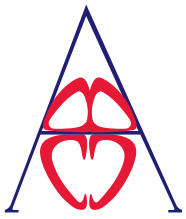

BRITISH CONGENITAL CARDIAC ASSOCIATION

Requirements for Provision of Outreach Paediatric Cardiology Service

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On behalf of British Congenital Cardiac Association

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Introduction

The Kennedy report recommended that: "National standards should be developed as a matter of priority, for all aspects of the care and treatment of children with congenital heart disease. The standards should address diagnosis, surgical and other treatments, and continuing care. They should include standards for primary and social care, as well as for hospital care. The standards should also address the needs of those with congenital heart disease who grow into adulthood"

The care of patients with congenital heart defects is not confined to the tertiary centre. With the exception of a few defects, patients continue to need follow-up and/or further surgery during their lifespan. Therefore, for many patients who live at some distance from their tertiary centre, it is essential that their local health services are able to support them. These include GPs, paediatricians, health visitors, community nurses, who need to be able to provide care for conditions both related and unrelated to the underlying heart defect. There is considerable variation in the level of support that patients/parents receive from local health services around the country. Many patients and parents have felt that their local health services were unable to provide the support they needed, leaving them little choice but to travel to the tertiary centre.

For both initial consultations and follow-up care, it is inconvenient for patients to have to travel to the tertiary centre every time. Although tertiary centres have a system of peripheral outreach clinics, the quality of service and the degree of involvement of local clinicians, varies greatly. The PCCS Review noted that as a general rule patients/parents felt less well supported at outreach clinics than at the tertiary centre. The review further stated that an outreach clinic should deliver the same quality of care that parents/patients could have received if they had attended a tertiary centre, particularly adequate echocardiography. To achieve this, in future there may need to be some rationalisation of outreach clinics. The review also stated that "the concept of the managed clinical network is not a new one and seems ideal for the future running of this service." The aim should be to establish "these networks, with the tertiary centres taking the lead role, collaborating with other centres to establish the most logical and convenient network of outreach clinics, and helping with training and support to local clinicians, so that they can play their full part in the care of their patients."

The PCCS Review recommended various standards. These included:

- The tertiary centre should take responsibility for the quality of cardiac care that is provided across the clinical network. It should provide training/support to key staff across the network and be willing to intervene on behalf of the patient if local services are unable or unwilling to provide the necessary care or support.
- Specialist centres should work with local paediatric or cardiology services so that as much cardiac diagnosis and care as possible is provided in a network of locally accessible outreach services. The patient and family should be asked to travel to the specialist centre only when essential.
- A cardiologist from the specialist centre and the local clinical lead should jointly participate in outreach clinics. The local outreach services and specialist centres should work to agreed joint clinical protocols.
- Each designated paediatric unit should provide basic electrocardiography services for children, including ambulatory and event recording.
- Services, including echocardiography, in outreach clinics should be of the same high standard as at the tertiary centre including in the provision of information and cardiac liaison support.

Current Provision of Paediatric Cardiology Service

In **primary** care, the symptoms of congenital heart disease should be recognised and appropriate referral made to the local hospitals for further assessment and treatment. However, a large part of the work involves detection and differentiation of innocent from pathological murmurs.

In **secondary care**, the patients undergo evaluation of their symptoms and their appropriate investigations. In many cases (such as those with innocent murmurs), the local paediatrician is able to reassure patients and parents. However, the vast majority of patients with suspected cardiac problems are referred to a tertiary care paediatric cardiologist either at the tertiary paediatric cardiology unit or at an outreach clinic undertaken by a paediatric cardiologist jointly with a paediatrician. It is important for the patients and parents that such assessments in secondary or tertiary units are performed quickly and efficiently. In outreach hospitals, patients may be evaluated by two-dimensional echocardiography performed by a paediatrician or a visiting

paediatric cardiologist or a cardiac physiologist appropriately trained in evaluation of congenital heart defects. Much of the non-invasive assessment and diagnosis and management of patients with congenital heart defects can be carried out at the outreach hospitals. Although this type of service has major advantages for the patients, its delivery has stretched the services at the tertiary paediatric cardiology centres.

