National Services Division
Scottish Adult Congenital Cardiac Services

Service agreement with:
National Waiting Times Centre Board

For:
Grown-Up Congenital Heart Disease
2009/10
Annual Report
April 2009 – March 2010

1. Introduction

The year 2009-2010 represents the first complete year of the Service at the Golden Jubilee National Hospital.

Major developments in staffing over the year include:

- Re-appointment of clinical nurse specialist – Jim Mearns
- Re-appointment and expansion of secretarial staff – Liz McDade (full-time), Eleanor O'Neil and Jenny Reed (full-time job share)
- Appointment of second full time cardiologist as a replacement for Prof Hillis – Dr Niki Walker joined the Service in January 2010

Other developments within the service include:

- Reduction in cardiac MRI waiting time from 1 year to under 6 weeks by the end of the year.
- Commencement of a programme of Grand Round lectures to all Scottish Hospitals to improve awareness of adult congenital heart disease and the SACCS service
- Recognition of the need to further develop regional programmes providing more local access to services with support from SACCS with the start of discussions to achieve this.
- The process of developing protocols and referral pathways to divide National from Regional responsibility has begun

The report gives an overview of the work of SACCS during the year, including a number of key achievements.

This report is intended for a wide audience of clinical and managerial staff who have an interest in the SACCS. It also includes the relevant information required under the terms of the national service level agreement between the National Services Division in Scotland and SACCS.

Aims of Service

The SACCS aims to provide the highest quality specialist care of adults with congenital heart disease living in Scotland irrespective of geographical location.

A full range of inpatient and outpatient services at the Golden Jubilee Hospital in Glasgow combines with supported outreach clinics providing access and shared care for patients living in more geographically distant locations. Whilst the majority of interventions are performed in Glasgow, good links with other units in the UK facilitates referral for highly specialist treatment when required. SACCS maintains close links with the Scottish Advanced Heart Failure Service and the Scottish Pulmonary Vascular Unit.

Current location of Service

Outpatient Services

- A weekly SACCS clinic is held all day on a Thursday at GJNH comprising two sessions attended by both SACCS consultants. Each session offers 5 new and 15 return appointment slots with provision for urgent review when necessary. Dedicated ECHO and ECG support are available within the clinic.
- Outpatient appointment slots are available on all other days for clinical review by the team
- The monthly transition clinic is held at the Royal Hospital for Sick Children Area D attended by one of the SACCS consultants
- A combined cardiac obstetric clinic is held at the Sothern General Hospital every fortnight within the ante-natal department in conjunction with Dr Janet Brennand, obstetrician. Usually only one SACCS consultant supports this clinic
- Participation in outreach clinics in other areas of Scotland currently Edinburgh, Perth, Raigmore with one SACCS consultant in attendance. Other specialist outreach clinics include Aberdeen, Dundee, Kirkcaldy, and Borders. At the present time this second group of clinics is supported by Dr Jan Burns.

Inpatient Base

- Admissions to the GJNH occur to several areas within the hospital. Patients may be admitted from home, outpatient's clinic or via transfer as emergencies from other hospitals.
- The base for patients undergoing elective or emergency assessment and treatment is to the 2 nominated beds within the NSD pod on level 3. Additional beds can be made available within the pod or the adjacent surgical ward when needed.
- Admissions for inpatient cardiothoracic surgery occur to the surgical wards 3 East and 3 West.
- Admissions for catheter laboratory procedures and device implantation are to the cardiac ward on level 2
- Emergency admission to the coronary care unit on level 2 and the Intensive Care Units on level 3 as required.

Non-Invasive Investigations

The following cardiac investigations are available at GJNH on an outpatient or inpatient basis:
- Transthoracic and transoesophageal echocardiography (Cardiology level 2).
- Cardiac magnetic resonance imaging and cardiac CT (Radiology, level 2).
- Respiratory function and cardiopulmonary exercise testing (Respiratory function lab level 2).
- ECG, ambulatory BP, Holter and Event monitoring (Cardiology level 2 and SACCS clinic).

Staffing

Consultant cardiologists:-

Dr Hamish Walker, full-time – GJNH (SACCS Director)
Dr Niki Walker, full-time – GJNH

Consultant cardiothoracic surgeons – all have joint responsibilities to the SACCS and to the RHSC:-

Mr Kenneth MacArthur (Clinical lead for surgery)
Mr Jim Pollock
Mr Mark Danton
Mr Andrew McLean

Jim Mearns, full-time – GJNH (Clinical Nurse Specialist)

Man chun Mo, full-time – GJNH (Data Manager)

Medical Secretaries - Elizabeth McDade, full-time
Elenaor O'Neil & Jenny Reed, full-time job share

Out of Hours Cover

Dr H Walker and Dr N Walker can be contacted out of hours for advice. When unavailable, the on call paediatric cardiologist at RHSC can be contacted for assistance.

Junior staff cover for medical inpatients at GJNH is provided by the coronary care team covered by the duty consultant on call for the hospital.

Consultant cardiothoracic surgical cover is provided by the surgeon on call for RHSC. Junior staff cover for surgical patients is provided by the surgical team at GJNH.

Management of the Service

The local management of the service is within the Golden Jubilee National Hospital:-

General manager, Ms Lynne Ayton
Assistant General manager – Ms Claire Macarthur
Lead Nurse for Heart and Lung Centre – Ms AnneMarie Cavanagh

GJNH Medical Director, Mr Alastair Flowerdew

2. Activity Review

2.1 Service Level Agreement Activity Levels

For the year 2009/10, the service level agreement for cardiac surgery was 55 surgical procedures. The actual activity performed for the year 2009/10 was 75 procedures.

Interventional cardiology service level agreement for 2009/10 was 150 interventional cardiology procedures. The actual activity performed was 166 interventions.

A total of 49 SACCS clinics were held within April 2009 to March 2010. There were 21 teenage/transition cardiac clinics and 11 combined cardiac obstetric clinics with in this annual year.

The number of cardiac MRI Heart Scans performed for the year was 538.

3. Surgical Procedures

3.1 Overall Performance Against the Service Level Agreement

The service level agreement with the National Services Division is based on the number of procedures carried out on patients who were operated on and discharged during the period 1st April 2009 – 31st March 2010.

The post op discharge activity during 2009/10 was 75 cases.

