases at the GJNH allowing access to the specialist expertise of our Cardiac Anaesthetic and Critical Care teams, and Dr David Kay from GGC, Consultant Radiologist who is a national expert in biopsy and ablation of hepatocellular carcinoma. The patients are admitted under the care of SACCS and require post-procedural care in HDU.

The inpatient service is significantly more robust and efficient with the consultant of the week model within the SACCS cardiology team. There is now a 24-hour a day 7 days per week model of on-call support which is accessible across the country. This seeks to minimise delay to care and thus shorten inpatient stay.

The cardiac surgical pathway admits the patients to ward 3E then post-operatively through ICU, HDU and back to 3E. In 3E the nurses strive to cluster the SACCS patients within 1 area as this increases the opportunity for teaching and improves communication. We have ongoing teaching to the 3E nursing staff and advanced nurse practitioners.

The NSD pod off 3 West is significantly oversubscribed by all 3 of the specialist services commissioned by NSD. We would seek that any uplift in beds is aligned with the needs of all 3 services as the nursing demands are translatable across all 3 national services.

Summary of Resource Impact

A separate piece of work is progressing to review the bed utilisation and projected capacity requirements across the 3 NSD specialties hosted at GJNH.

Priority 6: Workforce

As described in Appendix 1, the ACHD service is delivered by a multidisciplinary team including medical, nursing, AHPs and Health Care Scientists administrative support. The population is growing as patients are surviving longer, and with this, increasing complexity of disease. The service has recently successfully recruited to increase the specialist cardiology and imaging resource in addition to recent recruitment of a dedicated psychology resource. However, it is recognised that as we progress the priorities described above; developing a modern outpatient assessment service with appropriate specialist imaging and inpatient capacity, there will be opportunities to modernise the workforce to align with redesigned patient pathways. The key areas for development and review are discussed in more detail below

i. Medical

Consultant

The service appointed a fifth ACHD consultant cardiologist in 2019 in agreement with NSD following the Peer Review, to strengthen the team and provide sustainability. The appointment has enabled the service to expand and deliver improved patient pathways, and is required to deliver a modern and comprehensive ACHD service fit for the future. This post has continued to be funded by GJNH as a cost pressure, and is a priority to be funded substantively and recognised as core to the service.

Junior Staff

Currently, GJNH has established clinical fellow posts that provide junior medical cover throughout the day and night across cardiology services. SACCS has specific funding for 2 of these posts.

Because of changes in junior doctor training it has become more difficult to recruit to these posts by the conventional pathways. At the same time, with the successful recruitment to the consultant cardiology posts within SACCS, we have a different cohort of clinicians contacting us seeking senior level specialist training in ACHD. This group of **advanced ACHD cardiology trainees** are more typical of those found within specialist centres caring for adults with congenital heart disease however such units have additional junior staffing for the day-to-day ward work.

Advanced trainees would offer increased functionality to the specialist service by being able to participate in outpatient clinics, advanced investigations and interventions. In addition, it would be usual for them to be involved in audit and research which again would be a significant contribution to the specialist service. Perhaps most importantly though, this would provide a vehicle for succession planning and ultimate sustainability of the service as trainees exposed to ACHD early on their training, then have the opportunity of potentially pursuing this in the longer term as a career choice.

Therefore, the priority for the service is to work in consort with the wider cardiology group to ensure junior level service provision whilst developing attractive senior fellow posts that would be advertised and appointed by competitive interview from an international range of applicants.

We recognise that the advanced heart failure service has already moved towards a similar model which followed the industry sponsored fellow in devices and electrophysiology. The coronary intervention service has an international reputation that also would benefit from the opportunity of more senior fellows.

In progressing this piece of work we need to understand the interface between GJNH and the West of Scotland Deanery of NES in the provision of junior doctor training, and also the potential to further extend the advanced nurse practitioner roles which have been successfully employed in the cardiac surgical wards at GJNH. It is worth highlighting that the curriculum requirements for specialist training in cardiology would be well supported by more formal rotation through the cardiology services from cardiac catheter lab to imaging and the acute care provision in coronary care and intensive care. Thus engagement with the training programme director will also be important.

Skilled support for our Consultant Congenital Cardiac Surgeons has long been recognised as key to successful procedural outcome. Almost 5 years ago funding was identified from NSD for **Congenital Cardiac Surgical Fellows**. Unfortunately, that has not translated into support within the adult congenital cardiac programme. It is a priority for the ongoing surgical programme to ensure that there is equity of access to the congenital cardiac surgical Fellows across paediatric cardiac services and the SACCS. Further discussion with the Scottish Paediatric Cardiac Service and the NSD we will seek to redress the balance. The role of the surgical fellow would be within the theatre environment and also importantly on the ward, critical care areas and outpatients. The fellow would seek to ensure continuity of care and communication with the consultant surgical team.

ii. Nursing

There is also a need to define the nursing workforce required to support specialist care delivery at GJNH as well as develop local ACHD nursing expertise. This includes the role of the ACHD clinical nurse specialists: education strategy, participation in research, core work shared across the team and definition of advanced practice roles that support service. A UK scoping of ACHD nursing is currently underway and work is being undertaken with NHS England to identify the role nurses and AHP can play in sustainable care for the ACHD population. SACCS should continue to engage with this process and alongside Clinical Nurse Management within GJNH and NSD, complete work to provide a strategy for ACHD nursing in Scotland across specialist and local care. This will provide the evidence needed for ACHD nursing to be identified as a priority in 2024 to enhance the ACHD workforce required to meet the needs of the growing ACHD population

iii. Diagnostic Teams

The workforce required to support the diagnostic and assessment pathways will be defined as part of the work to progress the outpatient assessment and the cardiac imaging models.

iv. Administration

The SACCS administrative team provide essential secretarial and booking support to the service. With the appointment of three new consultant posts in the past 2 years there has been a significant increase in the clinical and admin workload. The increase in admin work has been absorbed by the existing staff as best as possible however, it has stretched resources beyond capacity and frequently resulted in significant delays to typing and, on occasion, lost appointment slots.

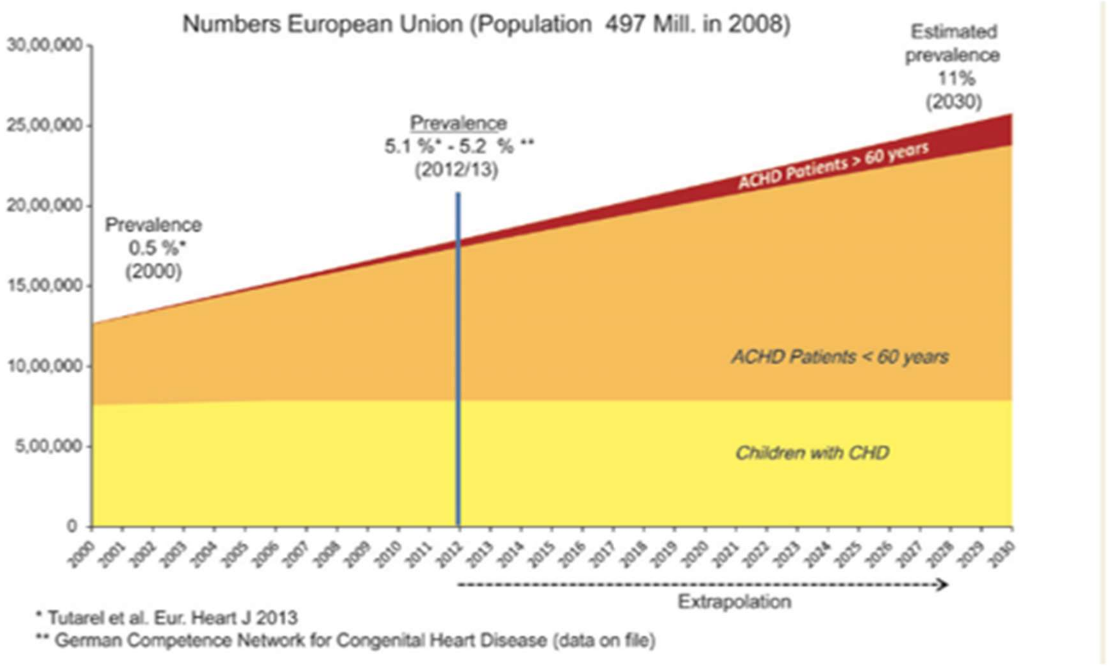
Developing a sustainable admin workforce and patient management system that supports an effective booking process has been identified as a priority.

Summary of Resource Impact

i. 1 wte Consultant Cardiologist – in post
ii. Junior Doctor Redesign to attract more senior applicants
iii. Nursing – align with the UK scoping work to be completed and local ACHD nursing strategy to be developed in 2024
iv. Diagnostic Team – as per Priority 3
v. Increase administration support and maximise opportunities offered by digital solutions

Priority 7. To request redefining of the national service and the introduction of a network model of care

The overview of SACCS provides a comprehensive description of the ACHD population. It is recognised that there will be a continued growth in the adult congenital population both in terms of patient numbers and also in terms of lesion complexity and comorbidities as a direct consequence of improvements in the diagnosis and treatment within paediatric cardiac centres. The potential scale of the growth is demonstrated in Figure 1, from a publication in 2014 *(H Baumgartner. Geriatric Congenital heart disease: a new challenge in the care of adults with congenital heart disease. Eur Heart J 2014;35:683-85)*. English prevalence was estimated in 2018 at more than 4 per 1000 adults The graph below indicates a projected growth in adult congenital cardiac patients reaching a prevalence of 11% in 2030. The current adult population of Scotland is 4,575,906 which would equate to an ACHD population of 50,334 with 5033 deemed to have complex disease – compared to current estimate of 1831 based on 4/1000 prevalence and 10% being in the complex category. Significant planning and redesign is required to ensure services are expanded to meet the needs of the growing ACHD population.



The current model is not sustainable to deliver care. In order to continue to deliver high quality care to the rapidly increasing ACHD population, a more robust shared care model is require whereby patients are supported to a greater extent by local provision. This will require investment in local cardiology and diagnostic services and a network approach to be adopted, similar to the model in NHS England.

A major review of the congenital heart disease services in Scotland has been commissioned, and a key priority for the service, will be a redesign of the current patient pathways to increase the safe management of simple and moderate lesions in local services.

Conclusion

Whilst these are the key priorities for SACCS in the next 3 years, it is critical that the ongoing work around an adequate administrative team along with a robust dictation service is completed with urgency. In addition, SACCS now has 5 consultant cardiologists with the frustration of inadequate physical clinic capacity and this requires immediate resolution.

There is real enthusiasm and dynamism within the SACCS service. We look forward to working with the wider teams and operational management and performance and planning as we seek to deliver and improve care for our patients. Ensuring engagement of patient representatives will be central to this workflow and the assessment of each cycle of change.

Appendices:

Appendix 1: overview of SACCS

Appendix 2: gap analysis of SACCS with NHS Scotland Standards for specialist centre for ACHD

Appendix 3: education strategy for SACCS 2021

Appendix 4: research strategy for SACCS 2021

Appendix 5: annual report for SACCS 2020-21

Overview of SACCS in 2021

Introduction

The Scottish Adult Congenital Cardiac Service aims to provide the highest quality specialist care to adults with congenital heart disease in Scotland irrespective of geographical location. The approach combines a comprehensive, multidisciplinary assessment with specialist congenital cardiothoracic surgical and catheter interventional expertise. The adult team works closely with the Scottish Paediatric Cardiac Service at the Royal Hospital for Children. SACCS aims to assess adults with congenital heart disease (ACHD) to improve life expectancy and quality of life by:

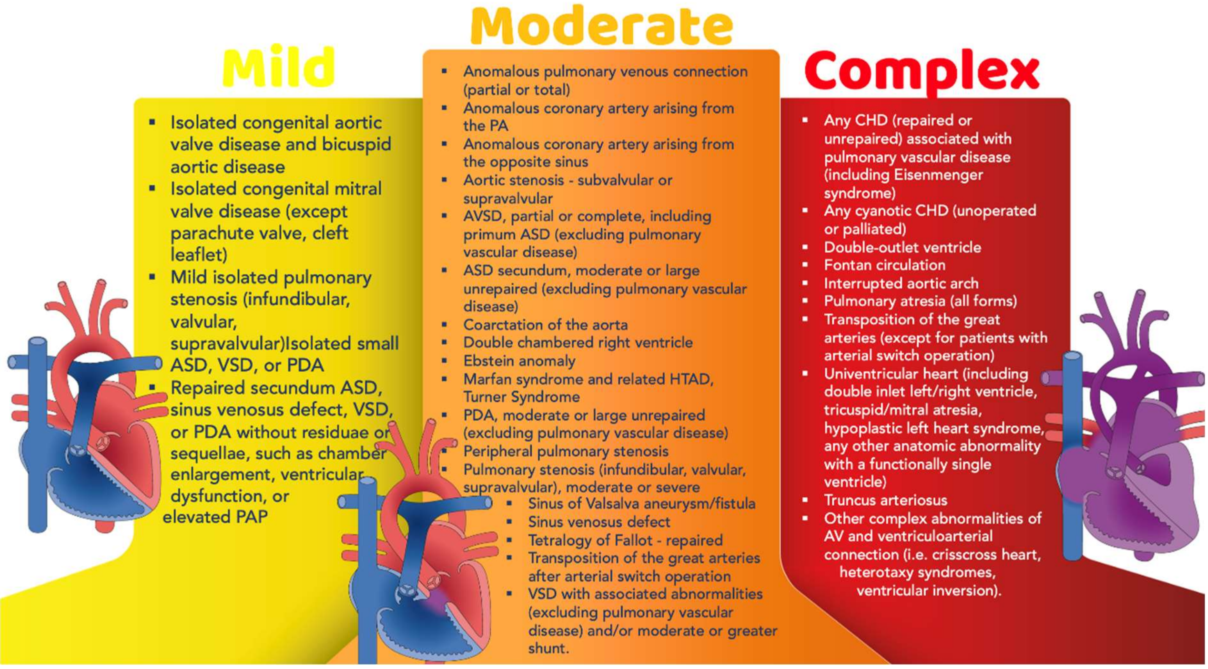
- ensuring smooth transition from paediatric to adult care
- providing timely and accurate diagnosis with anatomical and functional assessment
- agreeing multi-disciplinary treatment plans with patients and their families
- undertaking safe and effective congenital heart surgery and catheter intervention
- ensuring care co-ordination that meets the informational and psychological needs of patients and their families

The service is provided for adults who are resident in Scotland with complex congenital heart disease. Congenital heart disease can be diagnosed antenatally, during childhood or be undetected into adult life.

Many patients with congenital heart disease require ongoing specialist input to monitor the consequences of the underlying anatomy and residual lesions following earlier intervention. The major goal of ACHD care is to maintain cardiac function, thereby maximising the quality and longevity of life. For a proportion of these patients, repeated highly specialist interventions, including surgery, may be required to achieve this aim. A complicating factor in many situations is the lack of evidence clarifying the timing of intervention.

Congenital heart disease is a spectrum of conditions where altered cardiac structure impacts on physiological function. The conditions are classified by complexity according to the Bethesda classification (Warnes CA et al, JACC (2001) 37; 5: 1161-1198) and used in the ESC guidelines on ACHD from 2020:

Appendix 1 – Overview of SACCS



Mild

- Isolated congenital aortic valve disease and bicuspid aortic disease
- Isolated congenital mitral valve disease (except parachute valve, cleft leaflet)
- Mild isolated pulmonary stenosis (infundibular, valvular, supravalvular)Isolated small ASD, VSD, or PDA
- Repaired secundum ASD, sinus venosus defect, VSD, or PDA without residuae or sequellae, such as chamber enlargement, ventricular dysfunction, or elevated PAP

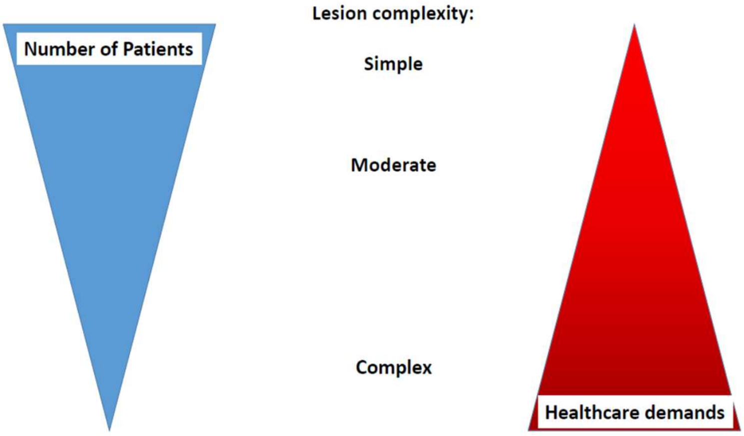
Moderate

- Anomalous pulmonary venous connection (partial or total)
- Anomalous coronary artery arising from the PA
- Anomalous coronary artery arising from the opposite sinus
- Aortic stenosis - subvalvular or supravalvular
- AVSD, partial or complete, including primum ASD (excluding pulmonary vascular disease)
- ASD secundum, moderate or large unrepaired (excluding pulmonary vascular disease)
- Coarctation of the aorta
- Double chambered right ventricle
- Ebstein anomaly
- Marfan syndrome and related HTAD, Turner Syndrome
- PDA, moderate or large unrepaired (excluding pulmonary vascular disease)
- Peripheral pulmonary stenosis
- Pulmonary stenosis (infundibular, valvular, supravalvular), moderate or severe
- Sinus of Valsalva aneurysm/fistula
- Sinus venosus defect
- Tetralogy of Fallot - repaired
- Transposition of the great arteries after arterial switch operation
- VSD with associated abnormalities (excluding pulmonary vascular disease) and/or moderate or greater shunt.

Complex

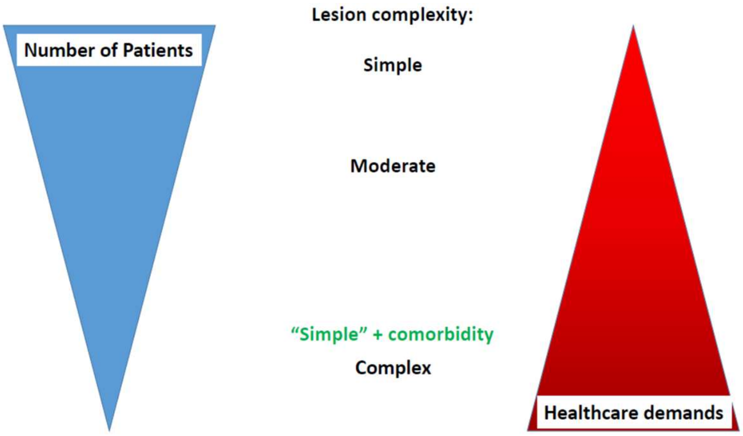
- Any CHD (repaired or unrepaired) associated with pulmonary vascular disease (including Eisenmenger syndrome)
- Any cyanotic CHD (unoperated or palliated)
- Double-outlet ventricle
- Fontan circulation
- Interrupted aortic arch
- Pulmonary atresia (all forms)
- Transposition of the great arteries (except for patients with arterial switch operation)
- Univentricular heart (including double inlet left/right ventricle, tricuspid/mitral atresia, hypoplastic left heart syndrome, any other anatomic abnormality with a functionally single ventricle)
- Truncus arteriosus
- Other complex abnormalities of AV and ventriculoarterial connection (i.e. crisscross heart, heterotaxy syndromes, ventricular inversion).

There are more patients with simple conditions than complex conditions as illustrated below.



However, if there is significant consequence of a simple lesion, for example pulmonary hypertension causing the Eisenmenger syndrome in a ventricular septal defect, then this patient becomes complex in their healthcare needs.

Appendix 1 – Overview of SACCS



It was long believed that the survival of these simple lesions when treated was likely essentially normal. However, a large systematic review found that survival was decreased in all forms of congenital heart disease. It was specifically noted that patients with mild or simple congenital heart disease were under represented in the literature and had poor survival than in the general population (Verheugt CL et al Int J Cardiol 2008, 131; 25-32). Interestingly a follow-up paper by the same group demonstrated that the risk of death in those with simple congenital heart disease was double the risk of the general population at a median age of 47. The risk of sudden unexpected death was increased 4-fold and the risk of cardiac death 6-fold. It was also noted that there was a 6-fold increase in the rates of morbidity in particular increased rates of cardiac surgery, heart failure, endocarditis, pulmonary hypertension, ventricular tachycardia and stroke (Videbaek J et al Circ 2016). **This data is an example of the need for a coordinated approach to the care of adults with congenital heart disease across Scotland to ensure an optimal outcome for all.** The approach to care should be based on a realistic medicine approach striving to deliver the correct level of care as close to home as possible for each individual but ensuring opportunity to escalate the specialist review in a timely fashion.

SACCS have been early adopters of the realistic medicine approach to care planning and offers shared care with local units with the aim of providing specialist input when required and allowing the patient to have a well-informed local service to provide more immediate support. A key component is specialist support of local services with attendance to local ACHD clinics by SACCS clinicians. If the result of the assessment is to offer intervention, this is taken forward. Local care is then continued in between the assessment and treatment visits.

The core activity of SACCS is the multidisciplinary assessment of patients. Specialist investigations such as cardiac MRI and CT, cardiopulmonary exercise testing and cardiac catheterisation are combined with detailed clinical assessment and multidisciplinary review to define the care plan and to decide whether intervention is indicated. In many patients, serial assessment is necessary, the interval varying from 1 to 5 years to determine change so that the optimum timing for intervention can be determined. In order to plan and deliver serial assessment a well-functioning database is essential to ensure loss to follow-up is avoided whilst facilitating planning of healthcare resource.

SACCS Population

Congenital heart disease remains the commonest birth anomaly with, on average 1 in 145 live births affected. A wide variation in complexity is seen and, fortunately, changes in many cases are minor and do not require treatment. For those patients requiring intervention, modern paediatric cardiac practice has had a major impact on outlook, with survival to adulthood increasing from less than 20% to over 85%. Adults with congenital heart disease (ACHD) therefore represent a new and rapidly growing population directly reflecting the major improvement in paediatric care. This is also reflected in the youth of the population with the commonest age group between 21 and 25 years. Most of the ACHD population are working full time and many are supporting young families.