Tertiary care paediatric cardiology units deliver highly specialised investigation and treatment of congenital heart defects. This includes non-invasive diagnosis by various specialised techniques, such as 2-dimensional and transoesophageal echocardiography, magnetic resonance imaging, and invasive procedures, such as diagnostic and interventional cardiac catheterisation, electrophysiology studies, pacemaker implantation and surgery. Invasive investigation and treatment and cardiac surgery is performed exclusively in tertiary centres.

Outreach clinics:

Outreach clinics services are offered by paediatric cardiologists in many hospitals within their regions. These clinics may be undertaken jointly between the paediatric cardiologists and the local paediatricians, but there is considerable variation. Many of these hospitals are able to offer non-invasive services. It is important that patients and parents have easy access to the diagnostic services in the secondary care units and a co-ordinated access to the tertiary care units.

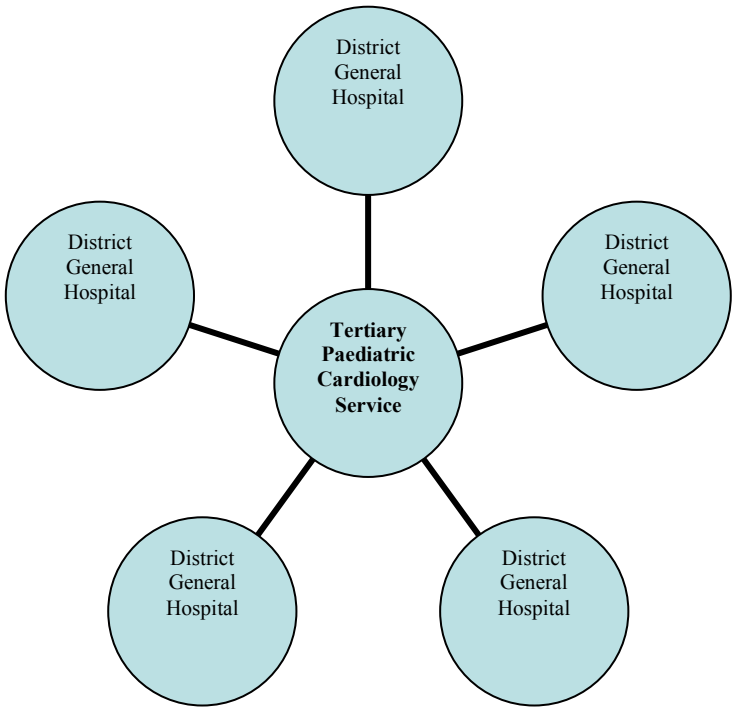
Current Provision of Outreach Clinics

- Paediatric cardiologists usually undertake regular outreach clinic in several outreach hospitals. Working closely in collaboration with consultant paediatricians in the outreach hospitals, paediatric cardiologists provide outpatient facilities for either new patients referred for a cardiac opinion, or for those who have been investigated and treated in the tertiary centre and have been discharged back to the outreach hospital for future follow up.

Consequently, these patients do not need to travel regularly to the tertiary unit, and care is provided near to the patients' home.

- The service is undertaken by paediatric cardiologists travelling on a half day or full day once a month or once every two or three months to the outreach hospitals. Even in this, there is considerable variation because of variations in the workloads.
- The workload in the outreach clinics is usually heavy and varies between a high proportion of patients for evaluation of murmurs to a high proportion in whom a diagnosis has already been made at the tertiary centre or by a paediatrician in the outreach hospital.
- Further strains have been placed on the service provision because of the need to comply with other guidelines, such as screening of babies with various syndromes, screening of families with inherited cardiac disorders such as Marfan's syndrome, screening of children with neuromuscular disorders and assessment of children presenting with syncope.