Figure 3.11 below illustrates surgical discharge activity against service level

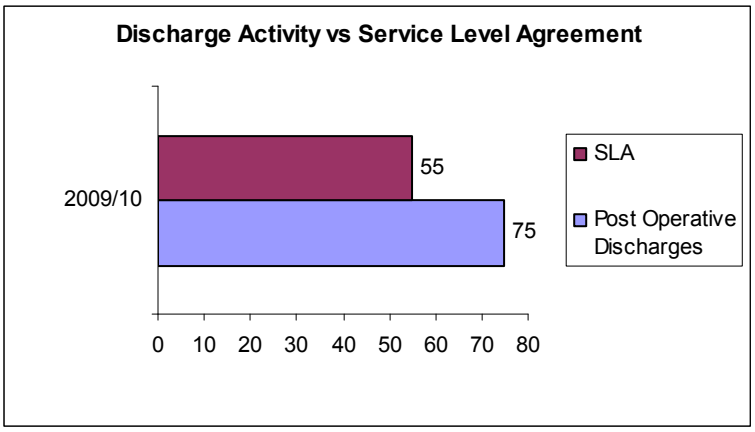

Figure 3.11

ANALYSIS OF ACTIVITY BY HEALTH BOARD OF RESIDENCE

Cardiac Surgery by Health Board of Residence
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Note: Some patients have been grouped in one or more in the table.

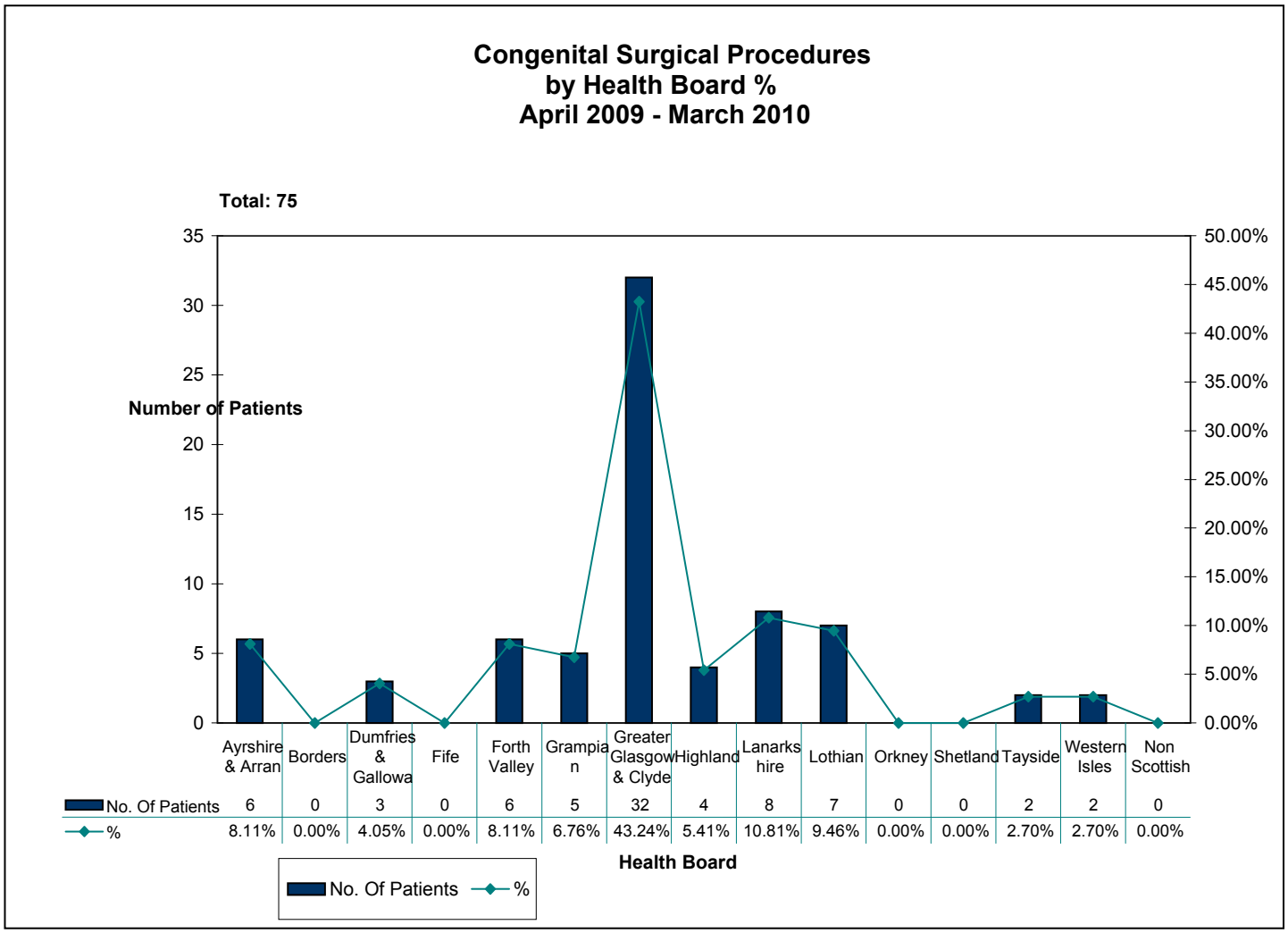


Figure 3.13

The highest number of surgical procedures was carried out on patients from GGHB, followed by Lanarkshire, Lothian respectively.

There were 71 elective procedures, 2 urgent procedures, and 2 emergency procedures.

Surgical Inpatient Stay Analysis

The following tables detail the breakdown of surgical in-patient stays and duration of CICU (Cardiology Intensive Care Unit) and HDU (High Dependency Unit) stays.

Analysis of Total Inpatient Length of Stay	
Mean Length of Stay (Days)	8
Median Length of Stay (Days)	7
Range of Length of Stay (Days)	3-34

Analysis of Cardiology Intensive Care Unit (CICU) Length of Stay	
Mean Length of Stay (Days)	2
Median Length of Stay (Days)	1
Range of Length of Stay (Days)	1-14

Analysis of Total High Dependency (HDU) Length of Stay	
Mean Length of Stay (Days)	2
Median Length of Stay (Days)	1
Range of Length of Stay (Days)	1-8

Analysis of Total Number of Bed Days	
Overall (Days)	543
CICU (Days)	127
HDU (Days)	104

Surgical Waiting Times	
Mean Length of Stay	25
Median Length of Stay	20
Range Length of Stay	1-82

Waiting Times for Non-Urgent Patients

No patients breached the 12 weeks waiting times agreement. With the new 9 week waiting time's agreement as of April 2010, no patients have breeched the new waiting times agreement.