The demographics of congenital heart disease are changing due to increasing survival of children into adult life. There are increasing numbers of adults with congenital heart disease with the English prevalence in 2018 estimated at more than 4 per 1000 adults. The number of patients with complex disease is increasing with 10% of the adult congenital heart disease population now falling within the complex group.

Using these statistics and the current population statistics of Scotland (2019) having a population of 5,454,000 with 83.9% age 16 or over (adult population of Scotland = 4,575,906), then there are 18,304 adults with congenital heart disease in Scotland with 1,831 deemed to have complex disease. However, contemporary epidemiology research published in Circulation in 2016 indicates that the prevalence of congenital heart disease is 0.8% of the population with 0.1% falling into the severe category, then the total number of adults with congenital heart disease is (0.8% of adult population) = 36,480 and the total adult population with severe ACHD is 4,560.

Appendix 1 – Overview of SACCS

Population of USA in **2010**
309.3 million
2.4 million affected
= 0.8% of the population
= **Scotland 42,400**

5% annual growth
2021 = 72,520 all ages

300,000 with **severe** CHD
= 0.1% of the population
= **Scotland 5,300**

5% annual growth
2021 = 9,065 all ages

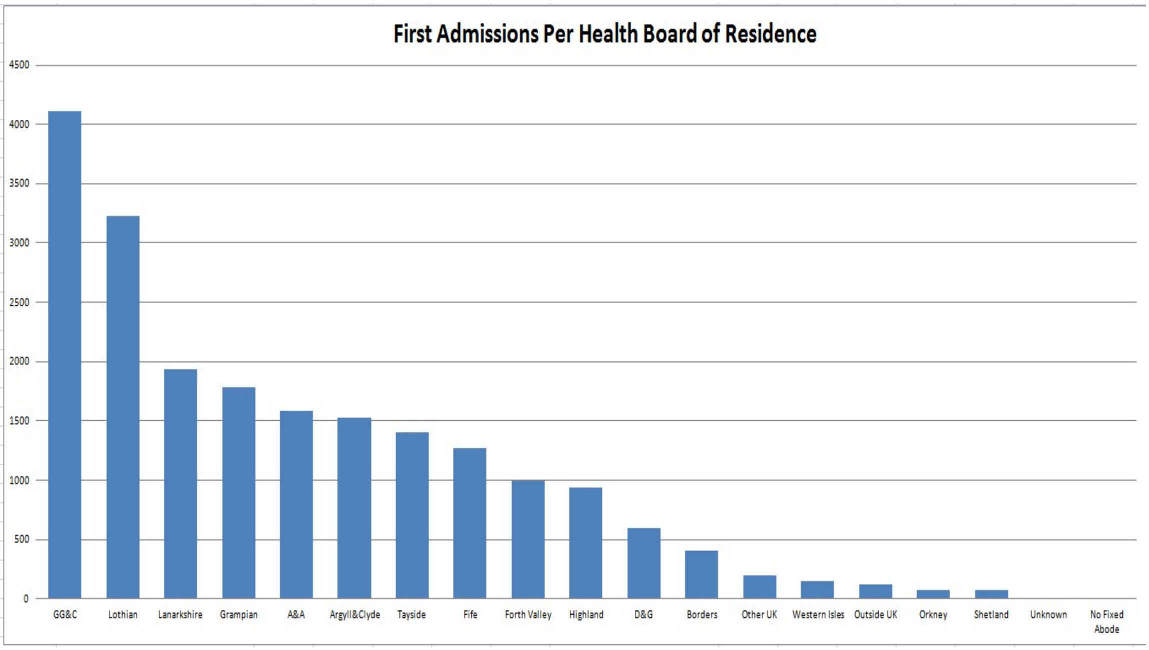

Circulation. 2016;134:101–109. DOI: 10.1161/CIRCULATIONAHA.115.019307

Description of the population

Adults with congenital heart disease live throughout Scotland. In line with many adult units we do not have complete data about the cohort of patients across the spectrum of congenital heart disease within Scotland. This is a consequence of loss to follow-up over many years compounded by inadequate data capture. One of the key themes going forward will be improved data base utility to ensure the correct patients have access to care and facilitate planning of healthcare resource.

From the inception of the Scottish Adult Congenital Cardiac Service there has been question about a perceived West-centric bias in the population under review. In 2015 a dataset was extracted from the Information Services Division of National Services Scotland that captured individuals admitted to Scottish hospitals with a diagnosis of congenital heart disease. The period of review was 25 years. This data has been analysed and demonstrates that there appears to be excess of cases within the West of Scotland. This data is demonstrated in the table below. When one considers the proportion of health board populations caring for the Scottish population in general, the difference is less striking: West (including GGC, FVRH, Lanarkshire, A&A, DGRI) = 49%; SEAT (Lothian, Borders, Fife and Tayside) = 33%; North (Highlands and Grampian) = 18%. The main difference is noted is an excess in the West of Scotland with a reduction in North cases. Because of the geography involved it may be that patients who live in Argyll and Bute for example are cared for in West of Scotland hospitals rather than Highland health board hospitals. Further assessment of these differences is required. It does however appear that the location of the National service is appropriate. Knowledge of the distribution of admissions is helpful. Outreach services are however planned on general population numbers rather than the admission numbers.

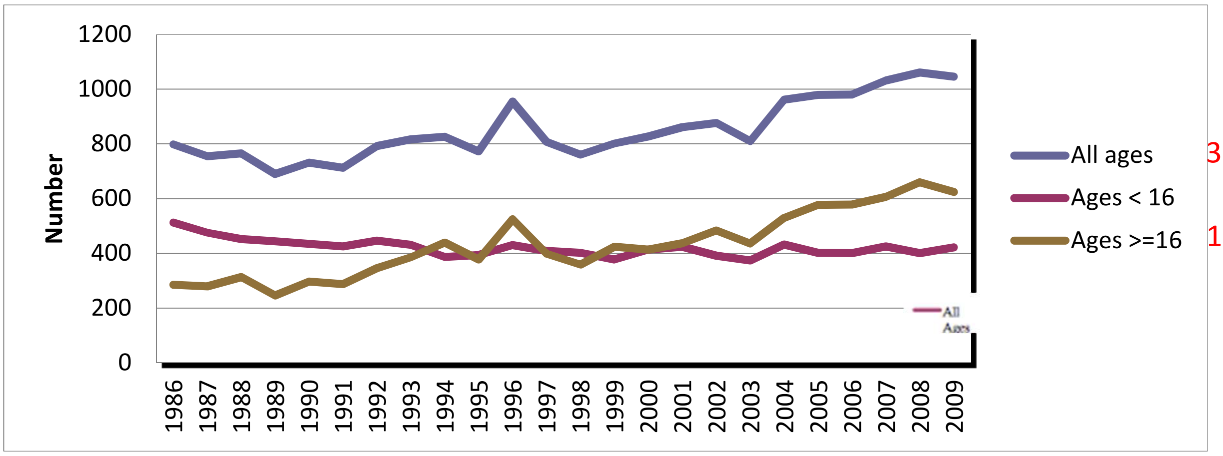
Appendix 1 – Overview of SACCS



Estimated population from this data:

West	54.6%
SEAT	31.9%
North	13.4%

Congenital heart disease is by definition a condition present from birth. In the data available from the ISD data extraction, the population of patients under 16 is static over the 25 years studied. The population of patients in the adult cohort is increasing. This is demonstrated in the graph below.

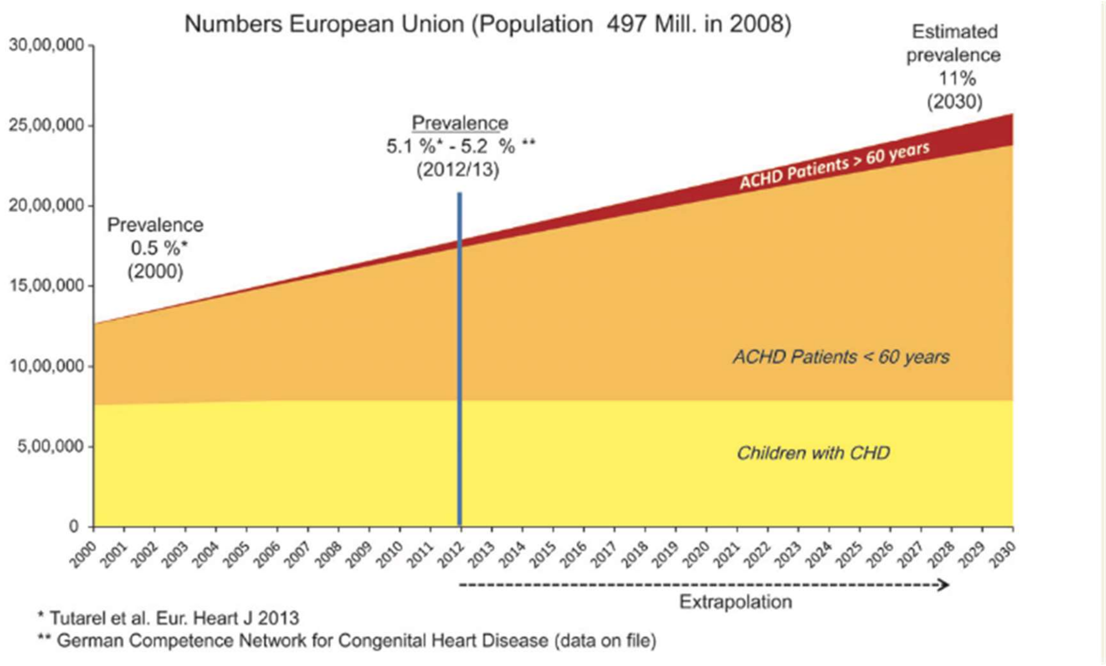


30% change

119% change

The growth and population of adult congenital heart disease is recognised internationally as demonstrated in this graph from a publication in 2014 *(H Baumgartner. Geriatric Congenital heart disease: a new challenge in the care of adults with congenital heart disease. Eur Heart J 2014;35:683-85)*. It is recognised that there will be continued growth in the adult congenital population both numerically in terms of patient numbers and also in terms of lesion complexity and comorbidities. This is a celebration of paediatric cardiac services. It does however require significant planning to ensure ongoing care to the adult years.

Appendix 1 – Overview of SACCS



* Tutarel et al. Eur. Heart J 2013

** German Competence Network for Congenital Heart Disease (data on file)

Current Pathways of Care

The section above highlighting the increasing patient population evidences the need to redefine the specialist service that SACCS is commissioned to provide. The increase in specialist Cardiologists is well-timed to enhance the support to local ACHD teams, allowing more of the care to be provided locally, and ensuring that the patient's benefit in attending GJNH is clear for all.

SACCS at GJNH offers a specialist service for the ACHD population in Scotland. This is described as follows:

Assessment:
- Clinical opinion
- Advanced care planning
- Pre-pregnancy counselling
- Multidisciplinary team review

Anatomical assessment:
- Echo
  - Transthoracic echo (TTE)
  - Stress TTE
  - Contrast TTE
  - Transoesophageal echo (TOE)
- CT
- MRI
  - Cardiac MRI
  - Stress MRI
    Physiological
    Pharmacological

Functional assessment:
- 6 minute walk test
- Cardiopulmonary exercise test

Haemodynamic assessment:
- Cardiac catheterisation
  - Stress cardiac catheterisation
    - Physiological
    - Pharmacological

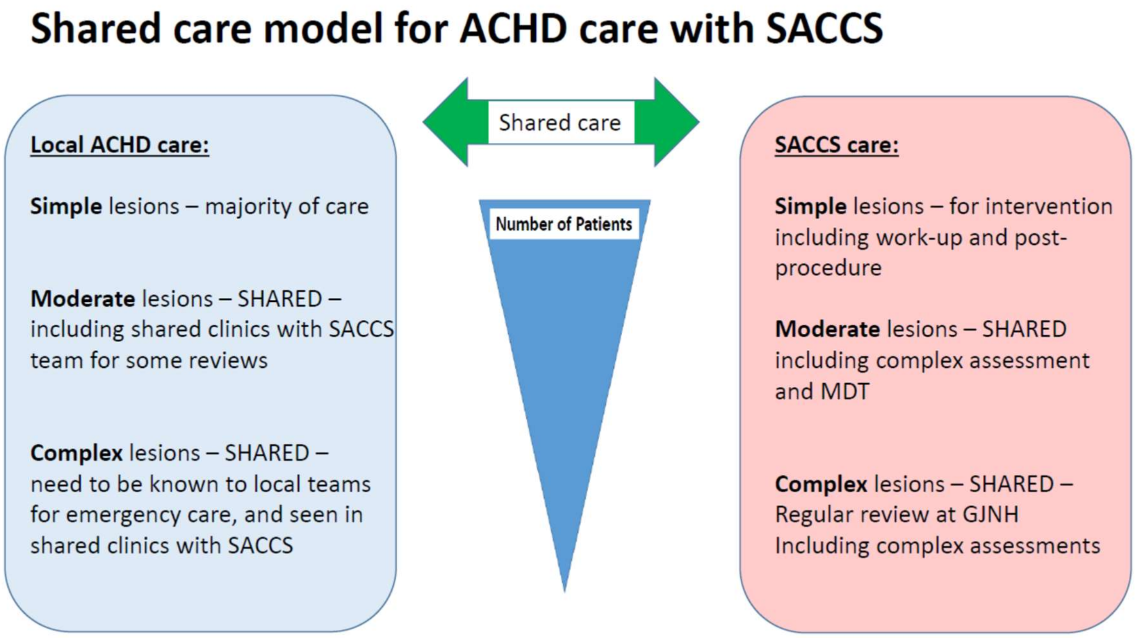
Intervention:
- Catheter based structural intervention
- Electrophysiological studies +/- ablation
- Complex pacing

- Surgical interventions
  - Structural
  - Electrophysiological
  - Device based
    - Pacemaker
    - ICD

- Non-cardiac surgical interventions
  - General surgery
  - Obstetric

Appendix 1 – Overview of SACCS

It is essential that patients are known to their local Cardiology teams as this is the location for their emergency admission and non-cardiac presentation. SACCS Cardiologists support shared clinics in local centres to assist in the shared care. These clinics offer the patient local review and the local teams access to education and update in the management of ACHD patients.



Shared care model for ACHD care with SACCS

Local ACHD care:

Simple lesions – majority of care

Moderate lesions – SHARED – including shared clinics with SACCS team for some reviews

Complex lesions – SHARED – need to be known to local teams for emergency care, and seen in shared clinics with SACCS

SACCS care:

Simple lesions – for intervention including work-up and post-procedure

Moderate lesions – SHARED including complex assessment and MDT

Complex lesions – SHARED – Regular review at GJNH Including complex assessments

Position against the standards (see appendix 2 for detailed gap analysis)

Adult congenital heart disease (ACHD) is the success story of paediatric cardiac services. The increasing population of adults with congenital heart disease and particularly the increasing complexity of conditions, and associated comorbidity, reflects improvements in the surgical, anaesthetic, critical care, medical and diagnostic care work within paediatric cardiac centres. ACHD centres around the world, including the United Kingdom, describe both a numerical and complexity increase in this patient group.

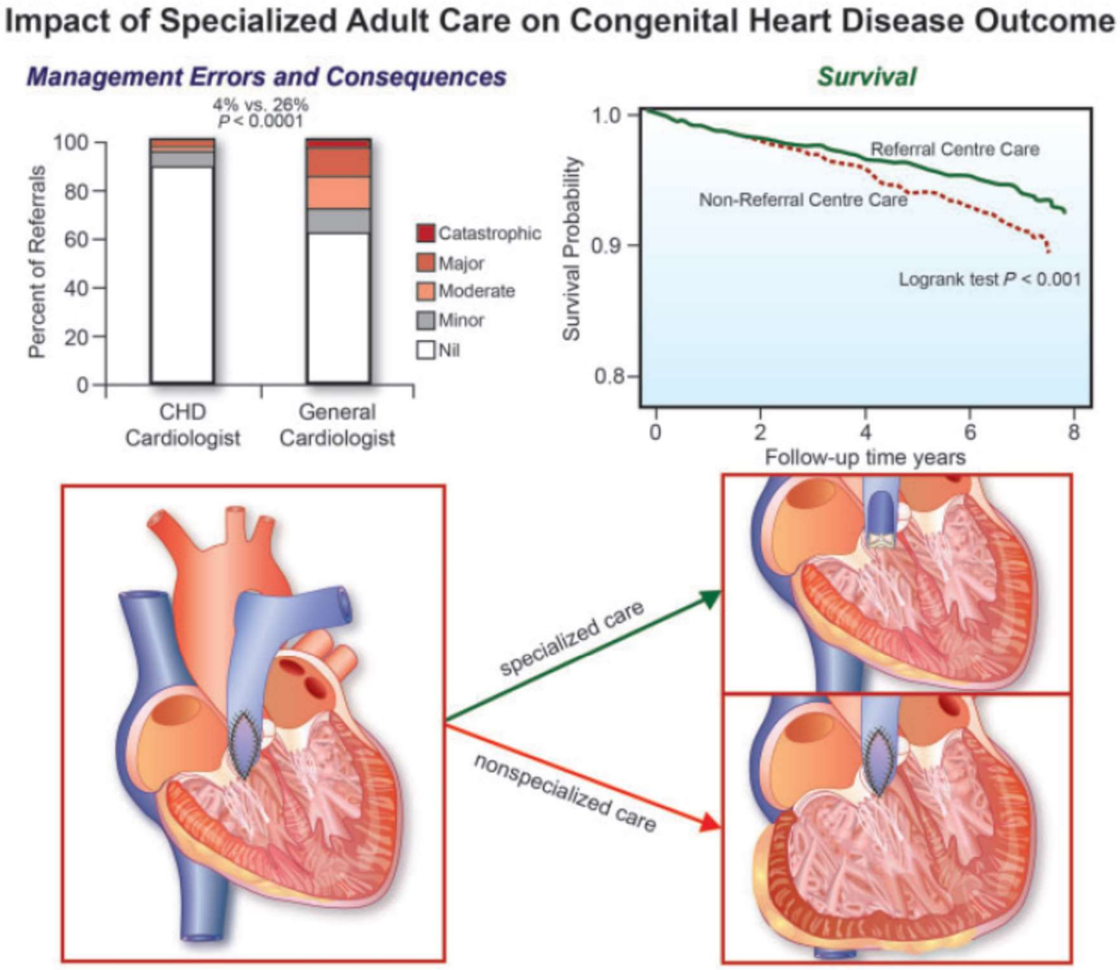
The majority of adults with congenital heart disease are well and in full-time employment. They are busy living their lives. Despite this, long-term specialist surveillance is essential to proactively identify changes in anatomy or physiology that may lead to cardiac morbidity and mortality.
The Scottish Adult Congenital Cardiac Service (SACCS) was commissioned in 2007 in response to a document from the British Cardiac Society. Within the United Kingdom, there has been significant review of congenital cardiology services under a number of guises including the "Safe and Sustainable" review process. In 2016 NHS England launched the congenital heart disease standards and specifications. These were reviewed in NHS Scotland and Scottish standards for congenital cardiac care were released in 2018. The commission of SACCS specifically highlights the long-

term care of adults with complex disease. It also states that all adults with congenital heart disease should have access to the specialist National service.

The utility of the standards is in describing the scope of the commission of the National service, and in reassuring patients that the service commissioned by NHS Scotland is comparable to the specialist services in NHS England in Wales. The standards relate to the specialist commissioned service. Standards have been described for local services however as the local services are not commissioned it is more challenging to incorporate them into practice. Work has been initiated through health improvement Scotland to describe key performance indicators that will seek to ensure the standard of local ACHD services around Scotland.

The benefit of specialist ACHD care as described by standards and guidelines was studied. In 2014 Mylotte et al (Circulation 2014 May 6;129(18):1804-12.) published a study of the impact of the implementation of guidelines into practice. The mortality benefit of specialist care complying with guidelines was striking and in excess of many pharmacological therapies marketed. This was further reviewed in 2018 demonstrating the impact of specialist care in ACHD with the results summarised in the panel below. This data highlights to clinicians, commissioners and patients the benefit of access to specialist ACHD care.

Appendix 1 – Overview of SACCS



European Heart Journal (2018) **39**, 990–992

Benchmarking

The requirements to provide service for the adult congenital heart disease population within the NHS healthcare system were further described by a benchmarking process in 2018 comparing NHS Scotland with 3 comparable healthcare regions in NHS England - the Southwest network base in Bristol, the Royal Brompton and Harefield service in London, and Guy's and St Thomas's in London. The data collected is described in the table below. It should be noted that none of the services felt that they were at full capacity in terms of resource. It is also noteworthy that the funding of healthcare within NHS England are significantly different to NHS Scotland.

The NHS England centres work within commissioned networks with specific management structure that delivers a certain economy of scale in terms of audit, governance, research, education and strategic planning.