Current Format of the Outreach Clinic Service



- The outreach clinics may be undertaken in district general hospitals, which may be in close proximity to other district general hospitals.
- The clinics include a variety of referral patterns. Some patients referred by general practitioners directly to paediatric cardiologists are fitted into these clinics but the majority are referred by local paediatricians or community paediatricians.
- Many outreach clinics are for a full day. Some clinics may be for half a day, but this may result in the paediatric cardiologist being away from the tertiary unit for almost a whole day, when travelling time is included.
- Each clinic may include about 10 – 15 patients for half a day clinics to 20 – 30 patients for a full day clinics, although there are occasional clinics that include considerably more than these numbers.
- The appointment times for each patient vary from 5 to 15 minutes.
- Some clinics are so called 'stethoscope' clinics, in which patients are examined by the paediatric cardiologist without performing echocardiography. The patients are then either brought back to the tertiary unit (if no echocardiography machines are available at the outreach hospital) or to another outreach clinic specifically for echocardiography. Thus patients may attend more than once for a final diagnosis to be made.
- In other outreach clinics, an echocardiography machine is available so that a final diagnosis may be made during a single visit.
- There are a few outreach clinics, in which a local paediatrician has expertise in paediatric cardiology, so that echocardiography scans performed by such a paediatrician may be reviewed by a paediatric cardiologist at a subsequent visit or at the tertiary unit.
- The frequency of the clinics usually depends on the needs of the local population and the local outreach hospitals.
- Thus, each paediatric cardiologist may be away from the tertiary unit on average at least once a week and sometimes more. On occasions, this may impact on the cover within the tertiary unit, when several paediatric cardiologists may be away simultaneously. However, it does provide excellent

quality of care for the parents and support for the outreach paediatricians. Thus the standard of care is enhanced for the majority of patients.

Options for Future Provision of Outreach Paediatric Cardiology Service

Option 1:

All the paediatric cardiology service is provided only at the tertiary unit. This option is unsatisfactory as it has several disadvantages for the patients, the families and the medical personnel. The patients and families would need to make frequent visits to the tertiary unit for additional investigations that may be required. It excludes outreach paediatricians from the management of the patient. It is important to remember that the outreach hospital would be the first port of call for the patients in case of emergencies but with this option, they would be excluded from the care of the patient.

Option 2

Another unsatisfactory option is to leave the service unchanged from the way it is provided at present. This has the potential of a lack of progress and development without any major improvements to the service provision for the patients. The quality of service will be variable between outreach clinics and will therefore depend on where the patients live and facilities available at their local hospitals.

Option 3:

The tertiary unit will provide all the elements required to run the outreach clinics. This places the responsibility on the tertiary unit to organise the clinics, outreach nursing support, secretarial support for the arrangements and portable non-invasive equipment such as echocardiography machines. The local outreach hospital would only provide space to run the clinics. This option would have similar impact as option 1. Whilst this would place the whole burden on a tertiary unit for the provision of the provision of service, it does have the major drawback of removing the local outreach paediatricians from providing the care jointly with paediatric cardiologists. A further major disadvantage is that the local hospital will not be involved at an early stage in

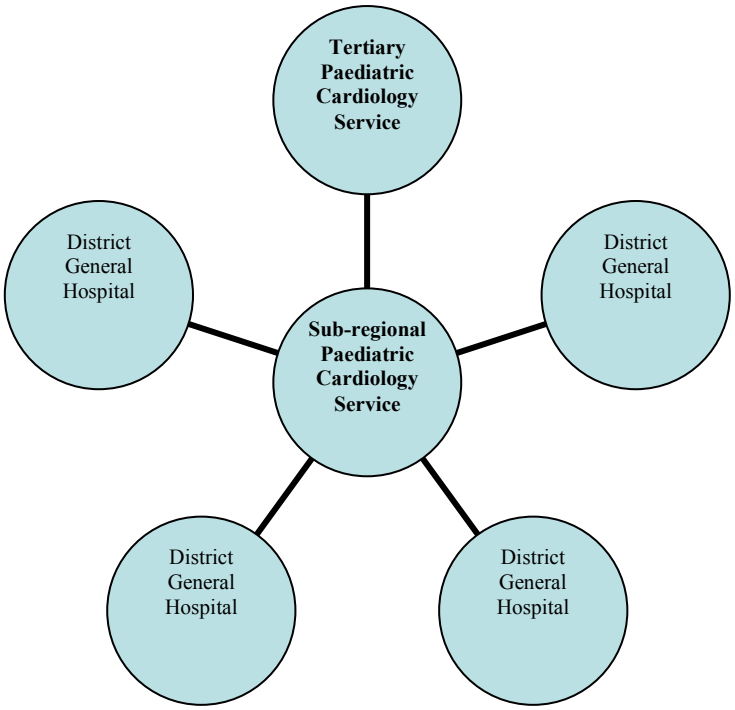
dealing with non-cardiac problems in babies with congenital heart defects, which require major input from the local paediatricians. This option will result in a fragmented service and introduces many barriers and so is also unsatisfactory.