Specific issues related to surgical procedures

1) Death within 30 days or during inpatient stay

Total 4 patients

2) Hospital acquired infections / other significant complications.

There were 5 patients (14%) that acquired a hospital infection/wound infection and they are classed as the following:-

Patient A	Septicaemia	(1.49%)
Patient B, C	Chest Infection	(2.82%)
Patient D	Urinary Tract Infection	(1.49%)
Patient E	Septicaemia, Chest Infection	(1.49%)

3) Required re-operation during their admission

No patients where required re-operation during their admission.

4. Interventional Cardiology

4.1 Overall Performance Against the Service Level Agreement

The interventional activity during 2009/10 was 166 cases.

Figure 4.11 below illustrates surgical discharge activity against service level agreement.

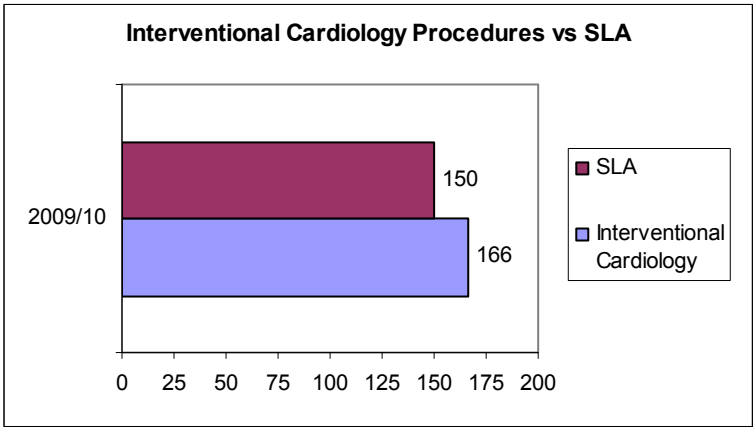


Figure 4.11

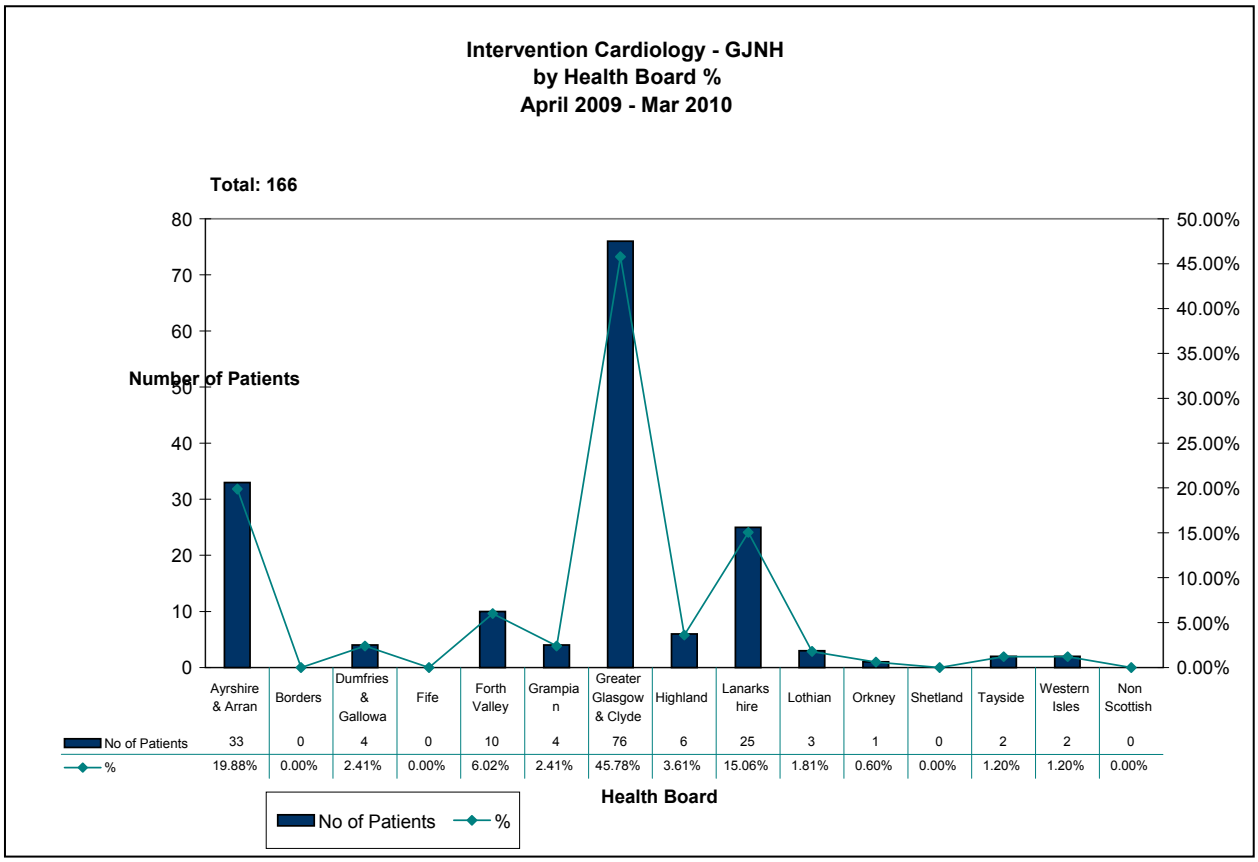


Figure 4.12

All cases are logged in the Minerva System for audit.

A total of 166 procedures where undertaken (164 Routine and 2 Urgent). Compared to the previous year 2008/09 there has been a slight increase +5 (161).

The highest number of interventional procedures was carried out on patients from GGHB and Ayrshire & Arran, followed by Lanarkshire.