Appendix 1 – Overview of SACCS

	Bristol **5.5 million**	**Brompton** **6.5 million**	**St Thomas** **5 million**
On call	1:6 (5WTE cons and 1 post CCT fellow)	1:5 (but recruiting to 6) (plus PH, SBN and WLi)	1:5 (recruiting to 6 and 7 in 2020) (plus SK & ER)
Clinics	10 per week (6-8 per clinic) inc pregnancy fortnightly and aortopathy	6 (8 per clinics) + pregnancy weekly and alt weekly, PH weekly, Aortopathy alt weeks PLUS DAYCASE	2 clinics per consultant inc aortopathy, PH, Obs, Transition, Intervention
Outreach	6-7 clinics per consultant per year	No	25 all day clinics per year between 4 centres
Nurses	3 (but actively recruiting 2-3 more)	3 for transition (PH separate) 3 for ACHD	5 WTE
Nurse led clinics	Post op and Minor lesions	Transition daily Post procedure Daily telephone clinics	Developing
Imagers	3 radiologists for MRI and CT	1 FT for MRI and 3 others, CT separate	3 – Cardiologist and radiologist plus fellows
Trainees	2 fulltime SpR	3 fulltime SpR and 2 SHO	1 fulltime SpR
In patients	3-4 medical plus 3-4 surgical	10-15 inc surgical	4-8 inc surgical
MDT	2hrs per week but needs more	9-mins per week 7-8 cases also PH MDT	2hrs weekly 6 cases - needs more

Appendix 1 – Overview of SACCS

Novel classification integrating anatomy and physiology:

In recognition of the increasing population of adults with congenital heart disease, international guidelines have described the need to base service planning not just on anatomic lesion but rather the complexity index that integrates anatomy with physiological consequence. This AP index is described below:

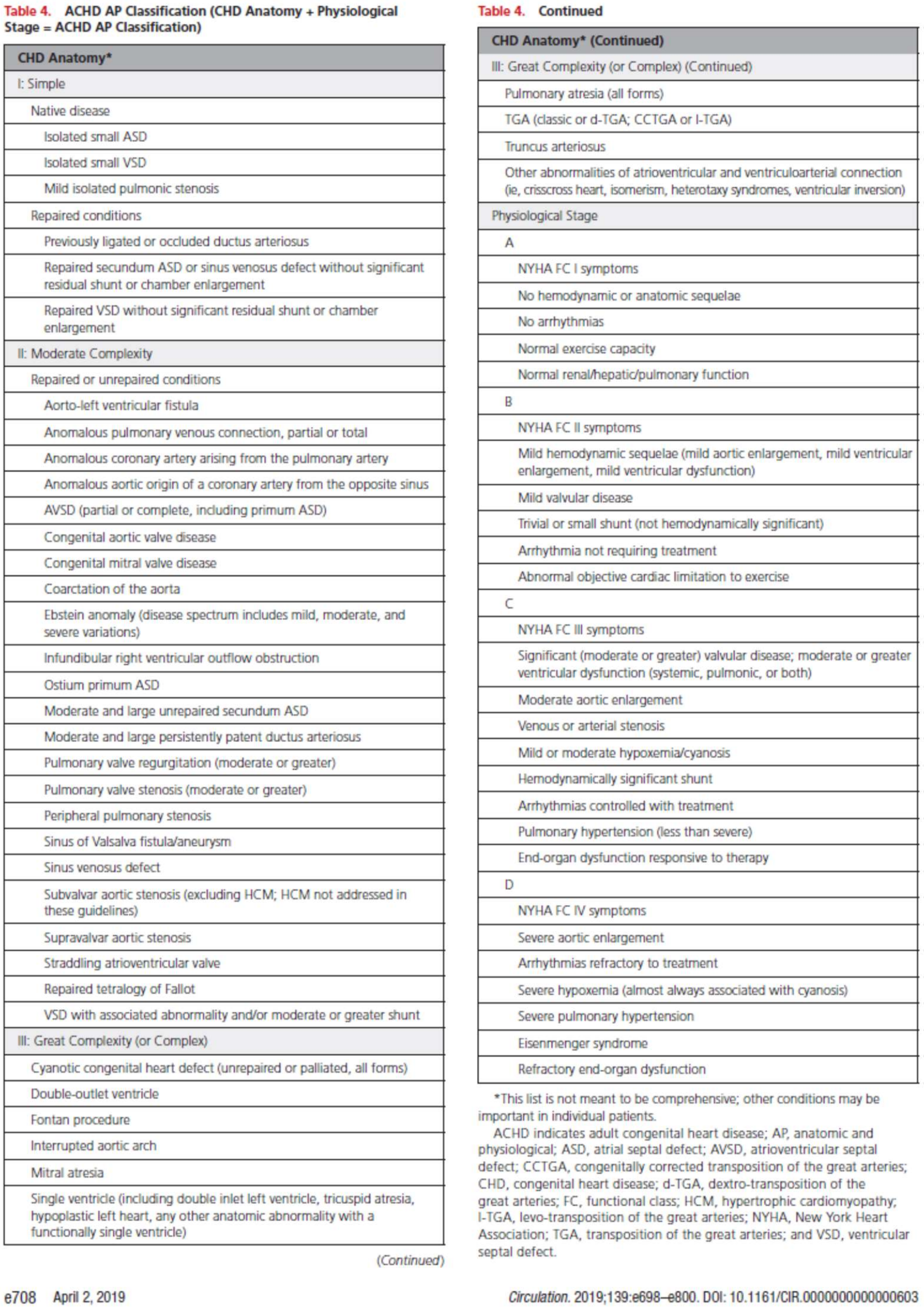


Table 4. ACHD AP Classification (CHD Anatomy + Physiological Stage = ACHD AP Classification)

CHD Anatomy*
I: Simple
Native disease
Isolated small ASD
Isolated small VSD
Mild isolated pulmonic stenosis
Repaired conditions
Previously ligated or occluded ductus arteriosus
Repaired secundum ASD or sinus venosus defect without significant residual shunt or chamber enlargement
Repaired VSD without significant residual shunt or chamber enlargement
II: Moderate Complexity
Repaired or unrepaired conditions
Aorto-left ventricular fistula
Anomalous pulmonary venous connection, partial or total
Anomalous coronary artery arising from the pulmonary artery
Anomalous aortic origin of a coronary artery from the opposite sinus
AVSD (partial or complete, including primum ASD)
Congenital aortic valve disease
Congenital mitral valve disease
Coarctation of the aorta
Ebstein anomaly (disease spectrum includes mild, moderate, and severe variations)
Infundibular right ventricular outflow obstruction
Ostium primum ASD
Moderate and large unrepaired secundum ASD
Moderate and large persistently patent ductus arteriosus
Pulmonary valve regurgitation (moderate or greater)
Pulmonary valve stenosis (moderate or greater)
Peripheral pulmonary stenosis
Sinus of Valsalva fistula/aneurysm
Sinus venosus defect
Subvalvar aortic stenosis (excluding HCM; HCM not addressed in these guidelines)
Supravalvar aortic stenosis
Straddling atrioventricular valve
Repaired tetralogy of Fallot
VSD with associated abnormality and/or moderate or greater shunt
III: Great Complexity (or Complex)
Cyanotic congenital heart defect (unrepaired or palliated, all forms)
Double-outlet ventricle
Fontan procedure
Interrupted aortic arch
Mitral atresia
Single ventricle (including double inlet left ventricle, tricuspid atresia, hypoplastic left heart, any other anatomic abnormality with a functionally single ventricle)
Pulmonary atresia (all forms)
TGA (classic or d-TGA; CCTGA or l-TGA)
Truncus arteriosus
Other abnormalities of atrioventricular and ventriculoarterial connection (ie, crisscross heart, isomerism, heterotaxy syndromes, ventricular inversion)
Physiological Stage
A
NYHA FC I symptoms
No hemodynamic or anatomic sequelae
No arrhythmias
Normal exercise capacity
Normal renal/hepatic/pulmonary function
B
NYHA FC II symptoms
Mild hemodynamic sequelae (mild aortic enlargement, mild ventricular enlargement, mild ventricular dysfunction)
Mild valvular disease
Trivial or small shunt (not hemodynamically significant)
Arrhythmia not requiring treatment
Abnormal objective cardiac limitation to exercise
C
NYHA FC III symptoms
Significant (moderate or greater) valvular disease; moderate or greater ventricular dysfunction (systemic, pulmonic, or both)
Moderate aortic enlargement
Venous or arterial stenosis
Mild or moderate hypoxemia/cyanosis
Hemodynamically significant shunt
Arrhythmias controlled with treatment
Pulmonary hypertension (less than severe)
End-organ dysfunction responsive to therapy
D
NYHA FC IV symptoms
Severe aortic enlargement
Arrhythmias refractory to treatment
Severe hypoxemia (almost always associated with cyanosis)
Severe pulmonary hypertension
Eisenmenger syndrome
Refractory end-organ dysfunction

*This list is not meant to be comprehensive; other conditions may be important in individual patients.

ACHD indicates adult congenital heart disease; AP, anatomic and physiological; ASD, atrial septal defect; AVSD, atrioventricular septal defect; CCTGA, congenitally corrected transposition of the great arteries; CHD, congenital heart disease; d-TGA, dextro-transposition of the great arteries; FC, functional class; HCM, hypertrophic cardiomyopathy; l-TGA, levo-transposition of the great arteries; NYHA, New York Heart Association; TGA, transposition of the great arteries; and VSD, ventricular septal defect.

e708 April 2, 2019

Circulation. 2019;139:e698–e800. DOI: 10.1161/CIR.0000000000000603

Appendix 1 – Overview of SACCS

The drivers to change

There is a large established population of patients with congenital heart disease in Scotland. However, despite this, these patients are poorly characterised and few have access to coordinated care that adheres to the principles of **Right Care, Right Time and Right Place**.

The field of ACHD is currently experiencing two strong demographic trends. Firstly, the established population is aging and with this brings further inevitable complications and the imposition of additional comorbidities. The second driver is the waves of adolescents with more and more complex congenital heart lesions that are in transition and due to transfer to adult care. Many of these patients have multi-system disease (such as the Fontan), neurocognitive disabilities and other syndromic health problems. As shown above, there are multiple sources all describing significant growth in the numbers of patients currently requiring care and future projections of growth.

All of the established ACHD centres around the world are experiencing similar changes. A more than doubling of the numbers of ACHD patients with heart failure, adult intervention and arrhythmic complications are reported over the last 15 years.

Barriers to change

Scotland has many advantages when coming to address these issues. A single focused specialist centre, a series of local ACHD clinics, an effective national radiology portal and a single healthcare provider (NHS) are envied in other parts of the UK. There are, however, several major deficits – challenging geography, the lack of a fit-for-purpose electronic patient management system and a general under provision of specialised cardiac imaging in Scotland.

At present there is, in some areas, a degree of redundancy of care; and in others challenges to access any specialist care. With the maturing of ACHD provision across Scotland there is now a desire to proactive reconfigure services and future proof care. As the majority of ACHD patients come from paediatric care we have the unique opportunity to plan services knowing the populations of patients who are coming through to adult practice in the next 5-10 years.

Key components of a fit for purpose service

The key components of a comprehensive SACCS service include a skilled team of professionals across the range of professional groups including Cardiac Surgeons, Cardiologists, Anaesthetists and Intensivists, Specialist Nurses, Cardiac and Respiratory Physiologists and Radiographers. The ongoing education and training of this team is essential to maintain the level of skill and expertise that can maintain the specialist service and support the local services whilst contributing to the training needs of associated professionals (eg Obstetrics, Palliative Care, Physiotherapists, and Dentists to name a few). The service then requires:

Appendix 1 – Overview of SACCS

1. To facilitate the upskilling of the local ACHD clinics to deliver first line protocolised care.
   These lesion specific protocols will allow, when appropriate, patients to be seen as near to home as possible. It will also establish clear triggers for referral to the SACCS team at the GJNH. Effective local care will reduce the need for 'safety backup appointments' at the GJNH and will also reduce the needless duplication of investigations.

2. A patient database that allows the SACCS team to track and review any ACHD patient in Scotland.
   This will reduce the numbers of patients lost to follow up and again streamline the investigative pathway (see below).

3. The ongoing use of virtual care and patient led remote monitoring
   The last year has highlighted the effectiveness of virtual care for many of our clinical interactions with patients. Any reconfiguration of services must include video and remote care capabilities. In addition, patient-led healthcare monitoring is becoming well established in subspecialist areas of cardiac care such as in the management of heart failure in our young ACHD patients.

4. A comprehensive one-stop patient centric imaging, assessment and expert review hub.
   This will replace the majority of traditional outpatient visits. This will necessitate an increase in the provisions for specialist imaging.

Current backlog

As we are coming out of COVID and a period of underprovision in the SACC service there is a considerable backlog of clinical activity. This bottleneck is currently at the investigation stage. Complex imaging (advanced echo, MRI and CT) and functional testing (CPET) are slowing the progress of patients through the system either towards surgery/intervention or back to local follow-up. At present the weekly capacity is outstripped by the total numbers of patients waiting.

Where SACCS wants to be in 5 years:

1. a **shared care model** that ensures patients are supported by local provision but can access expert level of care when required;
2. **specialist clinical input** at local ACHD clinics from the National Service;
3. a clinical **Adult Congenital Heart Disease network** supported by the National Service managed through a governance framework;
4. a structured **education, research and training** programme for current and future cardiologists to secure the sustainability of ACHD care; and
5. an improved model of **effective communication**, education and clinical support to ensure the highest quality of clinical care is provided.

Appendix 1 – Overview of SACCS

Referral pathway

Referrals to SACCS come from a wide range of sources. The vast majority of our moderate and complex anatomies are transferred from paediatric care. New diagnosis of or simple lesions and moderate lesions occurs in adulthood. These referrals may come directly to SACCS from GP practices or via local cardiology teams. In addition, patients may move to Scotland and be referred by their ACHD specialist teams or may make contact themselves with the National service. Clear referral pathways should be in place for patient self-referral, GPs and local hospital physicians so that there is a coherent model of care within each local health economy.

It is essential that patient self-referral to the specialist ACHD centre is feasible and accepted by GPs.

It should be noted that traditional ‘New to follow up appointment’ ratios cannot be applied to this patient group due to the lifelong nature and complexity of the conditions.

Clear links between SACCS and the Genetics service, Transplantation services both the SNAHFS and the centre at the Freeman Hospital in Newcastle that has expertise in transplantation in congenital heart disease, and the SPVU should be in place.

Whilst SACCS is focused on the delivery of care to the CHD population, our surgical team is recognised for their expertise in the management of aortopathies with a well-established valve sparing aortic root replacement programme and also management of hypertrophic cardiomyopathy with surgical myomectomy +/- enlargement of the left ventricular outflow tract. Finally, the translation of skill within the congenital arena is of great value in the management of carcinoid heart disease, with the surgical procedure carefully supported by our cardiac critical care specialists with their experience in the management of right heart failure. Therefore, the SACCS service discusses these cases through our multidisciplinary team meeting to ensure careful case selection and optimal team support for the individual patient through their procedure.

Vision in the next 5 years

Over the next 2 years we anticipate refreshing our referral pathways to make them more robust. This will include consideration of electronic referrals which to date have been challenging as the current electronic referral does not allow upload of documentation such as previous clinic letters or procedural notes which are essential in the transition of complex patients.

Work around the referral pathway interfaces closely with our database project and also the work to improve and personalise the assessment pathway.

Finally, we have an active program of work improving our nurse led transition pathway and the referrals around that, including ensuring clear signposts for referral for non-congenital cardiac conditions as they exit paediatric care and ensure access to appropriate adult care.

Where we are now with Transition and Transfer from Paediatric cardiac services

The importance of a patient centred transition service has been widely acknowledged as have the implications for patients when transition does not occur. We also recognise that there needs to be equitable service provision for all patients that can be delivered regardless of where they live in Scotland.

A successful transition to adult care involves

- Education about their heart condition
- The importance of life long follow-up and what to expect in adult services
- Promoting responsibility and empowerment in care, process of consent
- Awareness of potential symptom burden
- Medication awareness and understanding
- Contraception and family planning
- General lifestyle advice

Current transition service

- Consultant to consultant medical referral between paediatric and adult hospitals
- Referral vetted to SACCS CNS to provide virtual transition consultation via NHS near me before first appointment for medical review
- Annual transition event aimed at patients aged 15 - as a result of COVID this is now run virtually allowing equity of access on a national level

Vision within the next 12-18 months

- Continue with current referral pathway
- Offer and provide education to patients on or around their 16th birthday while under the care of their paediatric team via NHS near me for Scotland wide referrals. This would follow on from the initial consultation that is provided by the nurse specialists at the RHC.
- Initiation of joint paediatric and adult MDT for complex cases
- Identify and deliver a transition pathway for patients diagnosed with simple lesions
- Identify pathways and events for patients with additional needs.
-

Inpatient care

The SACCS service is based at the Golden Jubilee National Hospital. Whilst the majority of our work is outpatient assessment, we have an important in patient service. In line with other services around the country the inpatient cohort is changing with time.

We have a consistent inpatient surgical cohort who are in the perioperative phase following an assessment process and multidisciplinary team discussion. There are day case and short stay patients related to catheter lab activity such as diagnostic catheterisation, structural intervention, and electrophysiological procedures including pacemaker and ablation. There are also complex medical admissions under the SACCS team including advanced heart failure, endocarditis, and pulmonary hypertension.

The patient pathway for the surgical and catheter lab cases is well described and works well. This includes their care within intensive care and high dependency units at the Golden Jubilee. The medical admissions, who are increasing in number and complexity with time, should be accommodated within the National services division bed compliment of Ward 3 W. Unfortunately, because of bed pressures it is common for these patients to have delayed transfer to the Golden Jubilee National Hospital and or not be accommodated within the NSD pod. Work is ongoing with the operational management team to describe the needs of this cohort of patients along with other similar complex cardiology patients at the Golden Jubilee to identify an appropriate inpatient care location.

The SACCS patients benefit from the specialist nursing available within each ward area. In addition, with the increase in consultant Cardiology staffing there is now a 24-hour a day 7 day per week on call consultant Cardiologist rota for the in patients and also as consultation to our colleagues around the country. Recent change in staffing within our specialist nursing team have led to a temporary reduction in support of the daily ward rounds, although there is ongoing support for the inpatients. NSD funds to clinical fellows to support the junior doctor role for the service. Changes in junior doctor training have led to a reduction in applicants for these posts this year which has created a challenging environment to support inpatient care. This is an ongoing focus of concern at organisational level.

The inpatient surgical service is supported by advanced nurse practitioners in the cardiac surgical ward who interface closely with the SACCS consultant Cardiologist and directly with the SACCS consultant cardiac Surgeon. There is a robust out of hours rota for the consultant Congenital Cardiac Surgeon who covers the Scottish Paediatric Cardiac Service as well as the SACCS.

Our inpatients at the Golden Jubilee National Hospital also benefit from expert rehabilitation teams including physiotherapists and occupational therapists who interface with local rehabilitation teams to facilitate discharge planning. Our inpatient areas are supported by specialist cardiac pharmacists. Our longer stay patients benefit from the facilities available at the Golden Jubilee National Hospital including well-equipped rooms and access to hospital Wi-Fi.

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Outpatient assessment

The Scottish Adult Congenital Cardiac Service (SACCS) is commissioned by National Services Division of NHS Scotland. A major service review was anticipated for 2019-20 however the COVID pandemic led to a deferral of this review.

In anticipation of the major service review, and in recognition of the need for an improved patient-centred model, the SACCS team propose a quality improvement project that seeks to rejuvenate our diagnostic assessment pathway. We have approached the Chief Executive to seek their support with dedicated project management and change management expertise.

The current outpatient model brings patients with moderate and complex conditions for regular review at the Golden Jubilee SACCS. Essential diagnostic tests include ECG, echocardiogram, cardiopulmonary exercise test, MRI and CT. The patient often has to attend on a number of visits for these diagnostics and then attend the outpatient clinic review with a consultant.

This current model is not fit for purpose and we propose a reconfiguration around a more patient centred model. Our outpatient failure to attend rate is currently high and reflects the competing needs on our patients' time including work, child care and local follow-up. This also reflects inefficiencies in IT to support robust booking processes. There is little coordination between local and Golden Jubilee follow-up. In addition, the increasing population demands re-evaluation of the current assessment model to ensure that the correct patients are able to access advanced diagnostics in a timely fashion. The increasing complexity of patients also demand subspecialty clinics such as advanced care planning, pulmonary hypertension, heart failure and pre-pregnancy counselling.

To support such a model, **investment in the local clinics** is essential to ensure that they are appropriately empowered to look after a sizable majority of the ACHD cohort. Work is well advanced in developing **protocols** that would seek to describe anticipated pathways for the majority of our conditions including **red flag triggers for re-referral to the specialist service**.

There is an established network of local Cardiologists with an interest in ACHD:

Appendix 1 – Overview of SACCS

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	Ayr Hospital	Dr Gavin Nicol
West	Dumfries and Galloway Royal Hospital	Dr Laure d’Allones Bruchou
West	Wishaw General Hospital	Dr Caroline White / Dr Graeme Tait
SEAT	Royal Infirmary of Edinburgh	Dr Patrick Gibson
SEAT	Borders General Hospital	Dr Anne Scott
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

To prepare for the major service review we have a valuable opportunity to review the current service model and patient pathways with a particular focus on the outpatient pathways. Adopting a service redesign approach and working with patients, families and carers to understand what works well and what could be improved would enable us to identify potential changes to deliver an improved person-centred service model and associated pathways.

There are several potential changes to the service model and pathways that have been identified (outlined below) but further co-design with patients and service users is required.

Appendix 1 – Overview of SACCS

The proposed service design would include short, medium and long term objectives. A quality improvement approach will be embedded in the project to test and adapt changes prior to fully implementing them and ensuring they meet the needs of the patients and are supported by the SACCS team.

a. In order to progress restructuring of the outpatient assessment model we need to complete several processes. An initial review of the service model is required with: audit of sample of recent 100 patients to consider pathway delivered vs optimal pathway
b. patient consultation about the current service and identification of opportunities to improve
c. survey of service users including GPs, local Cardiologists, Obstetricians, Anaesthetists, and Cardiologists with an interest in ACHD seeking their opinions on the service model

Potential changes that would support service development and redesign have been identified and listed below. An early piece of work that could be completed in parallel with the service review proposed would be to identify which of these changes could be progressed now in advance of future service redesign proposals and associated options appraisal.

Early implementation:

- protocols to describe proposed ACHD assessment at local level with red flag triggers for re-referral for assessment at the specialist centre, with review of these protocols by both the specialist teams and local teams. A well-integrated assessment service may allow opportunities such as the virtual specialist review of stable patients (such as a well patient with tetralogy of Fallot with minor pulmonary regurgitation) rather than simply triggering Specialist Centre review
- resumption of outreach consultant cardiology support to local clinics
    - IT solutions should facilitate SACCS to discharge to local care without “safety net” appointments which have been required to safeguard patient reviews
    - Administrative support to coordinate the patient pathway will be required, potentially as an identified coordinator role
- an ongoing process of audit and patient feedback to access any new model using recognised PROMS and PREMS tools.
-

Service model review considerations:

- robust data management tools to ensure that we have an accurate database of all patients with an ACHD diagnosis in Scotland ideally from cradle to grave, that would support planning of all services including transition, life-long assessment and local team care.