Option 4:

All outreach hospitals should provide echocardiography machines so that the outreach service is a one-visit service. This will have the advantage of being more efficient and reducing the number of hospital visits for the patients and parents. It will result in a more efficient use of the time of a paediatric cardiologist travelling to the outreach hospitals. The service would be provided in partnership with a local paediatrician. In many outreach hospitals, this may be difficult to sustain because of geographical considerations.

Option 5:

This would mean developing a more comprehensive non-invasive specialised paediatric cardiology service in an outreach hospital to which other district general hospitals nearby could refer patients, a sub-regional paediatric cardiology service. See below:



Options 4 or 5 allow the provision of the outreach paediatric cardiology services to be rationalised and developed satisfactorily to the benefit of the patients and should be the targets to be achieved. Both of these options are acceptable. Geographical and regional considerations will determine the choice of optimal service configuration between options 4 and 5.

Ideal Outreach Paediatric Cardiology Service:

An ideal outreach paediatric cardiology service should place patients and parents at the forefront. The service should be on a comprehensive one-visit basis. An adequate amount of time should be given for the appointments. Each new patient should have a minimum appointment time of 20 minutes and each follow up patient a minimum of 15 minutes.

Requirements for Options 4 and 5:

The specialised facilities require adequate space and highly qualified technical staff with the appropriate equipment to provide the services.

Facilities:

All the non-invasive investigations should be available at the outreach hospitals. These should include basic electrocardiography, chest radiography, 24-hour or ambulatory electrocardiography and blood pressure monitoring, treadmill exercise testing and a high quality echocardiography machine.

Administrative and nursing support:

Outpatient administrative support should be available locally. The clinic staff should ensure that all the patient details such as the name, address, postcode, contact telephone numbers and GP details are correct. The additional responsibilities of these staff are to ensure availability of the medical records for the clinics. If the records are missing, then together with the local secretary responsible for the clinic, previous letters, if any, should be found and placed in any temporary records made for the

clinic. If there are duplicate notes found for the same patient, these must be amalgamated into one set.

Secretarial support should be available locally to organise the clinics, type the letters from the clinics, arrange investigations, chase the results of these investigations, and arrange any future follow up.

Nursing support to check patients' height, weight, oxygen saturations and blood pressures should be available.

Support for the patients and parents:

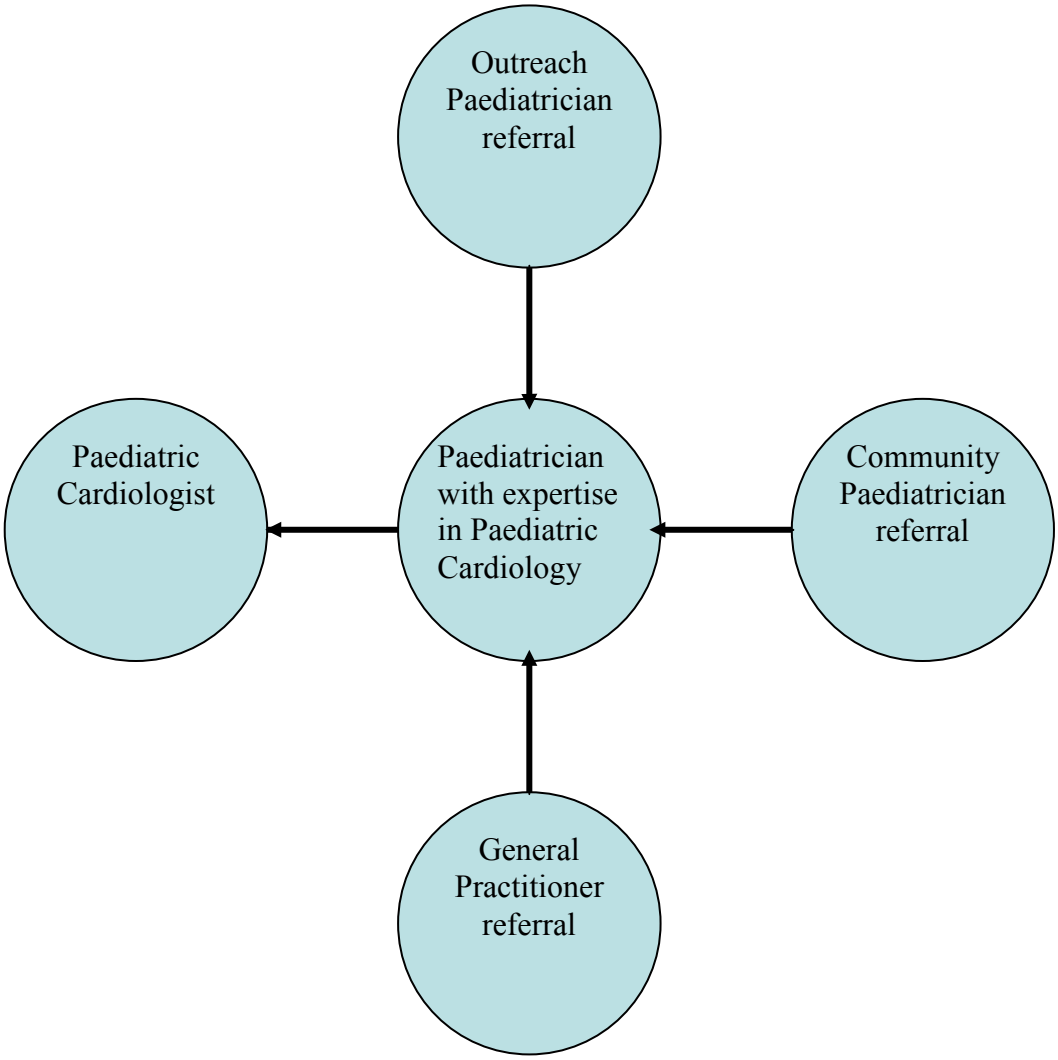
Cardiac liaison nurse support from the tertiary units is important and details must be provided of the named contact person to the parents and patients for information about heart defects and investigations and treatment, to co-ordinate visits and admissions to the tertiary units and to provide information about websites for parental support organisations. It is equally important that they network closely with the local services.

Support from paediatricians from the outreach hospital:

There should be a named paediatrician at the local outreach hospital, who should be closely involved in the organisation, running of and attendance in the outreach paediatric cardiology clinics.

Ideally, each outreach hospital should have a Paediatrician with expertise in Paediatric Cardiology, who should have received training in paediatric cardiology to the level of being able to manage paediatric cardiology patients in the outreach hospitals. Curriculum for this training has been developed and agreed by Joint Royal Colleges of Physicians Training Board (JRCPTB) and Royal College of Paediatrics and Child Health (RCPCH). Such paediatricians need to have educational sessions in the tertiary units for continuous professional development. Telemedicine facilities to link with tertiary units are essential in order to have the echocardiograms reviewed by paediatric cardiologists and establish communication all the year round.
Depending on the workload, in some outreach hospitals, the service may be supported

by cardiac physiologists with appropriate training in echocardiography in congenital heart disease, but with supervision by and responsibilities to a local Paediatrician with expertise in Paediatric Cardiology or a Paediatric Cardiologist. The physiologists may have a role in screening of babies with various syndromes, screening of families with inherited cardiac disorders such as Marfan's syndrome and screening of children with neuromuscular disorders and ventricular function studies.



With such a service configuration, facilities for high quality non-invasive imaging are essential in the secondary care units. The Paediatrician with expertise in Paediatric Cardiology would evaluate the patients and arrange the relevant investigations and echocardiography. The consultation can then be extended using telemedicine with a tertiary paediatric cardiology unit to review the echocardiogram or the review can

take place when the Paediatric Cardiologist visits the outreach hospital. Appointment of Paediatricians with expertise in Paediatric Cardiology needs to be an essential component of the service in the near future. These paediatricians will need educational links with tertiary units for their professional development.

Comprehensive investigation of patients in the outreach clinics, up to the time of referral to the tertiary centre, will form an important bridge between primary and tertiary care. Rapid access clinics at both secondary and tertiary centres will need to be developed in order to cope with the service requirements and the waiting targets set by the government.