Intervention Cardiology - GJNH
by Procedure Group
April 2009 - March 2010

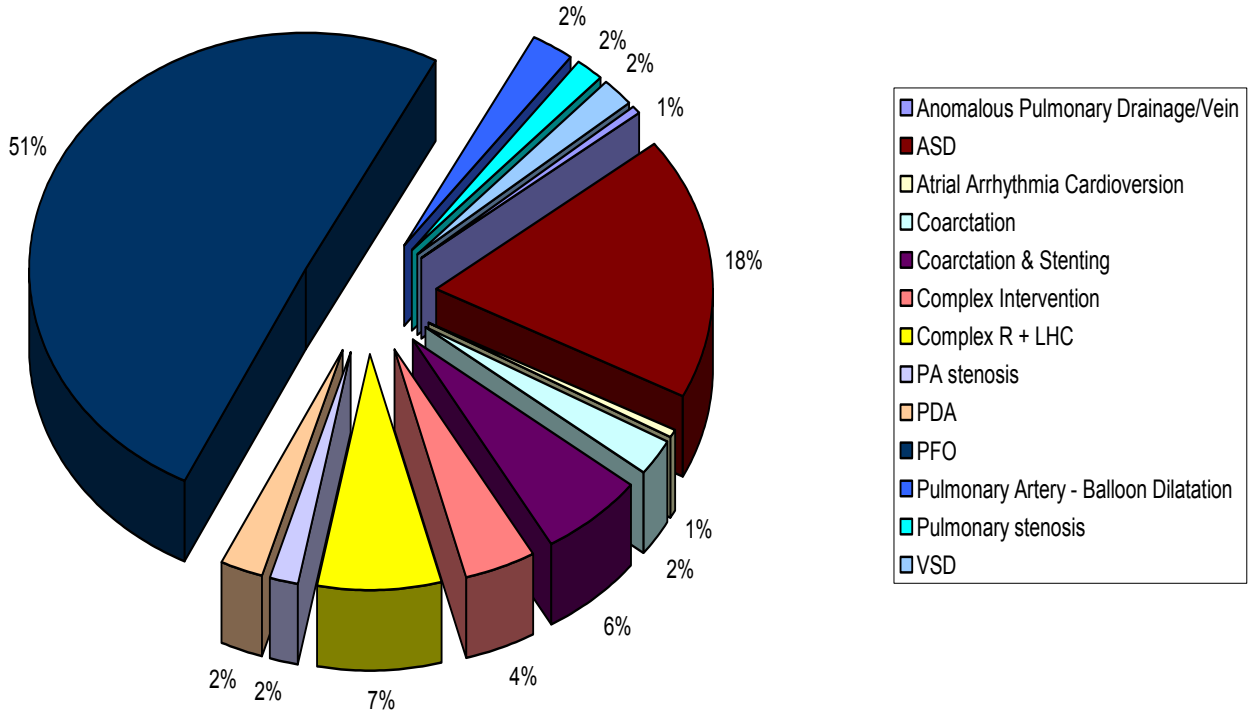


Figure 4.13

The highest number of interventional procedure carried out on patients in 2009/10 was PFO, followed by ASD, and Complex R + LHC.

Analysis of Total Inpatient Length of Stay	
Mean Length of Stay (Days)	1
Median Length of Stay (Days)	1
Range of Length of Stay (Days)	1-15

Waiting Times for Non-Urgent Patients

Analysis of Cardiology Intensive Care Unit (CICU) Length of Stay	
Mean Length of Stay (Days)	1
Median Length of Stay (Days)	1
Range of Length of Stay (Days)	1

Analysis of Total High Dependency (HDU) Length of Stay	
Mean Length of Stay (Days)	2
Median Length of Stay (Days)	2
Range of Length of Stay (Days)	1-2

Analysis of Total Number of Bed Days	
Overall (Days)	232
CICU (Days)	1
HDU (Days)	3
Waiting Times	
Mean Length of Waiting Time (Days)	48
Median Length of Waiting Time (Days)	57
Range of Waiting Time (Days)	1-81

No patients breached the 12 weeks waiting times agreement. With the new 9 week waiting time's agreement as of April 2010, no patients have breeched the new waiting times agreement. Please note there was a patient found to have 130 days (19 weeks) to the waiting time's agreement and this was found to be a system error and the patient has not breached.

Specific issues related to interventional procedures:

1) Death within 30 days or during inpatient stay

Total 1 patient

2) Hospital acquired infections / other significant complications.

Total 1 patient

5. Patients on Review

5.1 SACCS Adult Congenital Clinic – Golden Jubilee National Hospital, Glasgow

49 clinics were held within 2009-10.

A total of 1743 patients were reviewed by the service in outpatient clinics. 1411 (280 New and 1131 Return) patients attended the Adult Congenital Clinic at Golden Jubilee National Hospital, reflecting 81% of overall activity.

For 2009/10 there was 332 DNA (58 New and 274 Return), which correlates to 19%.

Total Number of Clinics held between 01/04/2009 - 31/03/2010: 49
Average Patients/Clinic: 35.57

- Total NEW Appointments: 338
- Total FOLLOW UP Appointments: 1405
- Total Patients DNA: 332
- TOTAL APPOINTMENTS: 1743

TOTAL ATTENDED: 1411
% ATTENDANCE: 81.95
PATIENTS REFERRED BY GLASGOW HEALTH BOARD - GGHB: 780
PATIENTS REFERRED BY OTHER HEALTH BOARDS: 631