- description of assessment model for diagnostics and expert review. This would include consideration of all aspects including streamlined booking process, equity of access to assessment irrespective of geography, physical space requirements, diagnostic test requirements and reporting requirements.
- description of sub specialty clinics that would run in parallel with the assessment model considering the diagnostic assessment requirements of these clinics as additional to the assessment model.
- options appraisal for the assessment, education and transition of patients with non-complex congenital heart disease (for example, an online package of information that is signposted from paediatric transition team, and single review at local ACHD clinic.)

- a structured education programme for echosonographers in local centres
  - investment of SACCS time to upskill local echo teams is required to achieve a successful shared care model with care as close to home as realistic for the patient
  - different models to achieve the education can be considered mixing virtual learning with hands on scanning with trainer at GJNH for example
- assessment of education needs within local centres

The support of the executive directors is welcomed and important to advance in this work. The ongoing sponsorship by a member of the executive team would be of benefit. Their support would ensure that our work recognises the wider strategic plans of the organisation for example in developing a world class imaging centre and regional respiratory physiology assessments.

The key requirements for rejuvenation of the outpatient assessment service are:

1. **IT expertise to address the data management solutions**
2. **project management support – expertise and time**
3. **early input in discussions about physical clinic accommodation**

Priority within the program of work for the IT department is essential. Advances within the database work with National Services Division is critical to the success of this project.

Project management, incorporating change management skills, is required to develop an improved and contemporary assessment program for the SACCS patients. We wish to empower our patients and local units. The aim is to achieve an innovative ACHD program that is sustainable with the increasing population of patients and that is responsive to the commission. Such a program would be a winning solution for the patient, local ACHD units, the SACCS team and for the commissioners.

The physical clinic environment is important, as we seek to consider different models of outpatient assessment including face to face clinics, daycase assessments and virtual clinics including virtual clinics with multidisciplinary involvement (e.g. the pre-pregnancy counselling clinics with Obstetrician, Cardiologist and Nurse Specialist meeting with the patient and partner by video-call). The redesign of clinic accommodation at GJNH will need to incorporate space for these different consultations, including clinic rooms with high quality IT to support virtual clinics in an appropriate space to ensure patient confidentiality (rather than within shared office space).

A lean team approach to this project is attractive that can then integrate with patient groups management groups and specialist groups as required. We would strive for an ambitious, clever and innovative approach that is possible within Scotland because of the nature of our commissioned service.

Advanced Care Planning and Palliative care

The life trajectory for those living with CHD is varied. However, regardless of the severity of CHD, there is an increased risk of cardiovascular events with some CHD having a significant impact on life expectancy. Providing lifelong care to people living with CHD provides clinicians with opportunities to deliver information about future health, disease trajectory and potential for further interventions. For example, for some people with CHD this includes consideration of complex, high risk surgery or advanced heart failure strategies such as cardiac transplantation. There is an array of published literature that provides us with information regarding long-term complications in specific CHD lesions. Therefore, there is a need to support patients and those who are important to them to live well with CHD and to prepare for future events.

For some patients, there may be a slow decline that provides clinicians with time to have these discussions. For others, an acute event may be the first time the patient has considered what their care preferences are. Making these decisions in an acute setting is challenging for patients, relatives and clinicians. Therefore, being reactive to healthcare presentations means we have missed an opportunity to support our patients in making decisions related to their care.

Advanced care planning is not a one-off event. Rather it is a proactive process that informs, supports and empowers the patient to understand their current and future health. This allows clinicians, patients and their families to talk about preferred treatments and document decisions. It is adaptable and proactively responds to the patient’s potential care needs.

Palliative care “improves the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual. The quality of life of caregivers improves as well” (World Health Organisation). Therefore, palliative care is not solely relevant for when death is imminent. In CHD life-threatening illness occurs and although treatments may be available, the patient lives with life limiting symptoms thereafter. Therefore, palliative care supports symptom management, patient and relative expectations and the psychological burden associated with illness as well as plans for appropriate ongoing care provision.

Currently, advanced care planning and palliative care are not embedded across the CHD patient pathway. There are some examples of excellent ACP and palliative care demonstrating that patients have been supported to make decisions and access palliative care when required. Additional education, support and resources are required to ensure this is a core component of care for people with CHD.

Vision

A shared care model:

- Clinicians in local and national ACHD services should, initiate discussions relating to future health. For patients with moderate-complex CHD, this should be initiated by clinicians working in SACCS and enhanced by local care teams.
- All patients with moderate – complex CHD are offered a consultation with SACCS clinician (consultant and/or nurse specialist) with expertise in cardiac palliative care to facilitate advanced care planning or ongoing palliative care.
- Documentation relating to advanced care planning and palliative care is formalised, follows the patients care pathway and is available to all clinicians involved in their care and the patient.
- Relevant health and social care partnerships are developed and formalised to provide the range of expertise and practical support to patients making and document advanced care decisions and/or supporting quality of life.
- When a patient’s health status deteriorates, previous decisions should be discussed and changes to care preferences in line with should be documented.

Specialist clinical input at local ACHD clinics from the National Service

- When attending local ACHD clinics, SACCS will support ongoing advanced care planning and palliative care support. This may include ensuring patients

with advanced symptoms are reviewed in an outreach clinic to reduce the need to travel long distances to the national service.
- The national service will support ongoing MDT support in decision making relating to patient care and care planning using technology where necessary.

A structured education, research and training programme

The national services will support education, research and training by:

- Developing competence and confidence in communication skills required initiate and provide advanced care planning and palliative in collaboration with the patient and their family.
- At SACCS educational events, promote a life course approach to care and examples of advanced care planning and palliative care.
- Work with national programmes and groups to promote the needs of ACHD patients
- At outreach clinics and national clinics, provide support to clinicians and trainees in communication around advanced care planning and palliative care.
- Audit implementation of advanced care planning and palliative care in core ACHD care.

An improved model of effective communication, education and clinical support

- Develop and implement effective communication between services and patients in this area will support safe, effective high-quality care for patients with ACHD
- Develop pathways to support advanced care planning and palliative care, including referral to external agencies to support delivery of care

Diagnostic Pathway

Imaging in ACHD:

In 2018, the European Association of Cardiovascular Imaging published a position statement in support of multimodality imaging approach to adults with congenital heart disease (European Heart Journal - Cardiovascular Imaging (2018) 19, 1077–1098 doi:10.1093/ehjci/jey102). It was acknowledged that multimodality imaging in the a CHD population achieve greater diagnostic utility than the sum of the individual tests. In the next section information regarding echo, MRI and CT is presented and the key points from the position paper are referenced.

Echocardiography

Where are we now?

Appendix 1 – Overview of SACCS

Congenital echocardiography is a distinct subspecialty within echocardiography, and as such, is not universally undertaken in every cardiac physiology department across Scotland. Due to the diversity and complexity in anatomy and physiology of congenital cardiac patients requiring assessment, it is not anticipated, nor fair to expect that non-congenital physiologists should undertake these assessments in isolation.

The current team of echophysiologists at the GJNH consist of two full time physiologists, one part-time (0.7 WTE) and one retired physiologist who scans regularly (0.2WTE). All have accreditation in adult echocardiography with British Society of Echocardiography (BSE) and are very experienced echophysiologists. While none of physiologists currently have accreditation in congenital echocardiography, all have accrued a high level of scanning time over many years. There is a diversity of expertise in congenital echocardiography amongst them ranging from expert to a more intermediate level currently. They are supported by two ACHD consultants each with a specialist interest in congenital echocardiography (congenital echo lead with European Association of Cardiovascular Imaging (EACVI) accreditation).

One of the key roles of the congenital echo physiologist is to support outpatient clinics. Clinics have been reconfigured to allow for optimal scanning and reporting time, standardised to 1h per patient. Presently, during outpatient clinic for a single consultant (n=6-7 patients) there are only two dedicated echo rooms available set up with couch, echo machine and reporting station each accommodating a physiologist.

The equipment currently available in the echocardiography department consists of 2 x GE E9 machines, an older GE E95 machine and a contemporary GE E95 machine with Vivid Ultra software. In addition, there are two portable GE S70 machines utilised for inpatient scans when there is no available space within the dedicated echo accommodation. The department has recently had software upgrades to all departmental work stations enabling more advanced analysis tool utilisation including 4D capability when imaging acquired with the E95 machines.

The current quality assurance process consists of 2 x consultant-supported scanning sessions per week where consultants are available to help acquire images, and are involved in analysis and reporting. In addition, there are weekly congenital echo meetings where physiologists are encouraged to talk through challenging scans with opportunity for constructive critique in a supportive manner.

Where are we going?

The majority of the workload of the congenital echophysiologist will consist of supporting outpatient clinics. Patients who attend for outpatient assessment will have a congenital echocardiogram undertaken. In order to create the capacity for supporting a minimum of 8 clinic sessions per week, expansion in 3 key areas will require to be undertaken:

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- Workforce: Approximately 6-8 appropriately trained and accredited echophysiologists to support the SACCS service. A link physiologist in every regional department with expertise in congenital echo to support outreach clinics.
- Accommodation: Ideally 4 dedicated areas for scanning with a centralised area for reporting. This will enable at least 4 physiologists to be scan simultaneously to cater for outpatient and inpatient congenital echo scans.
- Equipment: Contemporary echo machines with 4D capability. One of the E9 machines is scheduled to be replaced in the coming year and will be upgraded to another E95 machine. EchoPAC work stations with connectivity to regional departments so imaging can be shared with ease for specialist opinion or MDT review

How do we get there?

There is a global shortfall of cardiac echophysiologists with departments investing in a “grow your own” strategy for future workforce planning. Key to achieving the goals stated above is an appropriately trained and resilient workforce of congenital echophysiologists which requires the following:

- Training: Training will be multi-faceted and consist of hands-on scanning, lecture and tutorial based teaching based on individual lesions and cases. There have been 2-3 echo physiologists all with BSE accreditation identified to be trained in congenital echocardiography. One has started a logbook for accreditation. Hands-on training will be overseen by the consultant team and lead congenital echophysiologist. Furthermore, utilisation of lesion-specific echo protocols launched in 2018 by ISACHD should ensure there is standardised acquisition of images in patients regardless of where the scan takes place.
  There are two team teaching sessions per week 1h each. One dedicated to congenital echo and another with a mixture of congenital and acquired echo teaching with a plan to expand to include regional echophysiologist colleagues for virtual teaching session monthly. Online resources such as the EACVI Congenital Multimodality Imaging Tutorials and the ISACHD supported Heart University will be utilised in addition for self-directed learning.
  The ultimate goal is to train the GJNH workforce who can then offer on-site training to visiting echophysiologists from regional centres and cardiology trainees. In addition, the annual hand-on congenital echo training workshops will continue and we will seek to increase the frequency of these.
- Accreditation: The pursuit and achievement of accreditation is complementary to training and an assurance of a standardised assessment. The EACVI accreditation process for congenital echocardiography has been in place since 2015 with a similar process now administered by the BSE which launched last year. To assure quality in scanning it is expected that all

those undertaking such scans are either accredited or working towards accreditation.

- Quality assurance: Supervision and oversight of scans and the interpretation of such will be undertaken by accredited echophysiologists or clinicians.

EACVI position paper key points:

• Echocardiography is the first line imaging modality in the assessment and follow-up of ACHD patients.

• 2D speckle tracking-derived LV GLS appears to be feasible and reproducible for clinical use and can be included in the clinical follow-up.

• 2D speckle tracking-derived strain of the RV free wall, appears to be feasible and reproducible.

• Standard approaches to diastolic assessment are not always applicable in all ACHD patients.

• TAPSE and FAC for RV function are the suggested echocardiographic parameters for regular clinical follow-up of ACHD patients.

• 3D echocardiography, when feasible, is recommended to assess ventricular volumes, EF, valvular morphology, and better understanding of intracardiac anatomy.

• For the follow-up of RV size and function, when CMR is not feasible, not available or contraindicated, in centres with experience, 3D echo is recommended.

• Dedicated protocols for each specific lesion are strongly recommended.

• Echocardiography studies in ACHD should be supervised and reported by appropriately trained ACHD specialists.

Cardiac MRI

Cardiac MRI is the central advanced imaging technique for the assessment of adults with congenital heart disease. Cardiac MRI is unparalleled in its ability to combine anatomy, function, physiology and pathology in a single scan. As the technique of MRI expands the breadth of the assessment and utility of diagnostic information becomes ever more powerful. It has to be appreciated that we are only at the beginning of understanding the power of MRI to provide a window into the, often complex, world of congenital heart disease. Cardiac MRI offers the potential to image patients both at rest, and in response to pharmacological or physiological stress. The 3D and 4D aspects of imaging allow the creation of digital and physical models to assist with clinical decision making and pre-intervention planning as well as providing a fantastic educational resource for healthcare workers training in congenital heart disease.

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In the vast majority of patients MRI allows unrestricted imaging of the thoracic cavity, restricted only within the region of metallic artefact cast by previously implanted devices. Imaging of other regions of the body can be linked to expand the utility of the technique e.g. pelvic vessel imaging to help guide a femoral bypass approach in redo cardiac surgery. For patients undergoing repeat surgery in whom the re-sternotomy itself can be associated with major risk to life, MRI is able to assist in understanding how complex access to the heart is likely to be, not infrequently a major consideration in the decision to offer further surgery. Contra-indications to this imaging modality are becoming less as our knowledge of previous restrictions such as pacemakers are modified through emerging safety information. Only a relatively small number of patients are intolerant or non-compliant. If MRI is still felt to be of critical importance in this group, a scan under general anaesthetic can be performed.

For patients who are diagnosed with congenital heart disease in adulthood, cardiac MRI is often an essential tool in characterising and understanding the haemodynamic impact of the disease, allowing care to be optimised. Despite the dramatic improvement in outlook for patients born with congenital heart disease, many patients have an ongoing requirement for further surgical or other intervention to stay well, protect cardiac function and reduce the risk of life-threatening events. In these patients, and in the absence of evidence guiding clinical management, comprehensive serial assessment is essential to determine evidence of change and inform upon the need for further intervention. Cardiac MRI forms an essential component of this assessment.

Congenital cardiac MRI acquisition requires expert MRI radiographers who are trained in both MRI and also have a working knowledge of clinical congenital heart disease. Whilst basic scan protocols form the foundation of imaging, optimised imaging often requires departure from the standard in order to address particular clinical issues. Scan acquisition is often a lengthy process limiting the workflow through the scanner and, although there are techniques in development that may assist with reducing scan times, they are not clinically available currently. Added to this analysis of scan data is time consuming and requires specialist software.

Given the central role of cardiac MRI in the management of patients with adult congenital heart disease and, paralleling the global growth in the number of patients with ACHD, there has been a progressive increase in demand for this imaging modality. As the importance of the technique grows there is a growing need to augment our existing imaging with newer techniques such as 3D/4D modelling and stress imaging.

Where are we now?

Congenital cardiac MRI imaging is provided by a team of 5 expert radiographers supported by 2 consultant cardiologists. All studies are supervised either in person or remotely at the time of the scan. At the present time, the GJNH has the capacity to image 12 patients each week together with the ability to image emergency patients during office hours. There is no out of hours MRI service although elective weekend scan lists can be organised.

Infra-structure issues such as booking and reporting facilities have combined with limited access to scanner time to restrict scan numbers. It is no surprise that the resource available is significantly less than that required (at least 17 scans per week) and is insufficient to address either the existing backlog of patients awaiting imaging in a timely fashion or the ongoing need. The resource in also significantly less than in other major congenital centres in the UK.

Physiological stress MRI imaging used to be available at the GJNH through the use of an on-table ergometer but since the recent scanner upgrade, this technique can no longer be offered. At the present time clinical 4D techniques are not available and there is no mechanism to allow 3D digital or physical modelling. Whilst the quality of congenital cardiac MRI imaging is considered to be excellent at GJNH, the lack of development in this area over the last 5-6 years has resulted in the quality and breadth of MRI imaging falling significantly behind in comparison with other leading ACHD centres in the UK.

The paediatric cardiology unit based at the Royal Hospital for Children in Glasgow have their own congenital cardiac MRI programme. There is currently little communication or co-ordination of imaging approaches between the units. Several hospitals in Scotland have access to cardiac MRI imaging locally and some units such as Aberdeen and Edinburgh do run limited services focussing upon more simple congenital heart disease lesions. Assessment of more complex lesions is performed in GJNH. Most other units do not attempt all but the most simple congenital cardiac MRI, except in emergencies.

Where are we going?

The progressive increase in requirement for cardiac MRI imaging mirroring the growth in the ACHD population will need to be met.

- Increased need for congenital MRI imaging as the ACHD population grows and the imaging techniques expand
- Increased access to MRI scanner time
- Increased radiographer training
- Increased demand upon the infra-structure e.g. booking and reporting facilities
- Incorporation of newer scanning techniques and technology to maintain imaging excellence
- Re-introduction of physiological stress technique
- Need to have a common approach to MRI imaging between paediatric and adult centres and between adult centres in Scotland where local units are prepared to image congenital patients

H*ow do we get there?*

- Continued support of existing staff
- Investment in training of radiographer staff – support for the development of a training manual incorporating detailed scanning protocols

- Streamlining and development of a smart booking process to allow the optimum usage of available scanner time and limit DNAs
- Improved infra-structure supporting reporting – electronic transfer of scan data, remote access for analysis and reporting, improved voice recognition and report format tools with maintenance of report format between electronic patient platforms
- Recognition of need to provide a greater MRI scanner resource at GJNH
- Collaboration with the paediatric centre to standardise imaging approach
- Collaboration with imaging colleagues in other units with the potential development of a congenital imaging network assisted by a training manual and other educational activities to maximise utility of available local imaging resource
- Acquisition of MRI ergometer and re-introduction of physiological stress imaging for selected patients
- Development of existing techniques to include the acquisition of 4D imaging and post-processing software together with the establishment of a pathway for 3D modelling and printing when required

EACVI position paper key points:

• A baseline CMR is recommended for many patients at time of transition from Paediatric to ACHD programmes.

• CMR is the gold standard for ventricular volumes, EF, flow quantification, and the assessment of extracardiac anatomy.

• CMR frequency should be determined by the underlying defect and clinical status of the individual patient. Intervals between scans depend on the risk profile, findings at the first CMR study, and the expected rate of change. Intervals of 3 years or more are appropriate in most cases, but earlier restudy may be prompted by the onset or progression of symptoms, or the presence of a lesion liable to rapid progression.

• Additionally, CMR is recommended in the presence of clinical deterioration, non-diagnostic echo findings, and prior to surgical or transcatheter intervention.

• CMR studies in ACHD should be supervised and reported by appropriately trained ACHD specialists.

CT

Cardiac imaging is critical in the assessment of adults with congenital heart disease. Transthoracic echocardiogram is the primary imaging tool, but cross-sectional techniques add detail that cannot always be appreciated with ultrasound.

To date cardiac MRI has been our go to modality for sequential follow-up including volumetric and functional assessment. CT has been a more limited modality mainly because of concerns with regard to radiation doses in what is usually a young cohort.

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Contemporary CT equipment is substantially faster in its image acquisition with greater detail at substantially lower radiation doses. At the same time rising lesion complexity within the congenital cohort the additional information achieved from CT has become central to procedural planning. For example, delineation of coronary artery course and disease, identification of calcification within a conduit and sternal relations prior to reopening.

Image acquisition and interpretation requires training and knowledge of the underlying congenital lesion and appreciation of the clinical questions asked and potential complications not recognised.

Going forward SACCS will need increased access to gated cardiac CT with specialist reporting. For the majority of ACHD patients the scans will need to be performed at GJNH. Recognition of opportunity for local scanning must be maintained and achieved when appropriate for example for routine CT coronary angiography or CT pulmonary angiogram.

Functional CT which allows assessment of for example ventricular or valve function is now possible and is of benefit in patients who are intolerant or who cannot access MRI. Again this is possible with fast and contemporary equipment and specialist reporting. As part of the wider cardiac imaging strategy at GJNH we would hope that this becomes more accessible for all patients not just those of SACCS.

EACVI position paper key points:

- CT is superior to CMR in the setting of critically ill, or claustrophobic patients, when the length of a CMR acquisition may not be tolerable or practical.
- Cardiac CT allows concurrent evaluation of lung parenchyma or airways.
- CT is indicated when evaluation of calcification is needed (e.g. within vessels and surgical conduits prior to intervention) or if detailed evaluation for coronary stenosis is sought.
- CT can be considered in the presence of CMR non-compatible implants (e.g. pacing leads, non-MR compatible pacemaker/defibrillator) and in the setting of poor CMR image quality due to metallic artefact.

Functional assessment:

Sequential assessment of the functional capacity of patients with congenital heart disease is an important clinical tool. Whilst clinical consultation can lend an impression of a patient’s functional capacity, data from 6-minute walk tests or cardiopulmonary exercise testing is significantly more detailed and sensitive to change over time. Sequential assessment allows appreciation as to the cause of deterioration and the impact of physiological ageing rather than pathological process.

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Currently the respiratory physiology lab at the Golden Jubilee National Hospital is supported by staff from Gartnavel Hospital in Glasgow. This allows for integration in a larger service but can be challenging in terms of staffing. As the outpatient assessment model is refined for SACCS the capacity for functional assessment will need to be considered and supported.

Many of our patients who have had multiple previous surgeries have significant abnormalities of their respiratory physiology that are important in the impact on symptom burden for example of breathlessness. Therefore, detailed pulmonary function testing is also required particularly in the preoperative assessment.

Finally, the 6-minute walk test is a well validated tool in the sequential assessment of patients with pulmonary hypertension including those on advanced pulmonary vasodilator therapies. It is imperative that there is an adequate service to support the SACCS pulmonary hypertension clinic which currently runs on a weekly basis.

The demands for functional assessment are likely to increase not just from SACCS but also from advanced heart failure services and the complex cardiac surgical cohort at the Jubilee. A more resilient service would be of benefit and would lend support to many of the research interests within the organisation including for example the orthopaedic service also.

Intervention

Cardiac Surgery for the Scottish ACHD population

Surgery in congenital heart disease has been transformative for the patient group. Surgery in infancy has been life-saving for patients with a wide range of conditions, and novel strategies supported by peri-operative care advances has continued to extend the potential anatomies and physiologies that can be repaired.

