



Orientation to the Bristol Adult Congenital Heart Service



The Bristol Heart Institute
University Hospitals Bristol NHS Foundation Trust
Bristol Royal Infirmary
Bristol
BS2 8HW

Trust switchboard: 0117 923 0000

The Bristol Heart Institute (BHI) was built in 2009 and is a £61m hospital dedicated to cardiology and cardiac surgery.

It is the hub for the regional adult congenital heart service for the South West and South Wales, and is the level 1 specialist centre. All invasive cardiology and cardiac surgery for congenital heart disease is undertaken here with some outpatient clinical care provided in partnership with district hospitals in the region.

Our team consists of cardiologists, cardiac surgeons, specialists ACHD nurses, cardiac radiologists and our admin team. We also work closely with

- Pulmonary hypertension team
- Cardiovascular genetics
- Cardiac obstetrics
- Cardiac intensivists and anaesthetists

We carry out 30 outreach clinic days per year in Barnstaple, Torbay, Exeter, Swindon, Cheltenham, Truro and Taunton.



The Cardiologists:

| | | |
|----------------------|---|---------------|
| Dr Stephanie Curtis | Imaging/pregnancy/ICC | Clinical Lead |
| Dr Radwa Bedair | Intervention | |
| Dr Graham Stuart | Electrophysiology/ICC | |
| Dr Mark Turner | Intervention | |
| Dr Demetris Taliotis | Intervention (paediatric cardiologist) | |
| Dr Rob Tulloh | Pulmonary hypertension (paediatric cardiologist) | |
| Dr Guido Pieles | ICC/functional cardiac imaging/exercise & sports Cardiology | |

The Cardiac Surgeons:

Mr Andrew Parry

Professor Massimo Caputo

Mr Serban Stoica

Specialist Nurses:

Sheena Vernon Lead Nurse Congenital Heart Disease

Caryl Evans Bleep: 3393

Wendy Visser Bleep: 3200

Jessica Gardiner Bleep: 2947

CNS Telephone advice line: 0117 342 6599

Cardiac Geneticists:

Professor Ruth Newbury-Ecob

Dr Francis Sansbury

Dr Ingrid Scurr

Cardiac Radiologists:

Dr Mark Hamilton

Dr Nathan Manghat

Dr Stephen Lynn

Cardiac Obstetricians:

Miss Louise Ashelby

Miss Aarthi Mohan

Miss Rebecca Simms

Miss Jo Trinder

Secretaries

Miriam Sturman (Dr Stuart and Dr Pieles) 0117 342 6576

Lisa Curthoys (Dr Curtis and Dr Taliotis) 0117 342 5967

Edith Taylor (Dr Turner and Dr Bedair) 0117 342 6575

Maureen Sutherland (Cardiac surgeons) 0117 342 6659

JCC Co-ordinator:

Miriam Sturman 0117 342 6661

Cardiology and cardiac surgery waiting list co-ordinators:

Esme Rogers 0117 342 6558

Agata Anders 0117 343 6559

Ismay Summers 0117 342 6557

Cardiology/Cardiac Surgery Wards in the BHI:

| | |
|--|---------------|
| Catheter labs (Cardiology) C602 | 0117 342 6538 |
| Cardiac Intensive Care unit/ Cardiac High Dependency unit C604 | 0117 342 0330 |
| Coronary Care unit C603 (Cardiology) | 0117 342 6527 |
| Ward C705 (Cardiology and Adult Congenital Heart Disease) | 0117 342 6551 |
| Ward C708 (Cardiac Surgery) | 0117 342 6652 |
| Ward C805 (Cardiology) | 0117 342 6653 |
| Outpatients | 0117 342 6505 |

Investigations/Interventions

Our cardiologists carry out a number of diagnostic and interventional procedures such as:

Investigations:

- Diagnostic cardiac catheterisation
- Echocardiography
- Exercise tests (treadmill tests)
- 24 hour ECG and blood pressure monitoring
- Cardiac MRI and CT

Interventions:

- Percutaneous Atrial Septal Defect and Patent Foramen Ovale device closure
- Coarctation stenting
- Percutaneous valve implantation
- Simple and complex pacing and ICD implantation
- Electrophysiology (EP) studies and ablations
- TAVI

Our surgeons perform many different operations including:

- Valve repairs and replacements
- Repair of septal defects
- Complex congenital surgery
- Aortic surgery

The Clinical Nurse Specialists

The CNS's support patients who are in hospital undergoing cardiac surgery and interventions. They also support young people arriving into adult services, patients with learning difficulties and patients needing end of life care. Sheena Vernon also does nurse-led clinics, in which she sees patients with ACHD lesions and post-operative follow-up. A telephone advice line is available for patients and professionals and deals with around 2000 calls a year.

Pulmonary Hypertension Service

Pulmonary hypertension is coordinated by Professor Robert Tulloh.