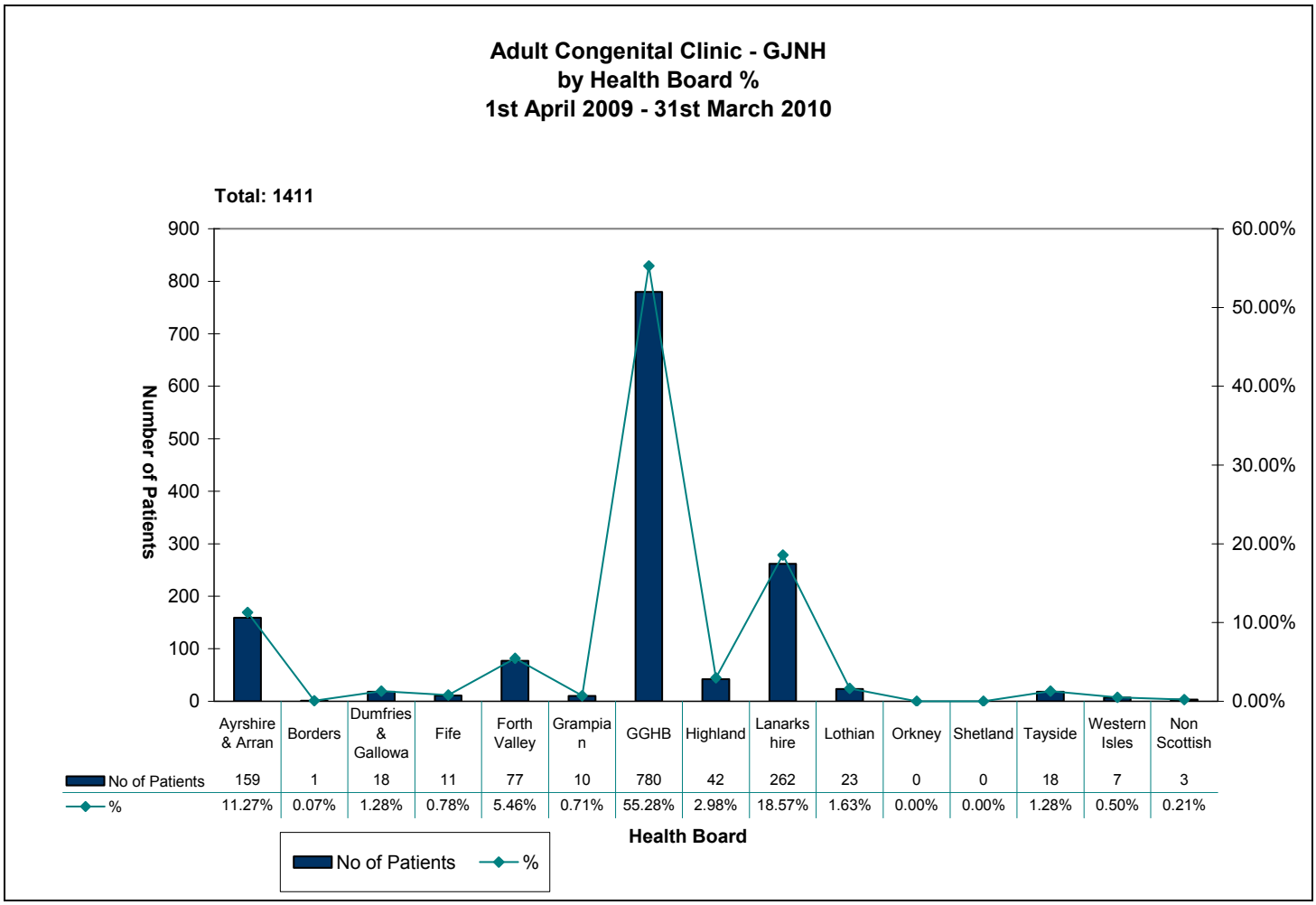


Figure 5.11

The majority of patients were GGHB, followed by Lanarkshire, and Ayrshire & Arran that attended the Scottish Adult Cardiac Congenital Clinic.

Adult Congenital Clinic - GJNH
New Referrals by Healthboard %
1st April 2009 - 31st March 2010

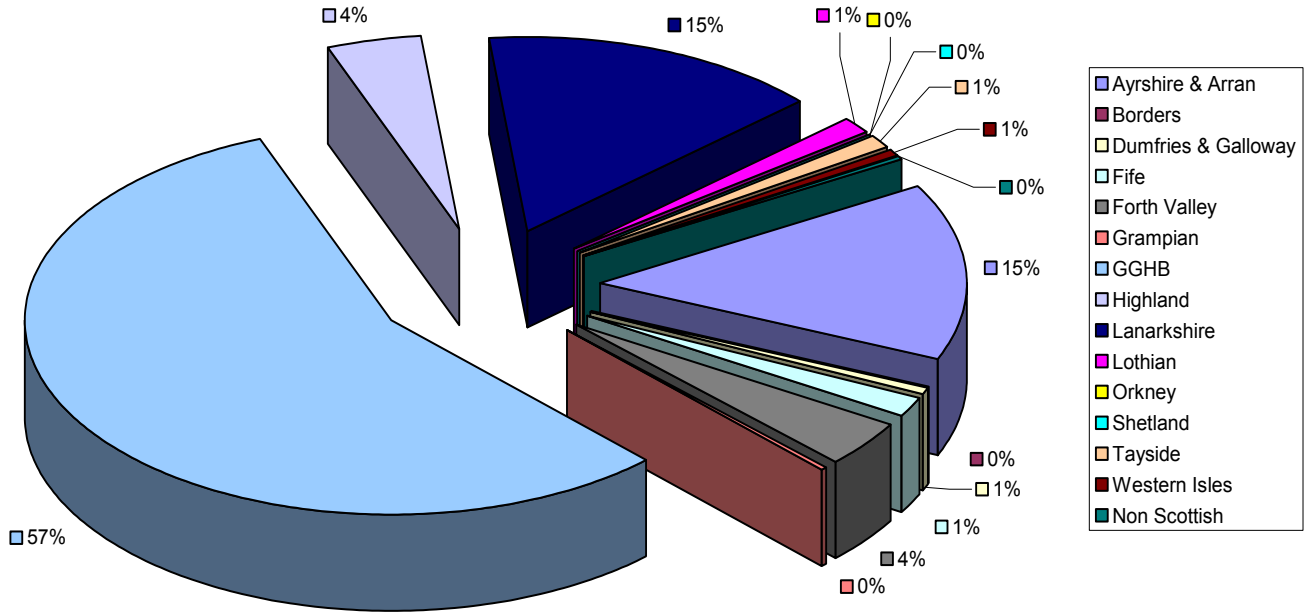
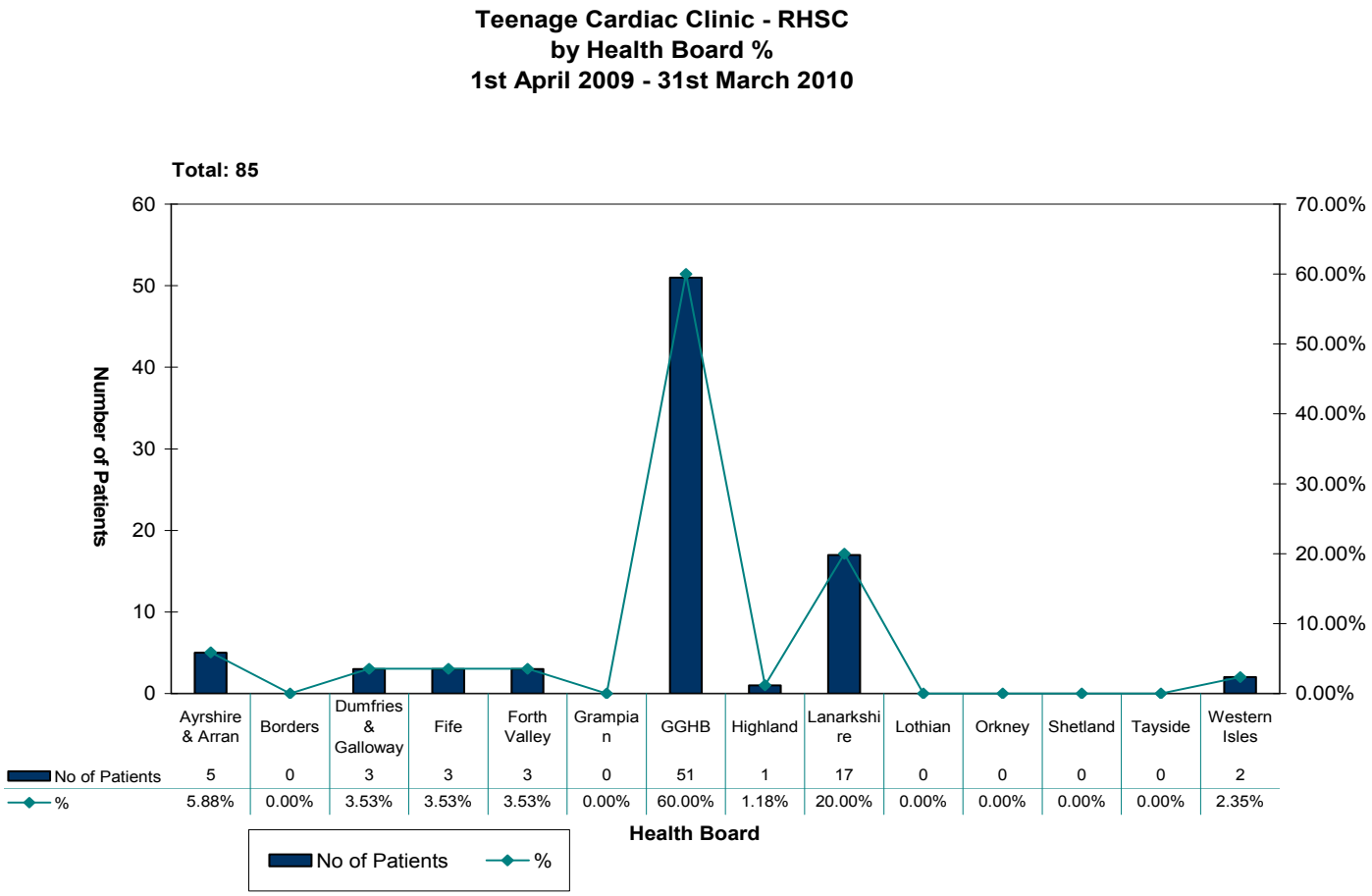