Cardiac surgery in ACHD is essential to maintain the well-being for many of our patients: few patients with congenital heart disease are fully “cured”. The majority of patients with conditions who undergo surgery during infancy and early childhood do not have a lifelong solution. The effects of scar formation, divergent growth between native and repair tissue and the use of prosthetic substitutes results in the need for repeat intervention. Therefore, as described above there is a need for ongoing surveillance to identify any late issues and determine the correct time for intervention. Some interventions are possible via transcatheter route, but largely remain within surgical domain.

Where we are now:

We are currently funded for 3 full-time Congenital Cardiac Surgeons who are employed by NHS Greater Glasgow and Clyde and have operating sessions at both Royal Hospital for Children and the Golden Jubilee National Hospital. 1 full-time Congenital Cardiac Surgeon is currently on sabbatical leave. His workload is covered by a locum Congenital Cardiac Surgeon with support and mentoring within the surgical team.

The majority of the Consultant surgical time is based at the Royal Hospital for Children in Glasgow. The service at SACCS is based on 3 full surgical days - 1 per Surgeon - and surgical outpatient clinics that are coordinated by the consultants' secretaries. The surgeons liaise closely with critical care in the perioperative phase, and in addition with the duty SACCS Cardiology Consultant, who also supports the perioperative care. An additional significant workload for the surgical staff is attendance at the weekly multidisciplinary team meeting and ad-hoc MDTs as determined by clinical needs.

There are currently no specific fellows or surgical trainees attached to the SACCS surgical programme, and junior support in operating sessions comes from the pool of middle grade in adult non-congenital cardiothoracic and transplant programs. In high-risk or complex cases, dual consultants operating can be facilitated.

In the current period, which has been significantly impacted by COVID, we have prolonged waiting list for congenital cardiac surgery in SACCS (and SPCS). This has been compounded by the change in consultant surgical staffing. Until 2020 we submitted data to the CHD national audit and this confirmed that we are a moderately sized surgical unit for congenital heart disease in the UK. It also confirmed that our outcomes were good in parallel with other units across the UK and we had good data quality within our audit.

A small volume of work is referred to centres out with Scotland every year. The majority of this is related to cardiac transplantation (or heart-lung transplantation or heart liver transplantation). We have also referred complex aortic arch work to the aortic centres in London.

Where are we going?

As described above congenital heart disease is an increasing population of patients particularly within the adult sector. Collaborative working in the multidisciplinary team meetings strives to identify opportunities for optimal interventions. This may translate to a surgical strategy in the short term to facilitate intermediate-term transcatheter, redo procedures before ultimately a long-term repeat surgical strategy. For example, a surgical pulmonary valve replacement may be advocated that can then be replaced transcatheter on several occasions before requiring redo surgery. This strives to minimise risk for the patient. An additional facet of this style is the potential for hybrid interventions for example transcatheter stent deployment in theatre to a branch pulmonary artery at time of a redo surgical pulmonary valve or open ventricular access to achieve a transcatheter valve replacement.

Many of the more complex surgical or hybrid strategies can be pre-planned and bench tested with the use of cardiac model is based on an individual patient's cross-sectional imaging. Whilst 3D printers are readily available, the quality and detail required for clinical models is such that commissioning a bespoke company in the data preparation and model delivery is a far more economic solution. Most centres now use models for complex cases and find that they are financially beneficial by minimising kit and theatre utilisation.

This collaborative approach is the future for intervention in as many guises. There is an increase in recognition for surgical electrophysiology interventions, which include biatrial Cox-Maze, modified right atrial Maze procedures or RVOT cryoablation for ventricular tachycardia at time of cardiac surgery. This is complimented by surgical heart rhythm devices such as epicardial pacemakers and subcutaneous implantable cardiac defibrillators. It also extends to the recognition of the need for dual consultant operating becoming much more common occurrence. The additional consultant support is recognised to improve outcomes both technically and in terms of operative duration. An increase in 2 consultant working does however challenge staffing levels.

The benefit of senior staff involvement in perioperative operative care as well recognised and is actively sought in the paediatric cardiac service. There are ongoing discussions to consider the need for a 4 consultant model in the surgical service for congenital heart disease in Scotland. This in particular recognises that we function on 2 separate sites geographically.

Robust surgical service includes performance review and audit. In addition, there is opportunity for research and innovation within the surgical sphere. There is insufficient time for reflective practice or research and is important to recognise the need for this within the SACCS surgical programme.

Our surgical team have trained extensively and internationally and this is reflected in their experience. Their continuing medical education ensures that they remain contemporary in their approaches and are early adopters of innovative strategies. Looking forward, this will remain essential within the surgical strategy and fits well with the stated ambitions of the Golden Jubilee National Hospital.

Within the Golden Jubilee, the congenital cardiac surgeons' portfolio of operations extends beyond the congenital and includes a successful aortic root programme and also carcinoid heart disease surgery, and hypertrophic cardiomyopathy. The surgeons work closely with the non-congenital cardiac surgical colleagues including working with each other for the optimal outcome of patients, such as congenital patients requiring coronary artery grafts or non-congenital patients with septal defects or complex valve repairs.

At present congenital cardiac transplantation is not performed in Scotland. This remains under review and could potentially be reconsidered as a longer term strategy. Careful learning from successful transplant services such as the Freeman Hospital in Newcastle would be essential in achieving a successful service. A successful cardiac transplant service particularly within the congenital cardiac patient population requires a parallel service with mechanical circulatory support. With expansion of current adult transplant and MCS program acquired heart failure program, consideration of such service for the congenital population may be a future possibility. Our congenital cardiac surgeons have had formal training on transplant/MCS support in congenital population and with extensive experience in complex redo surgery, this skill can be married along with transplantation surgery and supported by contemporary perfusion solutions.

How do we get there?

The next stages for the surgical programme at the Golden Jubilee for congenital heart disease include:

1. ***Surgical workforce and services expansion across sites***: increase availability of congenital theatre sessions to reduce waiting list time (and catch-up post pandemic), with expansion of surgical workforce from current 3 to 4 surgeons and from current 3 (0 in ACHD, 3 in paediatric) to 4-5 congenital registrars with potential dual-site cover
2. ***Co-operative scheduling between adult congenital and paediatric cardiac services***: improve planning and optimise provision of congenital surgical services and inputs across two-site
3. ***Quality enhancement in congenital cardiac surgery***: (i) within the Children's Hospital work to introduce and establish new skills such as Cone reconstruction, Nikaidoh operation, Double Switch operation with defined governance and clinical pathways for introduction and evaluation (ii) collaboration with non-congenital cardiac surgeons to establish aortic arch surgery and interventional program in West of Scotland (iii) upgrade of theatre equipment/supplies, such as camera for video recording (1 in RHC, 0 in GJNH), and new cryoprobe/cryoablation machine, haemostatic materials such as Veriset/Fibrillar as well as more NIRS probe monitoring (iv) improvement of surgical planning by increasing the use 3D models - commissioning an external service for model preparation is required, likely economy of scale if joint commission with paediatric cardiac services and SACCS (anticipated volume in SACCS of one per month initially)
4. ***Surgical Education and Training for Fellows*** (i) enhance exposure and experience in paediatric, ACHD and research on rotational basis (ii) establishing 2-weekly fellow led surgical teaching sessions (iii) enhancement of surgical teaching with video recording (iv) funding and provision of spare 3D models for teaching and hands-on surgical training (v) teaching using specimens from morphological collection within Scottish Congenital Cardiac Services (vi) integration of dual-site teachings
5. ***Audit and Research Assurance***: (i) the development of new replacement quality assurance and audit tool for congenital cardiac surgery and interventions (ii) participation in international databases such as ECHSA and WSPCHS (iii) demarcation of time for performance review and audit participation (iv) development of surgical research projects

Cardiac catheterisation lab strategy for SACCS

Within congenital heart disease the cardiac catheter lab plays a critical role both on diagnostics and in therapeutic intervention. The diagnostic role is complimentary to clinical assessment and imaging modalities in describing structure and haemodynamics. The time required to perform a diagnostic cardiac catheter study in congenital heart disease is frequently significantly longer than in non-congenital heart disease. This is a combination of patient factors including anxiety from previous procedures, learning disability and vascular access complexity, and also the need for multiple sampling regions throughout the vascular tree. A cohort of our patients requiring diagnostic assessment will require general anaesthetic to facilitate the procedure.

Structural intervention within the congenital heart disease population includes closing holes such as atrial septal defects, opening blood vessels such as pulmonary arteries or coarctation of the aorta, plugging abnormal communications such as patent ductus arteriosus, and transcatheter valve replacement for example in the pulmonary or tricuspid position. These procedures often take place under general anaesthetic and can be difficult to predict in terms of procedure time. All patients proceeding to structural intervention are discussed through a multidisciplinary team process that seeks to ensure optimal timing and planning for procedures.

Electrophysiology intervention within congenital heart disease includes diagnostic electrophysiology studies and ablation procedures for abnormal rhythms. In line with centres around the world, as the as the ACHD population matures there is an increase in arrhythmia burden for our patients. As is seen in many complex physiology is the maintenance of sinus rhythm is important in maintaining optimal function and symptom status. The SACCS team host monthly electrophysiology multidisciplinary team meetings with our colleagues in electrophysiology. We strive to ensure that the correct patient cohort progress to EP assessment and intervention in the correct location and with the correct team at the optimal time. This means that if possible we involve regional electrophysiology teams, but when necessary procedures are planned at the Golden Jubilee National Hospital with specialist electrophysiologists in an environment supported by the SACCS team, with access to specialist cardiac anaesthetic support if required.

A small number of patients are identified every year who require access to specialist electrophysiology techniques not available within Scotland. This includes patients who require magnetic navigation to achieve ablation and those who require mechanical circulatory support backup for their electrophysiology procedure and are identified as potential cardiac transplantation recipients should they require mechanical circulatory support. These cases are identified to National Services Scotland and funding for their procedure out with Scotland requested through the National service SACCS.

Cardiac catheter structural intervention

Where are we now?

Due to the diversity and complexity in anatomy and physiology of congenital cardiac patients, all cardiac catheter diagnostic assessments and intervention procedures are completed by trained specialist congenital heart disease consultants. This is currently delivered at GJNH and comprises of one cath lab list (9am to 5pm) per week.

Appendix 1 – Overview of SACCS

It comprises both simple and complex diagnostic procedures, including as work-up for cardiac surgery and detailed haemodynamic testing for patients with congenital heart disease.

From an intervention perspective, the team are to accredited to deliver a number of procedures including ASD closure and transcatheter pulmonary valve replacement. In line with national and international standards the interventional procedures are performed by trained cardiologists. Local clinical governance has supported to consultant cardiologists performing the procedure is together to optimise case success and minimise risk. Because of the small number of procedures, we work in close collaboration with the Scottish Paediatric cardiac service based at the Royal Hospital for children in Glasgow. This style of working has been complimented by clinical and industry proctors who have attended to support cases. The congenital heart disease cath lab cases have support from the congenital cardiac surgical team and we working close collaboration to ensure the safety of the patient. We have already delivered a number of hybrid transcatheter procedures where the access has been surgical but the intervention has been transcatheter. This is likely to be an increasing requirement in the future because of complexity of cardiac anatomy and limitations of vascular access.

Where are we going?

As documented in the literature, there is an increasing population of adults with congenital heart disease and increasing number of adults with complex congenital heart disease. As our population matures it is predicated that this will have the following impact;

- Demand on cardiac catheter laboratory time will be maintained, or indeed, may increase in future
- Ongoing support for training and accreditation for new technologies/procedures
- Ongoing need for additional equipment to support cases. For example, contemporary echo scanners for transoesophageal echocardiography ideally with integration in lab to previously acquired cross-sectional imaging
- There have already been a number of hybrid procedures (requiring both surgical and cath lab teams) performed and this is likely to increase for complex valve interventions.
- The use of Biplane radiology imaging to support cases will remain or indeed increase.
- General anaesthetic provision will again likely increase with increasing complexity of cases.
- The ongoing provision of access to overnight cardiology beds

How do we get there?

- Agreed access to catheter lab list/lists each week which have provision for GA support and biplane radiology equipment and with access to overnight cardiology beds.
- Ongoing collaboration with anaesthetic and recovery colleagues.
- Ongoing collaboration with surgical colleagues
- Work is required to optimise cath lab efficiency, minimising delay between cases including planning around access to recovery areas.

Cardiac catheter electrophysiological assessment and intervention

People with congenital heart disease are living longer thanks to significant developments in our capacity to care for them. Crucially in refining the corrective surgeries in the past that allowed them to survive into adulthood, and in our means of supportive medical and interventional therapies in the present. Unfortunately, as the adult congenital heart disease (ACHD) population matures there is an increasing tendency to develop cardiac arrhythmias which, due to the complex and often precarious physiology involved, are often very poorly tolerated by patients with ACHD, who so crucially depend on sinus rhythm for normal function. It is striking that these problems frequently start to afflict young adults at a time when the pressures of life are often greatest, where young children need to be cared for, and full-time employment or higher education needs to be maintained. The impact of these arrhythmias is significant.

Consistent with the global experience, the SACCS team at the Golden Jubilee National Hospital (GJNH), in conjunction with the regional centres across Scotland, are contending with this surge in electrical instability in the ACHD population. The SACCS team host monthly multidisciplinary team meetings with our colleagues in electrophysiology. We strive to ensure that patients across Scotland with ACHD who need formal EP assessment and treatment receive it in the correct location by the correct team at the optimal time. Regional electrophysiology teams may be able to deliver necessary care, though frequently specialised interventions need to be planned and performed at the Golden Jubilee National Hospital by sub-specialised electrophysiologists in an environment supported by the SACCS team, with access to specialist cardiac anaesthetic support and imaging if required. A small number of patients are identified every year who require access to specialist electrophysiology techniques not available within Scotland. Predominantly this includes patients who require ablation by magnetic navigation, or those who require mechanical circulatory support backup for their electrophysiology procedure who may be identified as potential cardiac transplantation recipients. These cases are identified to National Services Scotland and funding for their procedure out with Scotland requested through the National service SACCS.

Where are we now?

An increasing number of patients with ACHD are presenting with heart rhythm abnormalities requiring intervention. These may be brady or tachyarrhythmias and broadly speaking, interventions will involve cardiac implantable electronic devices –

that either to be implanted or extracted, or invasive EP study and catheter ablation by radiofrequency ablation. If the anatomy is acceptable then transfer to the GJNH may not be necessary, however even the presence of relatively minor anatomical variations may mean that regional or local EP team request SACCS support. In such cases funding is sought from the health board to facilitate intervention at GJNH.

Device surgery may involve a conventional transvenous implantable cardiac defibrillator or pacemaker and the specific patient requirements and skills of the local team will determine whether this is done locally or whether transfer to GJNH is necessary. Subcutaneous defibrillators and leadless pacemakers are implanted in Edinburgh and Glasgow and may be implanted at either centre. We therefore discuss such patients through the multidisciplinary team meeting and establish the optimal location for the individual. Device surgeries can be complex, and often close working between Congenital Cardiac Surgeons and cardiac EPs is needed to achieve the optimal solution for the patient. This might include both epicardial, transvenous and subcutaneous components necessitating hybrid procedures. Unfortunately, mirroring trends in the general population, the number of patients developing infections relating to implantable devices is increasing, and this almost invariably indicates device extraction and reimplantation. This complex situation requires detailed planning and collaboration between our electrophysiology and pacing teams, cardiac surgical teams and the SACCS team.

Tachyarrhythmias are a particular problem in this population. Not only are they at risk of lethal ventricular arrhythmias, but they are particularly susceptible to a variety of atrial tachyarrhythmias that are generally very poorly tolerated, particularly in complex congenital heart disease. Patients can be highly symptomatic and are at risk of decompensated heart failure. These can be successfully treated by medical therapy for some patients, though breakthrough arrhythmia is very common, as are intolerable side effects, particularly with chronic therapy with potentially toxic antiarrhythmic drugs. Patients therefore often require catheter ablation to control arrhythmia. Catheter ablation of tachyarrhythmias in the congenital population can be very challenging due to the complexity of the anatomy and the abnormal circuits that develop, and it is recognised that specialist training and experience is necessary to treat such cases. There are also additional demands on the hospital resource for such cases as they may be more time consuming and require specific anaesthetic support. The MDT is particularly important for these cases, in order to get a range of opinions on the appropriate use of catheter ablation in these patients, and also to plan the procedure, including timing, location, personnel and equipment requirements, and the requirement for pre-operative imaging. SACCS currently has funding for 1 complex list per month for electrophysiology cases at GJNH including cardiac anaesthetic support. The is a waiting list is managed by the EP team.

Where are we going?

As documented in the literature, there is an increasing population of adults with congenital heart disease and increasing number of adults with complex congenital heart disease. As our population matures it is predicted that this will have the following impact:

- Increased demand on clinical EP time in the form of clinical consultations, MDT and follow-up.
- An increased demand for pre-procedural preparation requiring clinical support staff and an advanced nurse practitioner to facilitate a smooth patient journey.
- Increased demand on Radiology time for perioperative cross-sectional imaging.
- Demand on cardiac catheter laboratory time will increase.
- Increased access to ablation performed by remote magnetic navigation that is available in one centre in the UK. - It is unlikely within the next 5 years that this technology will be available elsewhere, but if efficacy of this technique is established a drive to adopt this technology will follow and this will require additional training.
- Increased training for Physiologists supporting cases.
- Ongoing support for training and accreditation for new technologies/procedures.
- Ongoing need for additional equipment to support cases. For example, increased access to electroanatomical mapping systems, high-density multi-polar mapping catheters, and intra-cardiac echo.
- An increased demand on overnight cardiology beds.
- An increased demand on local and regional services providing general follow up

How do we get there?

- Audit activity and allocate appropriate time and funding depending on requirements.
- Continued support of existing staff.
- Recognition of increased demand on Radiology resources.
- Agreed access to catheter lab list/lists which have provision for GA support and with access to overnight cardiology beds.
- Invest in training for Physiologists supporting cases.
- Recognition of technical requirements relating to equipment involved in catheter ablation procedures.
- Ongoing collaboration with anaesthetic and recovery colleagues.
- Ongoing collaboration with local and regional services.

As the National service for ACHD we have the privilege to care for this diverse group of young patients who carry a burden of chronic morbidity. We have the responsibility to provide world-class health care for them here at the GJNH. There is an increasing challenge to meet these demands, and we will be well placed to do this through good team work and collaboration; and institutional recognition, support and investment.

Cardiac Obstetrics

As this document highlights, the number of adults with CHD is increasing as is the complexity of the care they require. Both men and women with CHD require access to preconception care and counselling throughout their reproductive years (12-50 years). This includes information related to recurrence or inheritance of CHD in their offspring as well as optimisation of risk factors that can impact pregnancy outcomes and long-term cardiovascular health. In addition, women require an individualised approach to care before and during pregnancy to optimise maternal and fetal outcomes. The presence of maternal heart disease is associated with adverse cardiovascular events in pregnancy, some of which can have a lasting impact on the woman's cardiac status and longevity. Maternal heart disease is also associated with adverse fetal events.

Cardiac obstetric care is complex, involving cardiologists, obstetricians, and obstetric anaesthetists, cardiac anaesthetists, neonatologists, midwives and nurse specialists. It includes pre pregnancy counselling, ante natal, peri-natal and post-partum care. Co-ordinated care by clinicians with expertise in pregnancy and heart disease improves outcomes for mother and baby.

Preconception care and counselling

Preconception care is a proactive approach to improving the short and long-term health of men, women and their offspring. It allows early recognition of the impact of CHD on decision making relating to family planning as well as reduction or management of risk factors that prevent cardiovascular complications later in life.

Preconception counselling (PCC) allows for CHD specific risk stratification. It ensures robust assessment of cardiovascular risk and ensures planning of follow-up for all women with CHD especially those with moderate-high cardiovascular risk in pregnancy. It can also provide appropriate reassurance for women who have a low risk of CV events in pregnancy. PCC requires a personalised approach to care in partnership with the woman which will allow them to make an informed choice about whether or not to pursue a pregnancy. This will also inform contraceptive choice and decisions relating to pursuit of assisted conception therapies.

Antenatal care

A combined cardiac obstetric service was established in 2005. This service has evolved and currently delivers both a regional cardiac obstetric service, and a national cardiac obstetric centre for high-risk women. There is a joint cardiac obstetrics clinic held at Queen Elizabeth University Hospital every fortnight followed by an MDT. Patients are categorised according to the modified World Health Organisation (mWHO) categorisation of maternal risk and care delivered accordingly.

A shared care model:

- All men and women with CHD have equitable access to quality, comprehensive preconception care across their reproductive years when accessing local and national CHD services. This includes providing access to practical tools and strategies to support behaviour change as well as referral to health and social care professionals as required.

- Consideration is given to the social determinants of health and their impact on how we provide information, ascertain understanding & support compliance.
- Preconception care is delivered in an appropriate, culturally sensitive manner.
- Identify red flags: For women and men, ask if they are planning a pregnancy and use the answer to determine the need for further preconception care and/or contraception.
- Establish potential pregnancy risk and offer to facilitate preconception counselling.
- Antenatal care is provided according to the woman's cardiovascular risk with consideration of any co-morbidities and the impact they may have on antenatal care or delivery.
- Moderate-high risk pregnancies have care delivered in the most appropriate location to facilitate access to specialist care. This may mean travel across Health Boards or prolonged inpatient stay in a specialist centre.
- Pregnant women who present acutely with cardiac decline are assessed locally and referred to SACCS for expert multi-disciplinary advice/management. This may include advice to appropriately facilitate care locally or emergency transfer to GJNH in maternal interest.

Specialist clinical input at local ACHD clinics from the National Service

- The national service provides PCC to women attending national and local clinics.
- Moderate-high risk patients referred to SACCS for PCC have input from a multi-disciplinary team relevant to them including a consultant obstetrician.
- Delivery of PCC is adapted to the individual and virtual technology is used where appropriate to ensure equitable access to SACCS from across Scotland.
- Pregnant women can be reviewed at ACHD outreach clinic where appropriate
- Specialist advice in managing the pregnant patient with cardiovascular disease is available through referral to the clinic at the QUEH or through the SACCS consultant on-call

A clinical ACHD network supported by the national service managed through a governance framework

- Clinicians with interest/expertise in cardiac obstetrics have been identified in each health board.
- There are clear communication pathways between local and regional services and the SACCS clinicians.
- Delivery and development of the cardiac obstetric service is monitored through GJNH clinic governance.