Some other recommendations need to be emphasised:

- A Paediatrician with expertise in Paediatric Cardiology must be part of a Managed Paediatric Cardiology Network with a tertiary centre and should work with a link/named tertiary centre Paediatric Cardiologist. This should be on the basis of communication all the year round.
- Regular outreach paediatric cardiology clinics should be held in the outreach hospital.
- Inpatient services in the outreach hospitals will need to be addressed in order to co-ordinate the whole service. This includes protocols for transfer and agreement with the tertiary centre on which patients can be managed locally
- There should be clear pathways for management of patients between the tertiary centre and the outreach hospital and the tertiary centre should share its protocols and guidelines with the outreach hospital and with the Paediatrician with expertise in Paediatric Cardiology. Protocols and guidelines from the tertiary centres should be modified for local use, if appropriate.
- Clinical Governance and peer review systems should be in place.
- Every patient with congenital heart disease should have an agreed care plan.
- There should be clear arrangements for transition care of patients and co-ordination with the adult congenital heart disease services. The model for joint clinics will need to be extended to the adult services. Such examples include joint clinics between paediatric cardiologists and adult cardiologists locally, if appropriate.

- Agreement will be needed between the teams involved in the care of the patients on the prescription and delivery of drugs such as those used for pulmonary hypertension with protocols for prescribing, delivering, monitoring and funding.

In the future, the outreach work will need to be undertaken by Consultant Paediatric Cardiologists and Consultant Paediatricians with expertise in Paediatric Cardiology with educational links with tertiary centres. Such service development will make the patient journey from the GP referral to a specialist opinion and completion of cardiac care of prime importance.

GUIDANCE FOR OUTREACH PAEDIATRIC CARDIOLOGY OUTPATIENT CLINICS

Whatever the mode of provision of outreach paediatric cardiology outpatient clinics service, a state of the art high diagnostic quality echocardiography machine is essential, in addition to other support mentioned above.

Referral pathways

Emergency

Emergency referrals should be made directly to the tertiary paediatric cardiology unit after assessment and initial management in the outreach hospital.

Routine

These should be considered for assessment either by a Paediatrician with expertise in Paediatric Cardiology or in the outreach paediatric cardiology clinic.

Types of referrals

The types of referrals generally belong to the following categories:

- Prenatal diagnosis
- Follow up of previously diagnosed congenital heart defects either in the tertiary unit or at the outreach hospital
- Follow up management of arrhythmias
- Follow up of post-operative cardiac surgical or intervention patients
- Referrals from GPs, paediatricians, community paediatricians, nurse specialists (these referrals should be made to the Paediatrician with expertise in Paediatric Cardiology).

Prenatal diagnosis

If ***prenatal diagnosis of congenital heart defects*** has been made, then either the baby will need to be transferred to the tertiary unit or booked into the outreach paediatric cardiology clinic, as appropriate. Discussions need to take place with the tertiary centre about the location of delivery of the baby. If the baby is delivered locally in the

outreach hospital, the baby will require evaluation after delivery and discussions will be needed with the tertiary unit for transfer or for booking into the outreach paediatric cardiology clinic, as appropriate.

Neonates and young infants

Previously unsuspected congenital heart defect in a newborn with a murmur and otherwise clinically well:

1. These babies need a review in 4-6 weeks in paediatric clinics. Generally this will need to be determined on case by case basis. Clear instructions and guidance should be given to the parents and the GPs for earlier referral, if there are clinical concerns.
2. If echocardiogram performed locally soon after birth shows a cardiac defect, which is unlikely to be haemodynamically significant, such as a small atrial septal defect, patent arterial duct or ventricular septal defect, or minor degree of outflow obstruction, then the babies should be reviewed in 4-6 weeks in the paediatric/baby clinic, as clinically indicated.
3. If there is a persistent murmur at the 4-6 week clinic, then these babies should be booked into the local paediatric cardiology clinic managed by a Paediatrician with expertise in Paediatric Cardiology. The local paediatricians should decide on the timing of such appointments for the outreach paediatric cardiology clinics, if required.

These babies can be seen in the local paediatric cardiology clinic, the outreach paediatric cardiology clinic or the tertiary unit as appropriate.