Figure 5.12

A total of 338 patients where newly referred to the Adult Congenital Clinic based at Golden Jubilee National Hospital. GGHB 57%, Lanarkshire 15%, Ayrshire & Arran 15%.

5.2 Teenage Cardiac Clinic – Royal Hospital for Sick Children, Yorkhill



	Ayrshire & Arran	Borders	Dumfries & Galloway	Fife	Forth Valley	Grampian	GGHB	Highland	Lanarkshire	Lothian	Orkney	Shetland	Tayside	Western Isles
No of Patients	5	0	3	3	3	0	51	1	17	0	0	0	0	2
%	5.88%	0.00%	3.53%	3.53%	3.53%	0.00%	60.00%	1.18%	20.00%	0.00%	0.00%	0.00%	0.00%	2.35%

Figure 5.21

The Transition clinic at Yorkhill allows patients to meet the adult team within the more familiar environment of the paediatric hospital. The move to adult services is often a time of great unrest for both patient and their patients/carers with the perceived loss of familiar clinicians and members of staff. It is also a time of greater understanding and awareness of the patient themselves as they become more responsible for their own health issues. A well designed and effective transition service allows for planning of future care and minimised the loss to follow-up that plagues this age group.

The aim of the clinic is to review all patients who are still seen at Yorkhill or who are under shared care with a peripheral hospital. The team can be introduced and an appropriate plan for follow-up within the adult services structured.

At the Teenage Outpatient Cardiac Clinic a total of 85 patients have attended the clinic based at the Royal Hospital for Sick Children. The number of DNA was 41, which correlates to 22%.

In addition from the 85 patients, 30 (35%) patients had an ECHO undertaken and 48 (56%) patients had an ECG undertaken, while 23 patients had undertaken both.

Total Clinics: 21
Average Patients/Clinic: 8.71

Total NEW Appointments: 4
Total FOLLOW UP Appointments: 179
Total Patients DNA: 41
Total Cancellations OTHER REASONS: 57
TOTAL APPOINTMENTS: 183

TOTAL CANCELLATIONS: 98
TOTAL ATTENDED: 85
% ATTENDANCE: 46.45
PATIENTS REFERRED BY GLASGOW HEALTH BOARD - GGHB: 61
PATIENTS REFERRED BY OTHER HEALTH BOARDS: 122

5.3 Joint Obstetric Clinic – Southern General Hospital

The Cardiac Obstetric Service in Glasgow has developed following the move of the Queen Mother's Hospital to the Southern General site. A more coordinated structure for care of this group of women has been introduced and the team has grown to include 2 consultant obstetricians (Dr J Brennand, Dr J Richmond) and 2 consultant cardiologists (Dr H Walker, Dr N Walker). Greater anaesthetic involvement from both SGH and GJNH has also been possible.

All patients under ante-natal review or who are considering pregnancy and who are felt to be at risk from their cardiac condition can be offered review within the cardiac obstetric clinic, held every two weeks on a Monday afternoon within the ante-natal department at the Southern General Hospital. A consultant obstetrician and consultant cardiologist are in attendance for this clinic with support from anaesthetic staff as necessary. ECHO and ECG facilities are available within the clinic. When appropriate, a plan for ante-natal care and delivery is made with most patients continuing their care on a shared care basis within the service. The delivery plan and, in particular, the location of their delivery can be determined. This includes delivery of women at the highest risk at the Golden Jubilee.

The cardiac obstetric clinic remains a largely regional activity with the bulk of referrals from the West of Scotland. Links with the National Services do allow for advice and review of patients from all over Scotland when necessary.

6. Cardiac MRI

Cardiac MRI has become the central imaging investigation in the modern management of patients with adult congenital heart disease. It provides a comprehensive diagnosis and assessment, is used serially to optimise the timing of intervention as well as assisting in planning of the intervention and assessing its outcome. It is a highly specialised technique that requires expertise of both adult congenital heart disease and MRI techniques to ensure a complete assessment. In most cases, this imaging modality now forms the basis for considering intervention.