Appendix 1 – Overview of SACCS

- Mitigation of potential risks in the management of pregnant women in a non-obstetric setting at the GJNH includes:
    - Access to training in obstetric emergencies to staff involved in care of pregnant women with heart disease
    - Referral pathways
    - Access to a multi-disciplinary team with experience in high-risk cardiac obstetrics and representatives from relevant national services (SACCS, SNAHFS, SPVU) and cardiac and surgical intervention.

A structured education, research and training programme

- SACCS clinicians provide education and training in cardiac obstetrics through:
    - Presentations at local, national and international events.
    - Development of educational resources to develop competence in cardiac obstetrics.
    - Facilitating trainee's attendance at PCC and antenatal clinics. This includes cardiology, anaesthetic and obstetric trainees.
    - Collaboration with centres across the UK and the world to publish data relating to patient outcomes which informs care delivery

An improved model of effective communication, education and clinical support

- Working alongside the Scottish Obstetric Cardiology Network, SACCS continue to develop pathways of communication, education and clinical support to colleagues in local ACHD services and other healthcare professionals who provide care for women with heart disease of reproductive age.

Delivery of cardiac obstetric care in Scotland			
mWHO Class	Preconception counselling	Antenatal management	Location of delivery
I or II	Local ACHD centre	Local centre with 1 / 2 visits to the combined clinic. Will include national patients.	Local Hospital
II – III / III	Local ACHD centre/SACCS	Reviewed at the regional combined clinic. Will include national patients.	Regional Centre
IV	SACCS	Reviewed at the regional combined	Regional Centre - Small number

		clinic. Will include national patients.	considered for delivery at GJNH

- mWHO Class I: No detectable increased risk of maternal mortality and no/mild increase in morbidity
- mWHO Class II: Small increased risk of maternal mortality or moderate increase in morbidity
- mWHO Class III: Significantly increased risk of maternal mortality or severe morbidity. Expert counselling required. Intensive specialist cardiac and obstetric monitoring needed throughout pregnancy, childbirth and puerperium
- mWHO Class IV: Extremely high risk of maternal mortality or severe morbidity; pregnancy contraindicated. If pregnancy occurs termination should be discussed. If pregnancy continues care as for class III

Vision

Continuing to develop a shared approach to preconception care and counselling will facilitate opportunities to inform, empower and support those we encounter to adopt positive health behaviours that impact not only pregnancy outcomes, but also on long-term health. Empowering decision making, facilitating appropriate care can reduce adverse events in pregnancy.

Psychology

Where are we now?

The experience of having a long-term health condition often involving multiple surgical procedures, hospital admissions in childhood, adolescence and adulthood can have a detrimental impact on individual’s psychological well-being (5, 6). Psychosocial development can also be challenged by factors including impaired neurocognitive development, poor body image, parental anxiety, impaired peer relationships and a delay in transitioning to independent adulthood (7, 8).

Specific risk factors for diminished Quality of Life (QoL) in Congenital Heart Disease (CHD) include greater social impediments, lack of employment, lower educational level, psychosocial problems, negative self-statements, trait anxiety, cyanosis, orthopaedic problems, being over 23 years of age, and mitral atresia (7). Psychological distress impacts QoL and in ACHD small changes in mood have been shown to have a larger impact on QoL than changes in exercise capacity (9).

The extent of emotional distress, behavioural disturbance and corresponding psychological needs of people with ACHD has been recognised in the literature (10-16). A local audit within the SACCS service found that one third of patients who attended the routine out-patient clinic, experience psychological distress. This finding was consistent with other studies (10-16) and is notably higher than prevalence rates of anxiety and depression within the general population (17, 18).

Appendix 1 – Overview of SACCS

Despite the recognised prevalence and need, until recently, there was no dedicated psychological provision for ACHD patients in Scotland.

Where are we going?

Recently, the Scottish Government prioritised to improve the mental health of people with ACHD and funding for a clinical psychologist has been identified.

A dedicated psychologist will be a highly valued member of the SACCS team offering expert psychological assessment and interventions.

How do we get there?

- Implement a successful psychological screening program into ACHD outpatient clinics in order to identify individual psychological needs for our patient group.
- Identify clinical care pathways through which patients can access dedicated and expert psychological care.
- Identify an agreed resource library to signpost patients to. The resource library will consist of self-help resources and reliable information for common psychological disturbances.
- Ongoing assessment of the prevalence and nature of psychological distress within our population.

Non- cardiac surgery in ACHD at the Golden Jubilee National Hospital

It is recognised by our commissioners that some patients with complex congenital heart disease and its sequelae require access to cardiac anaesthesia and critical care even for non-cardiac surgical procedures. We have worked closely with specialists in a range of specialties from across Scotland to deliver care to this patient group. This has included laparoscopic cholecystectomy in Fontan physiology, urological reconstruction in systemic right ventricular physiology with pulmonary hypertension, oesophageal stenting in Eisenmenger physiology, dental work in our learning disabled population, and joint replacements in complex cardiac anatomies.

In addition, as described above, we have a carefully prepared pathway for the obstetric deliveries required for the highest risk cardiac conditions.

Each case is considered carefully and we working consult with the non-cardiac specialist to describe the procedural requirements and consider this with the individual patient's needs. If possible we support surgery in the local environment, but when necessary work with our operational management team to achieve surgery at the Jubilee have it is felt to be the correct location.

Appendix 1 – Overview of SACCS

Whilst not technically surgical, we have developed expertise in the assessment of patients with Fontan associated liver disease who have developed high risk lesions as adjudicated at MDT. In consultation with the hepato-biliary MDT and liver transplant teams in Edinburgh and Newcastle some cases have required lesion biopsy and percutaneous microwave ablation. Dr David Kay, consultant radiologist in greater Glasgow and Clyde, has the expertise to deliver the service. As the case numbers increase a defined service will be required with governance and transparency and in collaboration with the teams in Glasgow. The reason the cases have taken place at the Golden Jubilee is for access to specialist cardiac anaesthetic support and critical care backup.

SACCS governance and audit

Introduction

The primary responsibly for the delivery of clinical governance and quality initiatives sits within the divisional line management structures. The SACCS Clinical Governance (CG) Group oversees the development, implementation and ongoing review of a programme of clinical governance objectives.

Membership

The SACCS Clinical Governance Group will be chaired by a Consultant Cardiologist with support from fellow consultant/s in respect of annual leave cover. Membership should be flexible to ensure maximum participation from all staff from within the service.

The Governance meetings will be planned for the rolling CME day each month at 12.00 with quorate consisting of no less than 5 Core members. The frequency will be continually reviewed and amended if required.

Reporting

The SACCS CG Group is a sub-group of the Clinical Governance Risk Management Group (CGRMG). The SACCS CG group will provide formal reports to the CGRMG on a scheduled basis, no less than three times per year. The SACCS CG group will provide a formal report to the Boards Clinical Governance Committee once a year.

Responsibilities and Remit

The overarching function of the SACCS CG group is to:

- Collectively and continuously improve the safety and quality of clinical care within SACCS
- Provide assurance to the CGRM group that appropriate clinical governance mechanisms are in place and effective throughout the service.
- Ensure that systems are in place to provide effective assurance, support and delivery of healthcare services.
- Identify issues with current practice, enabling key risks to clinical quality to be assessed and managed
- Drive clinical improvement work across the service ensuring participation in relevant national programmes and local projects supporting agreed local priorities

Appendix 1 – Overview of SACCS

- Management of Significant Adverse Events
    - All SAER reports will be presented to SACCS CG for approval to ensure a robust review with remit achieved and actions agreed. The group will then monitor the agreed actions to ensure compliance.
- New Interventional Procedures
    - All new proposals must be discussed and agreed at SACCS CG before final approval from CGRMG
- Clinical Audit and Clinical Audit Policy
    - Review of report to ensure compliance with agreed policy and process and links to wider quality aims, including actions and recommendations from relevant clinical audit within the service
- Policy on Policies
    - Review to ensure compliance with agreed framework including the approval and supporting review of relevant Policies, Guidelines and Protocols

Group members have a formal responsibility to communicate the decisions and actions agreed at meetings with departments they are responsible for. They also have a responsibility to inform the Group of any issues that require management awareness or decision making.

Challenges in the next 5 years

The major challenge within audit and quality assurance for the SACCS team over the next years will be the transition from the well-established NICOR audit programme hosted by NHS England, to an as yet undeveloped Public Health Scotland replacement. There is active work ongoing involving the data management team and clinical team from the paediatric cardiac service and SACCS. Our patients, commissioners and clinical teams require the confidence gained from robust quality assurance with benchmarking comparison to our peers. The new Scottish audit programme has been challenged to deliver at least as good data if indeed not better. The SACCS team will continue to support the work in developing this project.

Appendix 2: gap analysis of SACCS with NHS Scotland Standards for specialist centre for ACHD

Congenital Cardiac Standards – Gap Analysis

Themes from the gap analysis 2021

NETWORK	Leadership and governance across the national network is still unclear and poorly developed.
NETWORK	Occasional practice for ACHD intervention still exists out with the specialist centre.
INFORMATION SYSTEMS	There is no robust internal database for audit or bench-marking Post NICOR there is no equivalent externally validated high quality procedural audit
INFORMATION SYSTEMS	Patient not given copies of letters/written care plans. There is no patient passport/direct patient access
INFORMATION SYSTEMS	Inadequate booking system to book complex long term follow-up No system in place to minimize lost to follow up across the network especially at transfer to adult care
INFORMATION SYSTEMS	Communication across the network with a seamless pathway of care does not exist. There are no joined up processes for investigations, booking appointments, or sharing results/data.
CAPACITY	Delays to discussion at MDT meeting due to difficulties retrieving local data e.g. echo images Long waiting times for investigations and treatments
CAPACITY	Timely transfer of care is limited by inadequate number of inpatient beds in the NSD pod. Multiple cancellations for surgery and intervention due to bed and staffing issues.
STAFFING	Congenital surgical oncall rota is still a 1 in 2 or 1 in 3.
STAFFING	Inadequate psychiatric and psychological input. (Psychology post has now been advertised).

Appendix 2: gap analysis of SACCS with NHS Scotland Standards for specialist centre for ACHD

STAFFING	No named nurses and no universal access to nursing staff in clinics Nurses do not rotate between the specialist centre and the local centres

Full SACCS Service Gap Analysis 2021

	A: The Service Approach	Status
1	The specialist service will be commissioned by National Services Division (NSD) and hosted by NHS GJNH Scotland will liaise with provider units across Scotland.	**GREEN**
2	The specialist service in partnership with the wider service and NSD will establish a model of care that delivers all aspects of specialised care and treatment of patients with congenital heart disease throughout their life. The model of care will ensure that all specialised congenital cardiac care is carried out only by congenital cardiac specialists (including advanced investigation, cardiology and surgery). The model of care will also ensure that as much care and treatment will be provided as close as possible to home and that travel to the specialist service only occurs when essential, while ensuring timely access for interventional procedures and the best possible outcomes.	**AMBER** Some devices still performed in non-ACHD centre
3	The specialist service is responsible for the care of patients with Congenital Heart Disease (CHD) across their whole lifetime including prenatal diagnosis, maternity and obstetric services, children's services, transition from paediatric congenital cardiac services and the local hospice palliative care team. The specialist services should work closely with other relevant services including foetal services, maternity services and intensive care services to ensure a joined-up approach with treatment continuity.	**AMBER** To direct links with local hospice palliative

4	The specialist service will adhere to clinical protocols and pathways of care that will: • achieve high quality of care at all stages of a seamless pathway in accordance with the model of care; • facilitate the development of as much non-interventional care and treatment as close as possible to home; • have a clear pathway for managing patients who self-refer out of hours, ideally using the patient passport or other equivalent electronic care record; • facilitate access to second opinions and referrals to other centres/services via the out of area teams and NSD; • address how ACHD cardiologists will work including with local services; and • address how the centre will communicate effectively with colleagues across the wider service to care for patients requiring non-cardiac interventions.	**RED** To linked database or patient management system to allow seamless care No patient passport No direct access

5	There must be an appropriate mechanism for arranging retrieval and timely repatriation of patients which takes into account the following: • Clinical transfers must be arranged in a timely manner according to patient need. • Acute beds must not be used for this purpose once patients have been deemed fit for discharge from acute cardiac care.	**AMBER** Bed capacity issues in NSD
6	There will be specific protocols for the transfer of patients requiring interventional treatment.	**GREEN ?**
7	All patients transferring across or between locations will be accompanied by high quality information, including a health records summary (with responsible clinician's name) and a management plan, which takes account of an co- morbidities and communication needs. The health records summary will be a standard national template developed and agreed by the specialist service, representatives of the local services and commissioners.	**GREEN ?**
8	The specialist service will develop and implement a nationally consistent system of 'patient-held records'.	**AMBER**
	Cardiological Interventions	

9	The specialist service will adhere to the clinical protocols and pathways of care that will: • require all ACHD surgery, catheter interventions, including atrial septal defect closure and diagnostic catheter procedures to take place within the specialist service; and • enable access to hybrid procedures (those involving both surgeons and interventional cardiologists) in an appropriate facility either in the specialist service or in another specialist ACHD surgical centre, if the need arises.	**AMBER** Some devices still performed in non-ACHD centre
	Non-Cardiac Surgery	
10	The specialist service will agree with the local services clinical protocols and pathways of care that will ensure 24/7 availability of specialist advice including pre-operative risk assessment for patients requiring non-cardiac surgery by an ACHD specialist, the most appropriate location for that surgery and advice to non-ACHD cardiologists across the wider service.	**GREEN**
	External Relationships	
11	The specialist service must have a close relationship with all maternity services and be able to demonstrate the operation of joint protocols.	**GREEN**

12	The specialist service must have a close relationship with the Specialist Paediatric service and be able to demonstrate the operation of joint transition protocols.	**GREEN**
13	The specialist service must have a formal relationship with the following, evidenced by agreed joint referral and care protocols: • the cardiothoracic transplant centres including one staffed by transplant surgeons with a congenital practice; • the national Pulmonary Hypertension Service; and • a cardiac pathologist with expertise in congenital cardiac abnormalities.	**GREEN**
14	Patients who require assessment for heart transplantation (including implantation of a mechanical device as a bridge to heart transplant) must be referred to a cardiothoracic transplant centre. The referring specialist is responsible for explaining to the patient the transplant pathway and the risks and benefits of referral and any alternative pathways to inform patient choice. The designated transplant centre is responsible for managing and developing referral, treatment and transfer pathways, policies, protocols, and procedures in respect of transplant patients.	**GREEN**
15	The specialist service must maintain links with community adult services to ensure the provision of a full range of community adult support services particularly for patients with complex medical and social needs.	**GREEN*** Local provision outwith SACCS remit
	Telemedicine and IT	
16	The specialist service will have telemedicine facilities as required to link with other hospitals. The level of telemedicine required will be agreed between locations. As a minimum this must include the facility to: • undertake initial assessments of echocardiograms; • support participation in multi-site VC MDT meetings; • handle emergency referrals; • allow timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various services; and • support video-conferencing for outpatient consultations from home when appropriate.	**GREEN*** Still rely on disc transfer of echos

Appendix 2: gap analysis of SACCS with NHS Scotland Standards for specialist centre for ACHD

	Multidisciplinary Team (MDT)	
17	The specialist service will have a dedicated specialist multidisciplinary team (MDT) that meets weekly to consider case management. Patients undergoing complex interventions or any surgical interventions must be discussed in an appropriate MDT meeting. All rare, complex and innovative procedures and all cases where the treatment plan is unclear or controversial will be discussed at the MDT. The attendance and activities of the MDT meeting will be maintained in a register.	**GREEN*** No formal register
18	Staff should be encouraged to attend MDT meetings in person or by video/teleconferencing and participate in the decision-making about their patient where necessary.	**GREEN**
19	• The composition of the MDT will be pathway driven, and adjusted according to the needs of different aspects of the service (for example: assessment, post-operative care, clinic, pathological and audit meetings). • An out-of-hours MDT meeting for emergency decision-making will include as a minimum a congenital heart surgeon, an ACHD cardiologist and an intensivist.	**GREEN**
20	The specialist service will hold regular MDT meetings for issues such as agreement of protocols, review of audit data and monitoring of performance. Meetings will be held at least every six months.	**GREEN**
	Leadership	
21	The service will have an appointed clinical lead with responsibility for the service in Scotland, who will be supported by the wider MDT. The clinical lead will provide leadership across the service and will be endorsed by NSD	**GREEN*** Clinical governance/ responsibility for network unclear

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	B: Staffing and Skills	**Implementation timeline**
1	The specialist service must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service within compliant rotas, including access to surgery and interventional cardiology. A consultant ward round will occur daily.	**AMBER** Surgeons on 1 in 2 to 3 rota
2	ACHD cardiologists and congenital cardiac surgeons must only undertake procedures for which they have the appropriate competence. In other cases, either: • the support of a competent second operator/interventionist must be obtained from within the service or another Specialist ACHD Surgical Centre; or • the patient must be referred to an alternative Specialist ACHD Service where a surgeon/interventionist has the appropriate skills.	**GREEN**
3	Arrangements must be in place in the specialist service both for ACHD cardiologists and for congenital cardiac surgeons to operate together on complex or rare cases.	**GREEN**
4	ACHD cardiologists and congenital cardiac surgeons will be mentored and supported by a lead interventionist or surgeon. Newly qualified consultants will initially share lists with more experienced colleagues.	**GREEN**
5	The specialist service must work with local services to develop and support collaborative arrangements that facilitate mentorship and referral protocols.	**AMBER** Limited mentorship at present
6	The specialist service will have a nominated lead.	**GREEN**
7	All patients requiring investigation and treatment will receive care from staff trained in safeguarding standards, in accordance with the requirements of their profession and discipline.	**GREEN**
	Surgery	
8	All adult congenital cardiac surgical cases must be carried out by a specialist congenital cardiac surgical team with expertise and experience in adult congenital heart disease.	**GREEN**

9	Consultant congenital surgery cover must be provided by consultant congenital surgeons providing 24/7 emergency cover. The specialist service must develop out-of-hours arrangements that take into account the requirement for surgeons only to undertake procedures for which they have the appropriate competence. The rota will deliver care for both children and adults. If this means that the surgeon is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.	**GREEN**
10	Congenital cardiac surgeons must work in teams of at least three surgeons, each of whom must be an operator in a minimum of 125 congenital heart operations per year (in adults and/or paediatrics), averaged over a three-year period. Cases should be submitted to the appropriate audit organisation.	**AMBER**~~??~~
11	Perfusion services and staffing must be accredited by The College of Clinical Perfusion Scientists of Great Britain and Ireland.	**GREEN**~~?~~
	Cardiology	
12	All adult congenital cardiology must be carried out by specialist ACHD cardiologists (BCCA definition).	**GREEN**
13	The specialist service must be staffed by a minimum of 4 ACHD specialists.	**GREEN**
14	The specialist service must deliver 24/7 elective and emergency care, with input from consultant specialist ACHD cardiology on-call cover for the specialist service and to provide advice across the service including requests for transfers.	**GREEN**
15	The specialist service must be staffed by at least two interventional cardiologists (ACHD or paediatrics), who may be included in the number referred to in Standard 13.	**GREEN**
16	Cardiologists employed by the specialist service and trained to the appropriate standards in interventional and diagnostic ACHD cardiology shall be provided with appropriate sessions and support to maintain and develop their specialist skills.	**GREEN**

17	Interventional cardiologists performing therapeutic catheterisation in patients with congenital heart disease must be involved as an operator in a minimum of 50 such procedures per year; averaged over a three-year period. Cases should be submitted to the appropriate audit organisation.	**GREEN~~??~~**
18	The specialist service must have access to an expert electrophysiologist experienced in ACHD. There must be appropriate arrangements for cover by a competent person. Cases should be discussed via an appropriate MDT process.	**GREEN**
19	The catheterisation laboratory must comply with the British Congenital Cardiac Association standards for catheterisation and have the following staff to operate safely: • dedicated and appropriately trained cardiac physiologists; • a radiographer; • a ‘running’ member of staff without other duties and with specific knowledge of the location of equipment required in congenital interventional catheterisation; and • a nurse with experience of congenital cardiac catheterisation.	**GREEN**
20	The specialist service must be staffed by a congenital cardiac imaging specialist (who may be a cardiologist or a radiologist), expert in both cardiac MRI and cardiac CT. There will be joint reporting (cardiologist and radiologist) and dedicated MDT review of complex cases. There will be shared protocols for cross-sectional imaging between the Specialist and local services.	**GREEN*** Limited shared protocols
21	The specialist service will have 24/7 anaesthetic support by consultants experienced in the management of ACHD patients.	**GREEN**
22	At the specialist service an ACHD cardiologist will act as the lead for congenital echocardiography. The lead must be European Association of Cardiovascular Imaging (EACVI) Congenital Heart Disease Echocardiography accredited (or have recognised equivalent accreditation or experience). The lead will have dedicated echocardiography sessions and will have responsibility for training and quality assurance.	**GREEN**