Neonates and infants diagnosed with congenital heart defects:

- Some of these babies may need close monitoring for the development of heart failure or cyanosis
- Some may need monitoring for arrhythmias and their control by medical treatment
- Some may need adjustment of doses of various cardiac drugs

New referrals of older infants and children from GPs or Paediatricians

These referrals generally fall into the following categories:

1. Murmur
2. Cyanosis
3. Chest pain
4. Palpitations
5. Syncope or dizziness
6. Referral for screening because of family history of congenital heart defect, cardiomyopathy or other syndromes
7. Kawasaki disease

These patients should be seen by a Paediatrician with expertise in Paediatric Cardiology:

1. ***Murmur:*** Evaluation of murmur and if available, an echocardiogram
    a. If the murmur is thought to be innocent and echocardiogram normal, then the patient can be discharged. This should not exclude general paediatricians from assessing the significance of the murmur.
    b. If the murmur is considered to be pathological, then the child should be referred to Paediatrician with expertise in Paediatric Cardiology.
    c. If an abnormality is suspected clinically or found on echocardiogram, then the patient should be booked into local paediatric cardiology clinic. However, minor lesions, such as small ventricular septal defects, or mild pulmonary valve stenosis may be followed up in the outreach paediatric cardiology clinic or by a Paediatrician with expertise in Paediatric Cardiology.
    d. If an echocardiogram has shown an atrial septal defect, then routine follow up in the local paediatric cardiology clinic in 6-12 months would be appropriate.
2. ***Cyanosis:*** Oxygen saturation should be checked. If this is normal and the echocardiogram locally is normal, then there is no need for Paediatric Cardiology referral. If there is evidence of cyanosis, then the patient should be booked into either the paediatric cardiology clinic or referral made to the tertiary unit depending on the degree of urgency.

3. ***Chest pain:*** Generally these patients and their parents require reassurance as to the musculo-skeletal nature of the chest pain. The patients can be seen in a general paediatric clinic. If a cardiac opinion is required, then they should be seen in the clinic managed by a Paediatrician with expertise in Paediatric Cardiology and investigations arranged. These may include chest x-ray, ECG, echocardiogram and treadmill exercise test, if indicated. If these are normal, then only in exceptional cases should a referral be made to outreach paediatric cardiology clinic, otherwise the patient can be reassured and discharged.
4. ***Palpitations:*** These patients should be seen in the general paediatric clinic and investigations arranged. These may include ECG, 24-hour ECG tape, chest x-ray and, if indicated, echocardiogram and treadmill exercise test. If all these investigations are normal, the patient can be discharged. If there is still doubt or of there is an abnormality found, then the patient should be booked into the local paediatric cardiology clinic.
5. ***Syncope or dizziness:*** Should be seen by a paediatrician in the general paediatric clinic initially to evaluate if the symptoms are cardiac or neurological in origin and appropriate investigations arranged. These may include ECG, 24-hour ECG tape, and, if indicated, an EEG. If there is still doubt or if there is an abnormality found, the patient should be seen in the paediatric cardiology clinic by a Paediatrician with expertise in Paediatric Cardiology to arrange an echocardiogram and tilt-test. The tilt-test may be available at the outreach clinic or may have to be performed at the tertiary centre. If there is still doubt or if there is an abnormality found, then the patient should be booked into the outreach paediatric cardiology clinic.
6. ***Referral for screening because of family history of congenital heart defects, cardiomyopathy, other syndromes***: These patients should initially be seen by a Paediatrician with expertise in Paediatric Cardiology. The investigations will depend on the specific condition and the family history. The screening investigations and the interval for screening should be undertaken according to the protocol of the tertiary centre.
7. ***Kawasaki disease:*** These children should be assessed by a Paediatric Cardiologist or a Paediatrician with expertise in Paediatric Cardiology, who is confident in identifying and excluding coronary artery abnormalities. All children with suspected or proven Kawasaki disease should have an

echocardiogram performed within 48 hours of diagnosis, after 1 -2 weeks and at 6 weeks, according to local protocols

Children and young people diagnosed with congenital heart defects

- Some of these patients may need close monitoring for the development of heart failure or cyanosis, depending on the underlying heart defect
- Some may need monitoring for treatment and control of arrhythmias
- Some may need adjustment of doses of various cardiac drugs

These children and young people should be seen by a Paediatrician with expertise in Paediatric Cardiology in the local paediatric cardiology clinic or in the outreach paediatric cardiology clinic or in the tertiary unit as appropriate.

Patients booked into an outreach paediatric cardiology clinic should have an ECG and chest x-ray and any other investigation arranged as appropriate before the attendance at the cardiology clinic.

Acknowledgements:

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