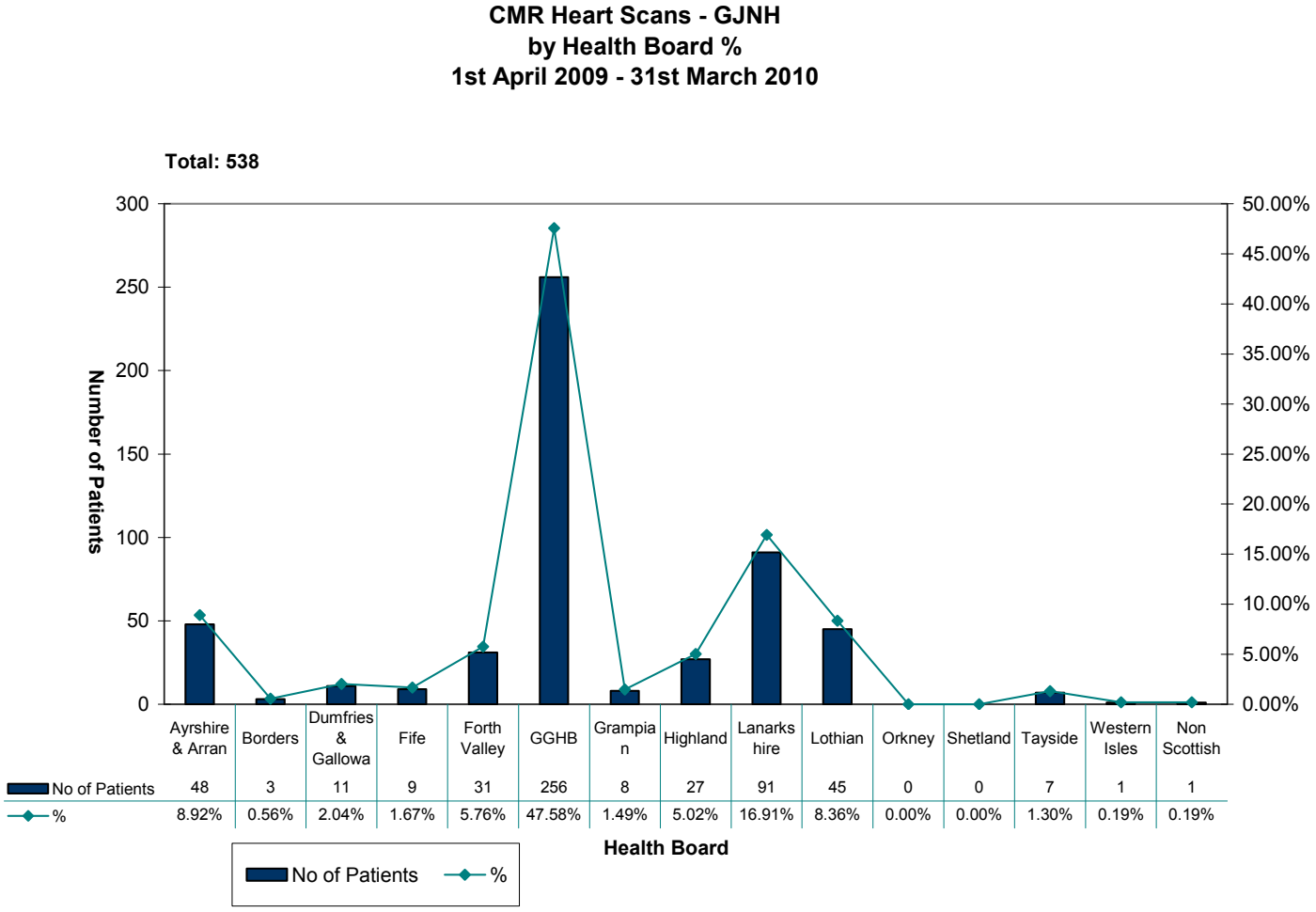


Figure 6.1

The total number of MRI Heart scans performed between the start of April 2009 and the end of March 2010 was 538 (7 In-patient and 531 Out-patient)

7. Quality of Care

During the year we have had three substantive complaints about the service.

A patient who was under follow-up with complex heart disease died suddenly. The procurator fiscal investigated the case and found no cause for concern regarding patient care. Dr H Walker and Mr Pollock met with the family and the matter was resolved

A patient who was under the care of SACCS was referred for device therapy which was successfully implanted. The complaint focussed on a series of perceived delays and inadequacies of ward care. It was dealt with formally through clinical governance and the matter resolved. The patient and her family have no wish to take matters further.

A patient underwent an attempt to relieve a severe stenosis of a right ventricle to pulmonary artery conduit. This resulted in the death of the patient. An internal multidisciplinary review was conducted which found no cause for concern regarding patient care. The case was reviewed by the Procurator Fiscal and has been referred for further consideration by the Crown Prosecution Service with respect to a decision regarding a Fatal Accident Enquiry.

8. Clinical Audit and Outcomes

Local Audit

All invasive investigational and interventional cases performed at GJNH are logged and reported on the Minerva System and audited at the Glasgow Catheter Laboratory Users Meeting. The Coronary Heart Disease Audit Team supports this system and identifies all in laboratory and in hospital complications.

National Audit

Our individual cases have been prepared in the standard fashion for submission to the National Audit Systems.

9. Activities

Staff Meetings

Weekly staff meetings have been introduced to address ongoing issues.

Multidisciplinary Meetings

Weekly adult congenital multidisciplinary meeting were commenced in Autumn 2007. Attendance by the cardiothoracic surgeons, anaesthetists, cardiologists, nursing and technologist staff at GJNH is combined with video-conference facilities to RHSC to allow participation by the paediatric team. It is envisaged that the video-link facility will extend to Edinburgh and further afield. The meetings have been very successful and the aim is to discuss all cases under consideration for intervention together with difficult management problems and learning points. This meeting additionally serves as a mortality and morbidity meeting.

A short business meeting is held to discuss organisation matters after the clinical meeting.

Collaboration with SPVU and SAHFS

Co-location of the three cardiovascular National Services at GJNH has allowed much greater collaboration and combination of expertise.

The fact the SACCS is working well with the Scottish Advanced Heart Failure Service and Scottish Pulmonary Vascular Unit is good news for our patients. We hope to continue with this co-operation.

10. Service Developments and Challenges

The growth of the service has brought with it new challenges and need for development. Major areas of interest that will need to be addressed during the next year are discussed below.