23	The specialist service will have a team of congenital echocardiography scientists (technicians), with a designated congenital echocardiography scientist (technician) lead who spends at least half the week on congenital echocardiography-related activity. All scientists should have or be working towards appropriate accreditation. The size of the team will depend on the configuration of the service, the population served, and whether the service is integrated with paediatric echocardiography.	**GREEN~~??~~**
	Intensive Care	
24	Intensive Care Unit (ICU) consultants with appropriate skills in congenital cardiac critical care must be available to the ICU on a 24/7 basis.	**GREEN**
25	Intensive Care Units and High Dependency care will be staffed in accordance with national standards. Patients must be cared for by nurses with appropriate training and competencies in adult congenital cardiac critical care.	**GREEN**
	Nursing	
26	The specialist service must have a nominated lead nurse with responsibility for the service providing professional and clinical leadership and support to the team of specialist nurses.	**GREEN**
27	Nursing care must be provided by a dedicated team of nursing staff trained in the care of young people and adults who have received cardiac surgery. The ACHD inpatient nursing team will be led by a senior nurse with specialist knowledge and experience of congenital cardiology and cardiac surgery.	**AMBER~~??~~**
28	The specialist service will employ the required number of specialist nurses that reflect the patient population needs and appropriate capacity to extend the role to all service providers for all aspects of the patient pathway, ensuring that both an in-hospital and outreach services. Each patient must have a named nurse specialist responsible for coordinating their care, and who acts as a liaison between the clinical team, the patient and partner/family or carers.	**AMBER** No named nurse and limited capacity
29	The specialist nurses will work closely with the paediatric specialist nurses to coordinate the transfer process for each patient.	**GREEN**
	Psychology	
30	The specialist service should have access to psychological services.	**RED**

	Administrative Staffing	
31	The specialist service will provide administrative support to ensure availability of medical records, organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow-ups and respond to patients and partners/family or carers in a timely fashion.	**GREEN**
32	The specialist service must have a dedicated congenital cardiac surgery/cardiology data collection manager, responsible for audit and database submissions in accordance with necessary timescales.	**GREEN**
	Other (See also section D: interdependencies for professions and specialties where dedicated sessions are required.)	
33	The host board will have a nominated lead doctor and lead nurse for safeguarding vulnerable adults.	**GREEN**

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	C: Facilities	Implementation timeline
1	There must be facilities in place to ensure easy and convenient access for partners/family/carers. Facilities and support include: • accommodation for partners/family members to stay; • the ability for at least one parent/carer to stay with any patient with learning disabilities in the ward 24 hours per day (except when this is considered to be clinically inappropriate); • access to refreshments; • facilities suitable for the storage and preparation of simple meals; and • an on-site quiet room completely separate from general facilities. Family accommodation should be provided without charge.	**GREEN**
2	All adult patients must be seen in an appropriate adult environment as an outpatient, be accommodated in an exclusively adult environment as an inpatient, ideally within a dedicated ACHD ward space, and offered cultural and age-appropriate cardiac rehabilitation, taking into account any learning or physical disability. The specialist service must provide 24/7 emergency telephone advice service for patients with urgent concerns about deteriorating health.	**GREEN** ? direct access
3	Patients must have access to general resources including books, magazines and free WiFi.	**GREEN**
4	There must be facilities, including access to maternity staff, that allow the mothers of newborn babies who are admitted as emergencies to stay with their baby for reasons of bonding, establishing breastfeeding and the emotional health of the mother and baby.	**RED~~??~~**
5	Patients and their partners/family/carers will be provided with accessible information about the service and the hospital, including information about amenities in the local area, travelling, parking and public transport.	**GREEN**
6	If an extended hospital stay is required, any parking charges levied by the hospital or affiliated private parking providers must be reasonable and affordable. Each hospital must have a documented process for providing support with travel arrangements and costs.	**GREEN**

7	There must be dedicated room space in which practitioner psychologists, cardiac physiologists, ACHD nurse specialists and social work staff can conduct therapeutic work.	**GREEN**
8	The specialist service must have local arrangements for transferring patients from airfields and helipads.	**GREEN**
9	All patients should have access to cardiac rehabilitation facilities.	**GREEN**

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	D: Interdependencies	Implementation timeline
	The following specialties or facilities **must be co-located on the same hospital site or within 30 minutes of the specialist service**. They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within **30 minutes**).	
1	General adult cardiology services, including acute cardiac care unit.	**GREEN**
2	Airway Team capable of complex airway management and emergency tracheostomy (composition of the team will vary between institutions).	**GREEN**
3	Intensive Care Unit: Level 3, capable of multi-organ failure support. High Dependency beds: Level 2, staffed by medical and nursing teams experienced in managing patients with ACHD.	**GREEN**
4	Specialised congenital cardiac anaesthesia.	**GREEN**
5	Perioperative extracorporeal life support with or without ventricular assist programme . (Non-nationally designated extracorporeal membrane oxygenation (ECMO)).	**GREEN**
6	Adult cardiac surgery.	**GREEN**
7	Vascular services including surgery and Interventional Radiology.	**GREEN**
8	The specialist service must possess the full range of non-invasive diagnostic imaging capabilities including CT and MRI scanning and suitable trained radiological expertise. The range of cardiac physiological investigations must include Electrocardiography (ECG), Holter monitoring, event recording, exercise testing, ambulatory blood pressure monitoring and pacemaker follow-up and interrogation, as well as standard, contrast, intraoperative, transesophageal and foetal echocardiography. The specialist service should be able to undertake Cardio-Pulmonary Exercise Testing (CPEX) and the six-minute walk test; if not provided on site they must have access to these investigations. The specialist service must have access to Isotope Imaging. Radiological and echocardiographic images must be stored digitally in a suitable format and there must be the means to transfer digital images between services.	**GREEN**

	The specialist service must offer invasive diagnostic investigation and treatment, including: • catheter intervention; • electrophysiological intervention; • implantable cardioverter defibrillator (ICD) and pacemaker insertion and extraction (including Cardiac Resynchronization Therapy - CRT); and • cardiac surgical intervention, including the provision of extracorporeal support of the circulation and hybrid catheter/surgical treatment (where clinically indicated).	
	The following specialties or facilities **should** be co-located on the same hospital site or within 30 minutes of the specialist service. They must function as part of the extended multidisciplinary team. Consultants from the following services **must** be able to provide emergency bedside care (call to bedside within **30 minutes**) 24/7. The specialist service must ensure that facilities are available to allow emergency intervention by these specialties if clinically indicated (i.e. without transfer).	
9	Specialist Paediatric Congenital Cardiac Surgery and Intervention. [This standard recognises shared staffing and out-of-hours cover.]	**GREEN**
10	General Surgery.	**GREEN**
11	Nephrology/Renal Replacement Therapy.	**GREEN**
12	Gastroenterology.	**GREEN**
13	Physiotherapy (service must be integrated with the ACHD team).	**GREEN**
14	General medicine and provision for diabetes, endocrinology and rheumatology services.	**GREEN**
15	Gynaecology.	**GREEN**
16	Neonatal unit (NICU): Level 3.	**GREEN**
17	Microbiology and infectious diseases.	**GREEN**
18	Obstetric unit with maternal foetal medicine specialist(s).	**GREEN**

19	Respiratory medicine.	GREEN
20	Urology.	GREEN
21	Pain management service.	GREEN
22	Bereavement Support, including nurses trained in bereavement support.	GREEN
	The following specialties or facilities **should ideally** be co-located on the same hospital site as the specialist service. Consultants from the following services must be able to provide urgent telephone advice (call to advice within **30 minutes**) and a visit or transfer of care within **four hours** if needed. The services **must** be experienced in caring for patients with congenital heart disease.	
23	Clinical Haematology.	GREEN
24	Clinical biochemistry.	GREEN
25	Orthopaedics.	GREEN
26	Acute stroke services.	GREEN
27	Neurology.	GREEN
28	Neurosurgery.	GREEN
29	Psychiatry (with dedicated sessions and 24/7 on call).	RED
	The following specialties or facilities must be able to provide **advice and consultation at least by the following working day**. The services must be experienced in caring for patients with congenital heart disease.	
30	Ear, Nose and Throat.	GREEN
31	Psychology.	RED
32	Dietician.	GREEN

33	Clinical Genetics.	**GREEN**
34	Dentistry.	**GREEN**
35	Clinical Immunology.	**GREEN**
36	Dermatology.	**GREEN**
37	Sexual health.	**GREEN**
38	Cardiac rehabilitation.	**GREEN**
39	Occupational therapy.	**GREEN**
40	Social work services.	**GREEN**

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	E: Training and Education	**Implementation timeline**
1	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including safeguarding, life support, pain management, infection control, end of life, bereavement, breaking bad news and communication.	**GREEN**
2	All members of the cardiac and ICU medical and nursing team will complete mandatory basic training on end-of-life care, breaking bad news and supporting patients and their partners, families and carers through loss. Identified members of the medical and nursing team will need to undergo further in-depth training.	**GREEN**
3	Nurses working within the specialist service must be offered allocated rotational time working within local services to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place. Similarly, nurses working within local services must be offered allocated rotational time working in the specialist service, with a formal annual training plan in place.	**RED**
4	The specialist service must demonstrate a commitment to the training and education of both core and subspecialty level training in ACHD cardiology, ACHD surgery and congenital heart disease in pregnancy, according to the latest Joint Royal Colleges of Physicians’ Training Board curriculum.	**GREEN**
5	The specialist service will have a formal annual training plan in place, which ensures ongoing education and professional development for all healthcare professionals involved in the care of patients with congenital heart problems. The specialist service must provide resources sufficient to support these educational needs.	**GREEN**
6	The specialist service must have one individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care, and to deliver standardised training and competency-based education programmes across all service providers. The competency-based programme must focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication. Skills in teaching, research, audit and management will also be part of the programme.	**GREEN**

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	F: Information, Governance and Audit	**Implementation timeline**
1	The specialist service must demonstrate a robust policy for collaboration with other specialist providers and NSD for audit, including formal inter-unit peer review every five years.	**GREEN**
2	The specialist service must have a dedicated management group for the internal management and coordination of service delivery. The group must comprise the different departments and disciplines delivering the service.	**GREEN**
3	All clinical teams within the congenital service will operate within a robust and documented clinical governance framework that includes: • regular continuous clinical audit and quality improvement; • regular meetings of the wider clinical team (in which patient representatives will be invited to participate) held at least every six months to discuss patient care pathways, guidelines and protocols, review of audit data and monitoring of performance; and • regular meetings of the wider clinical team, held at least every six months, whose role extends to reflecting on mortality, morbidity and adverse incidents; and resultant action plans from all units.	**GREEN*** No national governance structure or meetings
4	The specialist service will report on adverse incidents and action plans. In addition to contractual and national reporting requirements, the specialist service must demonstrate how details of adverse incidents are disseminated across all service providers.	**GREEN**
5	The specialist service will have a robust internal database and outcome monitoring tool based on standardised national audit coding. The database will have seamless links to that of local services. Audit of clinical practice should be considered where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NSD) of demonstrable clinical significance will be undertaken annually.	**AMBER** Post-NICOR unclear process

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6	Audits must take into account or link with similar audits across the service and other related specialties.	**GREEN**
7	Current risk adjustment models must be used, with regular multidisciplinary team (MDT) meetings to discuss outcomes with respect to mortality, re-operations and any other nationally agreed measures of morbidity.	**GREEN**
8	Patient outcomes will be assessed with results monitored and compared against national and international outcome statistics, where possible.	**AMBER** Post-NICOR unclear process
9	The specialist service must participate in national programmes for audit and must submit data on all interventions, surgery, electrophysiology procedures and endocarditis to the national congenital database in the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	**AMBER** Post-NICOR unclear process
10	The congenital heart database must allow analysis by diagnosis to support activity planning.	**RED**
11	The specialist service must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NSD. The specialist service will follow available guidance in discussion with NSD.	**GREEN**
12	Governance arrangements must be in place to ensure that when elective patients are referred to the MDT, they are listed in a timely manner. Where cases are referred to the specialist MDT meeting for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.	**AMBER** Only urgent cases discussed within 6 weeks
13	Admission for planned surgery will be booked for a specific date in line with referral to treatment target.	**AMBER** Frequent cancellations due to urgent cases delays care
14	All patients who have operations cancelled for non-clinical reasons are to be offered another binding date with the 12 week treatment time guarantee.	**AMBER** Frequent cancellations due to urgent cases delays care

15	The specialist service must inform local services of any relevant cancellations and the new date offered.	**AMBER** Frequent cancellations due to urgent cases delays care
16	Last minute cancellations must be recorded and discussed at the MDT meeting.	**AMBER** Frequent cancellations due to urgent cases delays care

17	If a patient needing a surgical or interventional procedure who has been actively listed can expect to wait longer than 12 weeks, all reasonable steps must be taken to offer a range of alternative providers, if this is what the patient wishes. The specialist service and local services must be involved in any relevant discussions.	**AMBER** Long waiting times for intervention
18	When the specialist service cannot admit a patient for whatever reason, or cannot operate, it has a responsibility to source a bed at another specialist ACHD surgical centre or specialist ACHD centre, if appropriate.	**GREEN**
19	A specialist nurse must be available to provide support and advice to nursing staff within intensive care, high dependency care and inpatient wards.	**GREEN**
20	The specialist service must implement a pain control policy that includes advice on pain management at home.	**GREEN**
21	Advice must be taken from the acute pain team for all patients who have uncontrolled severe pain. Particular attention must be given to patients who cannot express pain because of their level of speech or understanding, communication difficulties, their illness or disability.	**GREEN**
22	The specialist service must demonstrate that clinical services and support services are appropriate and sensitive to the needs of teenagers, young people and older people with congenital heart disease.	**GREEN**
23	The specialist service will provide a psychology service that extends across the service and ensure that patients have access to a psychology appointment: • within 5 working days for procedural distress, anxiety, low mood, adjustment, adherence or decision making difficulties that interfere with medical care; or • within 18 weeks for all other out-patient referrals.	**RED**
24	The specialist service will demonstrate that it has in place arrangements for psychology follow-up where needed, either through psychology appointments or by referral to other psychologists with experience of CHD closer to the patient’s home or other agencies.	**RED**

	G: Research	Implementation timeline
1	The specialist service is expected to participate in research.	GREEN
2	The specialist service must have, and regularly update, a research strategy and programme that documents current and planned research activity in the field of ACHD and the resource needed to support the activity and objectives for development. This must include a commitment to working in partnership with other Specialist ACHD Services and local services as appropriate, in research activity which aims to address issues that are important for the further development and improvement of clinical practice, for the benefit of ACHD patients.	GREEN
3	The specialist service must demonstrate close links with one or more academic department(s) in Higher Education Institutions.	GREEN
4	Where they wish to do so, patients should be supported to be involved in trials of new technologies, medicines etc.	GREEN

	H: Communication with Patients	**Implementation timeline**
1	The specialist service must demonstrate that arrangements are in place that allows patients to participate in decision- making at every stage in their care.	**GREEN**
2	Every patient must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	**RED**
3	Patients and partners, family or carers must be helped to understand the patient's condition and its impact, what signs and symptoms should be considered 'normal' for them, in order to be able to actively participate in decision-making at every stage in their care, including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the patient's and partner/family/carers' understanding must be considered. Information should include any aspect of care that is relevant to their congenital heart condition, including • exercise and sports participation; • sex, contraception, pregnancy; • dental care and endocarditis prevention; • smoking, alcohol and drugs; • tattoos, piercings and intradermal procedures; • careers; • travel; • welfare benefits; • social services; and • community services.	**GREEN**

4	When referring patients for further investigation, surgery or cardiological intervention, patient care plans will be determined primarily by the availability of expert care for their condition. The ACHD cardiologist must ensure that patients are advised of any appropriate choices available as well as the reasons for any recommendations.	**GREEN**
5	Sufficient information must be provided to allow the patient to make informed decisions, including supporting patients, partners, family or carers in interpreting publicly available data that support choice. The following should also be described: • other clinical specialties offered by alternative units, relevant to patients with co-morbidities; • accessibility of alternative units; • patient facilities offered by alternative units; • outcomes at units under consideration; and • consideration of the closest unit to the patient's home.	**GREEN**
6	The specialist service must demonstrate that patients, partners, family and carers are offered support in obtaining further opinions or referral to another specialist ACHD surgical centre, and in interpreting publicly available ACHD data that supports patient choice.	**GREEN**
7	Information must be made available to patients, partners, family and carers in a wide range of formats and on more than one occasion. It must be clear, understandable, culturally sensitive, evidence-based, developmentally appropriate and take into account special needs as appropriate. When given verbally, information must be precisely documented. Information must be interpreted or transcribed as necessary.	**GREEN**
8	The specialist service must demonstrate that arrangements are in place for patients, partners, family or carers to be given an agreed, written management plan in a language they can understand, that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.	**AMBER**
9	The patient's management plan must be reviewed at each consultation – in all services – to make sure that it continues to be relevant to their particular stage of development.	**GREEN**

10	Patients, partners, family and carers must be encouraged to provide feedback on the quality of care and their experience of the service. The specialist service must make this feedback openly available to patients, partners/families/carers and the general public, together with outcome of relevant local and national audits. The specialist service must demonstrate how they take this feedback into account when planning and delivering their services. Patients must be informed of the action taken following a complaint or suggestion made. The specialist service must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.	**GREEN**
11	The specialist service must have booking systems that allow for long-term follow-up (up to 5 years). Patients should be reminded of their appointment in line with NHS Board Did Not Attend (DNA) policy.	**AMBER** Poor quality system
12	Each patient must have access to a specialist nurse who will be responsible for coordinating care across all providers, acting as a liaison between the clinical team, the patient and partner/family/carers throughout their care. Patients with complex needs must have a named specialist nurse. Specialist nurse contact details will be given at each attendance at the outpatient clinic.	**AMBER** No names nurse
13	A specialist nurse must be available at all outpatient appointments to help explain the diagnosis and management of the patient’s condition and to provide literature.	**AMBER** Not at all clinics
14	The specialist nurse will support patients by explaining the diagnosis and management plan of the patient’s condition, and providing psychosocial support to promote adaptation and adjustment.	**GREEN**
15	The specialist nurse must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities. Support for people with learning disabilities must be provided from an appropriate specialist or agency.	**GREEN**

16	Where patients do not have English as their first language, or have other communication difficulties such as deafness or learning difficulties, they must be provided with interpreters/advocates where practical, or use of alternative arrangements such as telephone translation services and learning disability ‘passports’ which define their communication needs.	**GREEN**
17	There must be access (for patients, partners, families and carers) to support services including faith support and interpreters.	**GREEN**
18	Copies of all correspondence for GP and local centres must be copied to the patient in plain language to retain in the patient’s personal record in accordance with national guidance.	**RED**
19	Patients, partners, family or carers and all health professionals involved in the patient’s care must be given details of who, and how, to contact if they have any questions or concerns. Information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	**GREEN**
20	Partners/family/carers should be offered resuscitation training when appropriate.	**GREEN**
21	Where surgery or intervention is planned, patients and carers must have the opportunity to visit the specialist service well in advance of admission (as early as possible) to meet the team, including the specialist nurse that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.	**GREEN**
22	Patients must be given an opportunity to discuss planned surgery or interventions prior to planned dates of admission. Preliminary consent may be taken by any member of the medical team, at a pre-admission clinic or visit. Consent must be taken in line with GMC guidance.	**GREEN**
23	A specialist nurse must be available to support patients and carers through the consent process. When considering treatment options, patients and carers need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.	**AMBER**
24	Patients and carers must be given details of available local and national support groups at the earliest opportunity.	**GREEN**

25	Patients must be provided with information on how to claim travel expenses and how to access social care benefits and support.	**GREEN**
26	A psychologist experienced in the care of congenital cardiac patients must be available to support patients at any stage in their care but particularly at the stage of diagnosis, decision-making around care and lifecycle transitions, including transition to adult care.	**RED**
27	When patients experience an adverse outcome from treatment or care the medical and nursing staff must maintain open and honest communication with the patient and their family. Identification of a lead doctor and nurse (as agreed by the patient or their family/carers) will ensure continuity and consistency of information. A clear plan of ongoing treatment, including the seeking of a second opinion, must be discussed so that their views on future care can be included in the pathway. An ongoing opportunity for the patient to discuss concerns about treatment must be offered.	**GREEN**

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	I: Transition	**Implementation timeline**
1	The specialist service must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs. 'Lost to follow-up' rates must be recorded and discussed at the MDT meeting.	**AMBER** Lost to FU not tracked at MDT
2	The service must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.	**GREEN**
3	There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 14 years of age, taking into account individual circumstances and special needs.	**GREEN**
4	All patients requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and a specialist nurse, in a specialist MDT transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future management in a clearly specified setting, unless the patient's care plan indicates that they do not require long-term follow-up.	**GREEN**
5	Patients, partners, families and carers must be fully involved and supported in discussions around the clinical issues in accordance with the patient's wishes. The views, opinions and feelings of the patient must be fully heard and considered, and the patient must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.	**GREEN**
6	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	**GREEN**

7	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice. Management of young people arriving in the adult service will aim to ensure that they are fully confident in managing their own condition and health care. In the clinic, they will see a specialist nurse who will explain and discuss a range of issues including the impact of their condition, contraception and pregnancy, and lifestyle, in language the young person can understand. The cardiologist will discuss the treatment plan with the young person and discuss it with their family/carers when appropriate. The young person will have some independent time to talk with their ACHD Cardiologist and specialist nurse.	**GREEN**
8	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.	**GREEN**
9	Young people must have the opportunity to be seen by a psychologist on their own. Psychological support must also be offered to partners/family or carers.	**RED**

Appendix 2: gap analysis of SACCS with NHS Scotland Standards for specialist centre for ACHD

	J: Pregnancy and Conception	**Implementation timeline**
	Family Planning Advice	
1	All female patients of childbearing age must be offered personalised pre-pregnancy counselling and contraceptive advice by an ACHD cardiologist and a specialist nurse with expertise in pregnancy in congenital heart disease.	**GREEN**
2	All female patients of childbearing age must have access to a service that provides specialist advice on contraception and childbearing potential and counselling by practitioners with expertise in congenital heart disease. Written advice about sexual and reproductive health, and safe forms of contraception specific to their condition must be provided. They must have ready access to appropriate contraception, emergency contraception and termination of pregnancy. The principle of planned future pregnancy, as opposed to unplanned and untimely pregnancy, should be supported.	**GREEN**
3	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	**GREEN**
4	All male patients must have access to counselling and information about contraception and recurrence risk by an ACHD cardiologist and specialist nurse with expertise in congenital heart disease, and, where appropriate, by a consultant geneticist.	**GREEN**
5	Patients must be offered access to a psychologist, as appropriate, throughout family planning and pregnancy and when there are difficulties with decision-making, coping or the patient and their partner are concerned about attachment.	**RED**
	Pregnancy and Planning Pregnancy	
6	The specialist service must be staffed by ACHD cardiologists with expertise in pregnancy in congenital heart disease, with arrangements for appropriate cover within the centre.	**GREEN**
7	Patients actively considering pregnancy, for whom pregnancy may carry a moderate or high (WHO class 2-4) risk, must receive joint pre-pregnancy counselling with the cardiologist and a maternal medicine specialist (consultant obstetrician) with expertise in pregnancy in women with congenital heart disease.	**GREEN**
8	A plan for the care of a pregnant woman with congenital heart disease must be developed by an ACHD cardiologist with expertise in pregnancy in congenital heart disease immediately they are pregnant.	**GREEN**

	The plan must be made in conjunction with the obstetric services. This must include access to termination of pregnancy services. The individualised care plan must cover the antenatal, intrapartum and postnatal periods. It must include clear instructions for shared care with secondary services, when appropriate, including escalation and transfer protocols and clear guidelines for planned and emergency delivery. Decisions on place of birth must be made in conjunction with the mother, and sufficient information must be provided to understand any choices. The consequences of such choices must be clear, particularly the impact place of birth may have in relation to the separation of mother and baby in the immediate postnatal period..	
9	Pregnant women with congenital heart disease that carries moderate or high (WHO class 2-4) risk and who may require emergency surgery or intervention during pregnancy, must be managed at an obstetric unit or the specialist service, whichever is deemed most appropriate, during pregnancy, delivery and the puerperium.	**GREEN**
10	Women with moderate or high risk conditions, who are not at risk of requiring such emergency surgery or intervention during pregnancy, may be managed at an obstetric unit outside the specialist service with specific agreement and advice from the specialist service.	**GREEN**
11	Arrangements need to be made for postnatal follow-up of women and contraceptive advice. Arrangements also need to be made for women to be referred back to their regular long-term follow-up programme once the pregnancy is over.	**GREEN**
12	The specialist service must have a specialist tertiary maternity unit and nurse on the same hospital site or in a neighbouring hospital that functions as part of the extended MDT. Consultant obstetricians must be able to provide emergency bedside care (call to bedside within 30 minutes) 24/7. Care must be delivered within a dedicated multidisciplinary service staffed by an ACHD cardiologist with expertise in pregnancy in congenital heart disease or an obstetrician with a special interest in maternal medicine who has undergone training in pregnancy in congenital heart disease, and a supporting multidisciplinary team with experience of managing congenital heart disease in pregnancy. The MDT must include consultant obstetricians, midwives, consultant obstetric and cardiac anaesthetists and haematologists with expertise in the care of pregnant women with congenital heart disease.	**GREEN**

13	Regular joint clinics will be provided with the ACHD cardiologist with expertise in congenital heart disease in pregnancy, specialist obstetrician and with access to an obstetric anaesthetist. Regular specialist MDT case conferences must take place across the service with additional input including: high-risk obstetrics, cardiac and obstetric anaesthesia, haematology, neonatal and fetal medicine, contraception and pre-pregnancy care.	**GREEN**

Appendix 2: gap analysis of SACCS with NHS Scotland Standards for specialist centre for ACHD

	L: Palliative Care and Bereavement	**Implementation timeline**
	Palliative Care Note: Palliative care is the active, total care of the patients whose disease is not responsive to curative or life- extending treatment.	
1	The specialist service must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the patient and partner/family or carers. This must also include bereavement follow-up and referral on for ongoing emotional support of the partner/family or carers.	**AMBER**
2	Clinicians should use nationally approved palliative medicine guidance to plan palliative care from the point of diagnosis.	**GREEN**
3	When a patient is identified as needing palliative or end-of-life care, a named doctor and named nurse will be identified by the MDT in consultation with the patient and their partner/family or carers. These clinicians may change over time as appropriate.	**GREEN**
4	The named doctor and named nurse will work together with the palliative care team to ensure the patient and their partner/family or carers are supported up to, and beyond death.	**GREEN**
5	An individualised end-of-life plan, including an advanced care plan, will be drawn up in consultation with the patient and their partner/family or carers, and will include personal preferences (e.g. choice to remain in hospital or discharge home/hospice; presence of extended family). The partner/family or carers and all the professionals involved will receive a written summary of this care plan and will be offered regular opportunities to discuss any changes with the lead doctor.	**AMBER** Service not fully developed
6	The named doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all clinical staff understand the ongoing care and the reasons further active treatment may not be possible.	**GREEN**

7	Communication and end-of-life care discussions with patients and their partners/families or carers must be open, honest and accurate.	**GREEN**
8	The patient and their partner/family or carers must be offered details of additional non-NHS support services available to them.	**GREEN**
9	For patients remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their partner/family or carers can easily seek answers to questions and express wishes, worries and fears.	**GREEN**
10	The room and environment must be prepared to meet the palliative care needs and wishes of the patient and their partner/family/carers, and allow them the privacy needed to feel that they can express their feelings freely.	**GREEN**
11	All members of the clinical team must be familiar with the bereavement services available in their hospital.	**GREEN**
12	Patients and their partners/families or carers must be made aware of multi-faith staff and facilities within the hospital.	**GREEN**
	Discharge and out-of-hospital care	
13	Any planned discharge must be managed by the named nurse who will coordinate the process and link with the patient and their partner/family or carers.	**GREEN**
14	The named doctor, with the named nurse, will ensure that the end-of-life plan and discharge plan are shared with relevant community and local hospital services including local cardiologists, GPs, community nurses, out-of-hours GP and ambulance services and the local hospice. Written care plans must be provided for all members of the team. All equipment needed in the home must be available prior to discharge.	**GREEN**
15	Support for patients and their partners/families or carers must continue if they choose to have their end-of-life care in the community. Partners/families or carers must be given written details of how to contact support staff 24/7. Community and outreach provision must be planned prior to discharge.	**GREEN**

	Management of a Death (whether expected or unexpected)	
16	The team supporting a patient, and their partner/family or carers, at the end of their life must adopt a holistic approach that takes into consideration emotional, cultural and spiritual needs, their ability to understand that this is the end of life, and must take account of and respect the wishes of the patient and their partner/family or carers where possible.	**GREEN**
17	If a patient or their partner/family or carers would like to involve the support of members of their home community, the hospital-based named nurse, as identified above, will ensure they are invited into the hospital.	**GREEN**
18	Patients will be offered an opportunity to discuss the donation of organs with the donor team.	**GREEN**
19	Partners/families or carers must be allowed to spend as much time as possible with the patient after their death, supported by nursing and medical staff, as appropriate. It is essential that families have an opportunity to collect memories of the patient.	**GREEN**
20	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the fiscal and post-mortem. Where possible, continuity of care should be maintained. Help with the registration of the death and the organisation of a funeral will be offered, along with reference to bereavement support services.	**GREEN**
21	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.	**GREEN**
22	Contact details of agreed, named professionals within the ACHD cardiology team and bereavement team will be provided to the patient's partner/family or carers at the time they leave hospital.	**GREEN**
23	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	**GREEN**

	Ongoing support after the death of a patient	
24	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.	**GREEN**
25	Within six weeks of the death, the identified lead doctor will write to offer the opportunity for the partner/family or carers to visit the hospital team to discuss the patient’s death. This should, where possible, be timed to follow the results of a post-mortem or fiscal investigation. The partner/family or carers will be offered both verbal and written information that explains clearly and accurately the treatment plan, any complications and the cause of death. Partners/families or carers who wish to visit the hospital before their formal appointment should be made welcome by the ward team.	**GREEN**
26	When the service is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the partner/family or carers.	**GREEN**
27	If partners/families or carers are seeking more formal ongoing support, the identified specialist nurse/named nurse will liaise with appropriate services to arrange this.	**GREEN**

Appendix 2: gap analysis of SACCS with NHS Scotland Standards for specialist centre for ACHD

	M: Dental	Implementation timeline
1	Patients will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the ACHD cardiologist or specialist nurse.	GREEN
2	All patients with planned elective cardiac surgery or intervention must have a dental assessment as part of pre- procedure planning to ensure that they are dentally fit for their planned intervention.	GREEN
3	All patients at increased risk of endocarditis must have a tailored programme for specialist follow-up.	GREEN
4	The specialist service should have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All patients admitted and diagnosed with infective endocarditis should have a dental assessment within 72 hours.	GREEN
5	The specialist service must provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for patients with congenital heart disease.	GREEN

Education strategy for SACCS 2021-2026

This describes a brief outline to our proposals to improve medical, nursing and physiologist education in Adult Congenital Heart Disease (ACHD) at the Golden Jubilee. It will not, at this point, focus on patient education or more generalised advocacy for ACHD. Other areas out with this document are Pregnancy and Heart Disease, Consultant CME, education for research fellows and specific education for the local/outreach centres. However, it would be expected that clinical teams from the local centres may wish to avail themselves of the GJNH resources documented below.

MEDICAL STAFF

Core Cardiology Specialist Trainees/Registrars (Scotland Deaneries)

All adult cardiology specialist trainees are required to complete a set of ACHD competencies in their core training (ST3-5). Unfortunately, to date, training has often been rather piecemeal and trainees have identified inequity of access to training depending on their geography (data from 2020 BCS training survey).

The SACCS team will approach all of the Scottish Deaneries to suggest that they send their cardiology trainees for a minimum of 2 weeks to the national surgical ACHD centre (GJNH). In this time trainees will be expected to complete the JRCPTB training requirements (1). This will include access to inpatients, outpatient care, participating in multi-disciplinary meetings and exposure to specialist imaging. During their ACHD placement trainees will have a named SACCS supervisor who will assist them in completing their competency checklist.

In addition to their placement at the GJNH trainees will be expected to complete 20 of the Heart University short modules in basic congenital heart disease lesions (www.heartuniversity.org).

Core Cardiology Registrar Training Days/Conference

The SACCS team will also contribute to the West of Scotland and National Specialist Trainee/Registrar training days. We currently do this via the SACCS Conference (see below) and the Scottish Cardiology National Training Programme (allied to the Scottish Cardiac Society). The Training Programme Directors (TPDs) have agreed that attendance at the SACCS Conference is a mandatory part of the trainees' educational programme.

Junior ACHD Fellows

SACCS currently has funding for two junior ACHD fellows. The current system has been to rotate these fellows with other GJNH teams. This year this will include Internal Medicine Trainees (IMT). The junior fellows and trainees have limited cardiology experience. Over their placement with the SACCS team (usually 3 months) the fellows will be expected to gain knowledge and experience in simple and complex lesions. The focus will be on inpatient care and on the MDT meeting process of decision making. More complex components, such as echo can be added if the Fellow has had previous cardiac experience. Appendix 1 documents the learning objectives for the 3-month post.

Senior ACHD Fellow/Subspecialist ACHD Specialist Trainee (ST6-7)

These senior trainees will complete 1-2 years in ACHD. The first year will be generic and follow the JRCPTB Advanced curriculum (1). Trainees will be encouraged to develop a further subspecialist interest if completing the 2-year programme. These trainees will be given a named SACCS consultant as their Supervisor. The Supervisor will help complete their competencies and also offer career guidance and support.

Paediatric Cardiology registrars

All paediatric cardiology registrars must complete a 3-month block in ACHD. The GJNH team will accept one trainee at a time and will tailor the trainee's placement to their long-term career goals and to the curriculum (2).

It is anticipated that Paediatric cardiology trainees will be able to contribute to clinic and to the MDT meeting. Their inpatient role will be supernumerary. Paediatric trainees will continue to do oncall at the RHSC during this block.

Other trainees with an interest (genetics, anaesthetics, radiology, obstetrics)

Various other medical trainees come through the department. These trainees will require specific education and training objectives to be agreed before their block. The anticipation is that these trainees will be supernumerary observers only.

Undergraduate trainees attached to SACCS

Various undergraduate trainees ask to study with the team. These are often medical students undertaking a student selected component (SSC) of Year 3 or 4. The University of Glasgow learning contract will be completed prior to the student being accepted. A maximum of 2 students will be accepted at any one time each with a named SACCS supervisor. These blocks usually last for 4 weeks. Students will gain exposure to inpatients, outpatient case, imaging and procedures. They will be supervised at all times.

NURSING STAFF EDUCATION

In line with recommendations from the transforming Nursing Roles programme regarding Advanced Specialist Nurse/ Specialist Nurse Review there will be ongoing consultation in relation to a minimum educational qualification for this group. Currently, as a minimum, for the SACCS specialist nursing team this will include:

- Advanced Clinical Assessment Module
- Non-medical Prescribing Module
- Masters level /equivalent in ACHD

In House Education for nursing team in GJNH

The SACCS Nursing team are involved in a number of in-house education programmes for patients and staff. This also includes involvement in the provision of an Annual SACCS conference, held within NHSGJ.

SACCS nurse specialists facilitate education in relation to the clinical management within all ward areas where SACCS patients are cared for. This maintains the understanding of the clinical requirements specific to this patient group within the ward staff, thus improving the delivery of safe patient centred care.

External Education

To date there has been opportunities for members of the SACCS nursing team to present at National and International events, providing insight into many aspects of SACCS team delivery of care. This continue to be supported and developed for all SACCS Nursing team members.

Physiologists including Echo staff

Cardiac physiologists and other staff groups (such as radiographers) have learning needs related to ACHD. The most pressing educational requirements are, however, related to imaging and in particular echo. The education sessions currently running are documented below but these will need to be developed to include imaging education for medical staff and for the regional centres.

Weekly ACHD Echo Teaching Sessions

These lunchtime departmental sessions are tailored for the congenital echo physiologists who are studying for their accreditation in congenital echo (EACVI or BSE). These case-based lesion specific sessions include in-depth discussions of native and repaired anatomy and physiology. This forum also reviews challenging scans and represents an important facet of quality assurance within the echo department.

Dr Hunter and Dr Veldtman have also been tasked with providing hands-on supervision and training in echo to run in parallel with the weekly ACHD clinics (Tues and Thurs). These sessions provide immediate feedback to the specialised echocardiographers.

Monthly ACHD Echo Teaching Sessions

These monthly lunchtime sessions are embedded within the departmental adult echo teaching programme. The aim of these sessions is to teach a practical approach to echo assessment for physiologists and trainees with minimal ACHD echo experience. There is a hope to roll these sessions out to a wider general audience from across Scotland.

Annual ACHD Echo Training Day

This is an annual hands-on event open to echo physiologists and cardiologists out with the Golden Jubilee. There is opportunity and need to expand this provision, including extending the training to other imaging modalities. There is also potential to integrate some of this activity with the Roadshow (see below).

ADDITIONAL EDUCATION RESOURCES

Annual SACCS Conference

This is the prime national educational resource for engaging with the other ACHD providers in Scotland. These conferences, both face to face and virtual, have been well attended and highly successful. These will continue on an annual basis in November/December. In 2020 the attendance was approximately 100 delegates and the course covered subjects including Ebstein's Anomaly and Fontan. The 2021 conference will be a hybrid virtual and face-to-face meeting.

ACHD Road Show

In 2022 the SACCS team wish to launch a SACCS Roadshow. The aims of this would be two- fold:

1. To re-launch the SACCS service to the Local Centres post-COVID and post expansion of the team
2. As an educational tool to assist upskilling of the local teams.

This would include medical, nursing and physiology staff. The programme would offer to visit the local centres for a day with a morning clinic, lunchtime rounds and an afternoon teaching session. It would be hoped that a team of consultants, nurses and physiologists would visit from the SACCS team. Given the ongoing COVID pandemic it is envisioned that visits to Regional centres will occur in 2022. If there are still ongoing pandemic issues, then the options of a virtual visit will be explored.

Journal club

The SACCS team will trial a Whatsapp-based journal club for the whole of the Scottish ACHD 'network'. This will include a regular posting of recent relevant publications and the ability to interact with the SACCS team. Boundaries regarding numbers and timings of communications will be set. This project will be reviewed after 6 months.

Online resources

The Heart University (www.heartuniversity.org) is a free online teaching platform that is open to all healthcare professionals. It is useful for all levels of teaching from an introduction to the specialty to CME for consultants and CNS. The ACHD Basic Lectures 15-minute Learning Modules are particularly useful for those new to ACHD.

References

1. ACHD Core Cardiology Curriculum for Specialist Trainees/Registrars Generic https://www.jrcptb.org.uk/specialties/cardiology. Pages 103-5; Pages 124-130.
2. Paediatric Cardiology ACHD Curriculum for Specialist Trainees/Registrars https://www.jrcptb.org.uk/specialties/paediatric-cardiology. Page 63.

3. Transforming Nursing, Midwifery And Health Profession (NMaHP) roles: review of Clinical Nurse Specialist and Nurse Practitioner roles within Scotland.
https://www.gov.scot/publications/transforming-nursing-midwifery-health-profession-nmahp-roles-review-clinical-nurse-specialist-nurse-practitioner-roles-within-scotland/pages/19/

Appendix 4: research strategy for SACCS 2021

Research Strategy for SACCS– 2021-2026

Key Drivers to Change

High quality and innovative research is at the heart of the current research strategy at the Golden Jubilee National Hospital. The vision is to improve the health and well-being of Scottish patients and patients beyond our borders across the various clinical services being provided at the GJNH. This includes cardiovascular services and particularly that provided by The Scottish Adult Congenital Cardiac Service (SACCS). Given the increasing access to emerging advances in science and technology, management and business, population and implementation sciences, the need for a contemporary and collaborative approaches to research has never been more important. Adult congenital heart disease is a new speciality. It was only recognized as a unique subspecialty in the early 1990s. It has a considerable amount of catch up to do with regard robust scientific enquiry compared to other subspecialties. As such, it warrants specific attention and support. Understanding of the interplay of genome, environome, epigenetics, medical genetics, and the effects of ageing, are fundamental to congenital heart disease, more so than in other forms of cardiovascular disease, as much of congenital heart disease traces its origins to the 1st 4-8 weeks of intra-uterine life as the heart develops. Despite these genetic underpinnings, disease expression varies tremendously with a large variety of outcomes depending not only on medical intervention, but also on environmental exposure, socio-economic status, and age. This group of individuals thus present a unique opportunity, together with the emerging technologies currently available to fundamentally change the trajectory of outcomes for adult patients with congenital heart disease through a well envisioned research strategy.

Barriers to change

Research in the initial era of congenital heart disease practice, out of necessity focused on organization of care, health care delivery, and the changing profile of adults with congenital heart disease. Therefore, it was limited in its scope, and basic science output and translational output was essentially non-existent. Indeed, much of existing research output was aimed at patient outcomes, gaps in care, and characterising the ageing adult congenital heart disease population. There is now therefore a need for more mechanistic research, basic science, translational research, and research focused on identifying the interplay between genetic origins, epigenetic modulation, proteomics and metabolomics.

There is also a significant deficit in research utilizing novel diagnostic techniques in imaging such as MRI and advanced ultrasound techniques, stress cardiac catheterization, artificial intelligence, and a particularly large deficit in randomized placebo-controlled drug trials.

A major limitation is funding. Currently, funding agencies are cash strapped, and ACHD projects have traditionally not been sufficiently competitive to secure large scale funding. This has been due to the relative scarcity of the individual lesions being studied, poor patient participation, and relatively limited cross centre collaboration.

Another barrier has been created by limited availability of research staff, statistical support, and lesser prioritization of unfunded projects over commercially funded projects within institutions.

Appendix 4: research strategy for SACCS 2021

Key components of a fit for purpose research strategy.

1. An ACHD Research program should enjoy Institutional support to kickstart pilot data in order to initiate successful subsequent funding
2. Research should address and reflect the major clinical needs in ACHD
3. ACHD research should be sympathetic to the GJNH research vision
4. ACHD research should aim at bringing various research teams' skills together in a collaborative fashion and use cross specialty expertise to enrich research ideas and progression
5. ACHD research should employ advances in basic science and technology, developmental biology, genetic and -omics techniques, in initiating individual robust research projects
6. ACHD research should foster cross institutional partnerships including clinical collaborations with the Royal Hospital for Children and also other ACHD institutions in the UK and globally, and academic collaboration with the Universities of Glasgow, Strathclyde and Edinburgh and other academic institutions
7. ACHD research should also be opportunistic and exploit available resources that are not cost heavy

Core Research Strategy:

1. **Establish a national ACHD registry**
    - **Phase 1**: validation of the computer code and Artificial Intelligence tools employed to create the database
    - **Phase 2**: creating of prospective means of clinical data gathering to inform an ongoing registry i.e., to create a letter format that may allow creation of a pro-retrospectively collected data set
    - **Phase 3** widen participation in the database and for each establish external validation of the letter format
2. **Personalized Medicine Approaches using Cardiovascular and Body organ reserve in ACHD**

    To develop an echo stress program that assesses CV (using echo +CPET) reserve including diastolic reserve, cardiac output reserve, strain reserve, and endo-organ reserve.

3. **Developing Multisite Drug Trials**
    - To create a multi-institutional trial teams
    - Create multi-institutional SGLT2 and other drug trials that are funded
4. **Create Gene-Proteome, Metabolome integrated** projects in association with the University of Glasgow and other partners across the United Kingdom
5. **Develop research into ageing_**in association with the basic sciences division of the University of Glasgow, (Prof Christian Delles, Prof Valerio Orlando, Prof Colin Berry) and other establishments currently exploring premature senescence
6. **Promote low cost projects** utilizing retrospective datasets, metanalytic analyses applied to data already available on PubMed, or data previously collected within the institution

Appendix 4: research strategy for SACCS 2021

Generic Research Strategies

1. Obtain junior staff focused on research
2. Create research teams across a variety of institutions that contribute to collaborative research projects
3. Form global partnerships particularly with a number of American Institutions, The Prince Sultan Cardiac Centre in Riyadh, and with Congenital Heart Disease Partners in Australia such as with the Australian ACHD and Fontan Database
4. Promote research among all individual team members of the ACHD team such that each team member in involved in at least 1 active achievable research project
5. Create commercial partnerships to enhance research funding
6. Patient and Public Involvement

Funding Strategies for Research:

1. Funding from NSD + Matched funding from the Golden Jubilee Hospital
2. Dedicated research SACCS endowment fund with charitable donations
3. Funding agencies: BHF, NIHR, Industry
4. Promote Commercial partnerships
5. Promote research partnership with the University of Glasgow, Strathclyde, and other academically active academic institutions, and endeavour to engage in mutual funding applications.