10.1 SACCS register and patient management database

The service identified there where missing gaps in monitoring patient pathway, to address these issues the service has developed an in-house database patient tracking system, which allows patient activity to be monitored. The system is currently live and will be reviewed on a daily basis. Initial feedback has been largely positive and beneficial to the service. Developments are continuous and with further staff feedback and suggestions will greatly improve the system.

Within the year there has been a gradual increase in the number of patients registered in the SACCS register. All local and some outreach clinic correspondence is included. However further collaboration is needed to develop an all inclusive continuously updated register. The local eHealth department is in the process of implementing a new Heartsuite system based at the data centre at the GJNH. It will overcome the historical problems of accessing the Yorkhill database and would also allow the eHealth Dept to maintain the Server locally and to address any issues in an appropriate SLA. It is envisaged that the register will ultimately be accessible all over Scotland.

10.2 SACCS Website & Logo

This year the website (www.saccs.info) has now been launched. Though the content is very basic this will give the service a much need emphasis and a service presence. The website will be continuously developed and much awareness is needed to inform patients and relevant groups to the website.

10.3 Building links with other units

The success of the SACCS in Scotland depends not only upon providing excellent care for patients in Glasgow but also formed close links with all units involved in the care of our patients. The current shared model of care only works well if there is good collaboration and communication. Although outreach clinics are excellent at promote these links, time constraints at the present time do not allow involvement in all and there are some areas (e.g. Ayrshire, Lanarkshire) that do not have local clinics established. Much work needs to be done to increase awareness of the service and collaboration. The website will help with this, as will the programme of Grand Round lectures under way.

We have also begun the process of developing protocols to formalise referral to the Service. This will allow a much greater clarity of definition of National level activities whilst providing the basis for regional investment to develop local services.

10.4 Interventional cardiology development

It is a time of great excitement for interventional cardiologists working in structural heart disease. The advent of percutaneous and transcutaneous valve implantation has allowed major reductions in inpatient and recovery times, particularly in the area of pulmonary valve implantation. Other techniques such and percutaneous mitral valve repair are becoming moiré widespread. These techniques will have increasing relevance to patients with adult congenital heart disease and local expertise needs to be fostered. At the present time, such patients have to be sent to London at great expense to the taxpayer and inconvenience to the patient. Dr N Walker brings with her the training and experience with

which to start this programme in Glasgow and it is hoped that we will be able to offer percutaneous pulmonary valve implantation by the end of the year.

Dr N Walker has also re-designed the interventional programme, bringing it in line with other units in the UK and Europe. A more rigorous approach to pre- and post –procedure assessment has been introduced allowing for better decision making and assessment of outcome. The increase in provision of general anaesthetic means that we are able to offer general anaesthetic to a greater proportion of patients, a change that has been welcomed by both patients and staff. More complex procedures are now performed with two congenital interventionalists in attendance as a result of greater collaboration with the Yorkhill team.

10.5 Surgical development

Whilst interventional cardiology is able to offer less invasive solutions for some patients who previously would have required surgery, adult congenital cardiac surgery is becoming more complex and increasing being performed in older patients as our population ages. Many of the issues relate to the failing right heart following surgery and right heart support is becoming an ever more important issue in the management of the older patient and in those who suffer unexpected severe right heart compromise following intervention. We are now able to offer this support to patients if needed and this has already allowed more complex surgery to be considered and planned.

10.6 Electrophysiological treatment

Arrhythmias are a major source of morbidity and mortality in the adult congenital heart disease population. It has been demonstrated that they represent the commonest reason for admission to hospital and become increasingly commonplace as patients age. We can therefore expect an ever increasing healthcare burden due to arrhythmias in this group of patients. A separate area that needs to be addressed is the use of electrophysiology to plan and guide surgical ablation of arrhythmias. Whilst the electrophysiological team in Glasgow are very supportive they are overstretched by non congenital electrophysiological work and lack experience in the more recent developments in electrophysiology within this group of patients. There needs to be investment in manpower and training so that we can offer local solutions for our patients

10.7 Staffing

The year 2009-2010 will be one of growth and further development.

One of the ongoing staffing concerns has been the lack of junior staff support for the service. Whilst at the present time the coronary care team at GJNH cover the SACCS patients, this will become increasingly difficult as the re-organisation of junior staff progresses. It is also a lost opportunity for training for cardiology registrars and we have to find ways to increase exposure for general training purposes together with the more specific needs of trainees wishing to pursue a career in adult congenital heart disease. Whilst there has been some acknowledgement of the training potential and a period of training within SACCS will be introduced next year, this will only provide intermittent support for the service.

In the longer term, and as the service expands, we anticipate the need for a third full time consultant post to share in the duties together with supporting staff.

Conclusion and Summary

The expanding population of patients with adult congenital heart disease inevitably places an increasing burden on healthcare provision. Whilst many patients remain well and in full time employment, often with dependants, others have multiple and complex health needs extending far beyond cardiology. Even in patients who are well, preservation of this state may require further intervention and treatment. High quality investigation and a multidisciplinary approach are central to decision making in this regard. This is even more important given that the speciality is relatively young with an evidence base that is in its infancy.

Recognition of the needs of this population stimulated the rationalisation of Specialist services in England and Wales and the development of National Standards. Greater investment in these areas has allowed the standards to be met in many areas of the UK with a corresponding improvement in quality of care.

SACCS has expanded during the year 2009-2010 and continues to strive to provide an excellent quality of care. Staffing levels have increased leading to an improvement in the efficiency of the service although there is still much room for improvement. Whilst service level agreements have been met, concern remains about equity of access throughout Scotland. The activity figures presented within the report appear to support the view of a Service providing mainly to the West. In fact the figures do not capture the activity in Outreach clinics and assessments taking place outside clinic in Glasgow. A system is currently being implemented to capture this data for future years.

Whilst the Service does provide care across Scotland, a degree of inequality of access to specialist care between the regions undoubtedly exists. A review of the referral pathways and use of the Service in conjunction with local cardiologists under way will help to improve access to the Service whilst clarifying the regional components of care allowing appropriate resource allocation.

Despite the marked development of the SACCS service in Glasgow over recent years, we do not yet meet all of the National Standards. Whilst aspects of these standards will have to be modified to overcome the geographical distances in Scotland, further development of the Service will be required to bring the service into line with other units in the United Kingdom. A gap analysis will shortly be undertaken to clarify the areas in which further investment will need to be considered.