There are monthly clinics held on Thursdays and Fridays in the BHI jointly with the Hammersmith Hospital as part of the National Pulmonary Hypertension service. In the clinic, patients undertake a 6 minute walk test (see ATS protocol), echocardiogram (see protocol), ECG, clinician review and sometimes nurse assessment or psychology. Cardio-pulmonary exercise testing is arranged Dr Adrian Kendrick. Cardiac catheterisation for pulmonary vascular resistance study is arranged as a separate inpatient as are CTPA, Cardiac MR (Mark Hamilton and Nathan Manghat).

Acute admissions may be for commencing disease modifying therapy (prescribed by the Hammersmith Hospital) such as Sildenafil/Tadalafil, Bosentan/Ambrisentan, Iloprost (see protocol) or for investigation of cause of PH (see protocol). Unwell patients are cared for by the ACHD team with Professor Tulloh advising to ensure 24 hour cover.

Inherited Cardiac Conditions (ICC)

Inherited Cardiac Conditions are diseases, such as Marfan's syndrome and other connective tissue disorders, inherited arrhythmias and cardiomyopathies. Many patients with these conditions are referred to our service from childhood and we also see referrals from cardiologists and geneticists throughout the South West.

Coding, Audit and Research

Audit is an important part of our work. We submit data nationally for surgery, intervention and endocarditis (via CCAD) and also carry out internal audits. To ensure that we are correctly reimbursed it is important that our clinical coding is correct. Patients need to be identified as 'ACHD' on Medway. The department has two chairs (Professor Caputo in Congenital Cardiac Surgery) and Professor Tulloh (Paediatric Cardiology and Pulmonary Hypertension). There is a wide range of ongoing research projects and opportunities, including surgical, interventional, MRI and imaging, exercise physiology, electrophysiology, inherited cardiac conditions, cardiac obstetrics and pulmonary hypertension.

Cardiac Antenatal Clinic at University Hospitals Bristol

Almost two-thirds of patients seen in our cardiac antenatal clinic have congenital heart disease and managing the interaction between their often complex hearts and the changes during pregnancy and childbirth are challenging. Pregnancy places a unique stress upon the heart and women with cardiac disease may not tolerate this well.

These women require specialist advice regarding family planning, and specialist supervision throughout pregnancy, delivery and post-partum.

We see patients from all over the South West in our all day twice monthly clinic, staffed by the multidisciplinary team of maternal medicine obstetricians, obstetric anaesthetists,

maternal medicine cardiologists and midwives. The clinic takes place on the first and third Friday of the month in St Michael's Hospital in the Antenatal Clinic on Level E.

In addition we have a formal monthly MDT meeting of cardiologists, obstetricians, fetal medicine physicians, anaesthetists, midwives and cardiac specialist nurses, where all cases are discussed. A delivery plan is formulated, which is filed in the patient's delivery notes and on the Central Delivery suite.

Transition and the Young Person (YP) Clinic

Transition is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems. We know that patients often report negative experiences of transfer to adult services and loss to follow up is common. Adolescent patients often lack knowledge about their condition and how to prevent complications. Furthermore we know that poor transition results in adverse medical, social, and educational outcomes.

Annually we receive two hundred patients that transfer from the paediatric service to the adult service. It is a period during which patients become more involved in dealing with their heart problem and more responsible for their own health. The specialist nurse will discuss issues around growing up with congenital heart disease, including exercise, employment, insurance, and sexual health, and give information on support groups.

We currently run two young adult out-patients clinics per month, where patients between the ages of 16 and 24 are seen by a doctor and nurse specialist. We have specific UHBristol transition proforma on Medway, that is to be completed for all young people.

Formal Local Training in ACHD

Annual ACHD Study Day (run by Sheena Vernon CNS), October, Education Centre – aimed at nurses and allied health professionals.

ACHD Training Programme (run by Dr Curtis), March and October, Engineers' House, Bristol. Ongoing rolling workshop-style four day programme (basic, intermediate, advanced and specialist subject) over two years, aimed at cardiologists, specialist nurses and trainees.

National and International Conferences

British Cardiovascular Society annual Adult Congenital Heart Disease course. A 2 day course at the British Cardiovascular Society, London led by expert ACHD Cardiologists. A series of lectures, case based discussions and interactive Q&A sessions this is aimed at cardiology trainees and Consultants.

British Congenital Cardiac Association (BCCA) The Association meets annually in the autumn when one of the specialist centres hosts the Annual Scientific Meeting. Aimed at cardiologists.

British Adult Congenital Cardiac Nurses Association (BACCNA). A group of adult congenital nurses who provide support, information and advice to adults with congenital heart disease. Meetings are held twice yearly for information sharing and networking, discussing current issues related to practice, clinical education, service development, leadership and research aspects.

EuroGUCH. European Society of Cardiology provides an annual independent educational forum for healthcare professionals across Europe.

Canadian Adult Congenital Heart Disease Network. Annual international conference providing advanced education and collaborative opportunities for medical and allied cardiovascular professionals interested in ACHD.

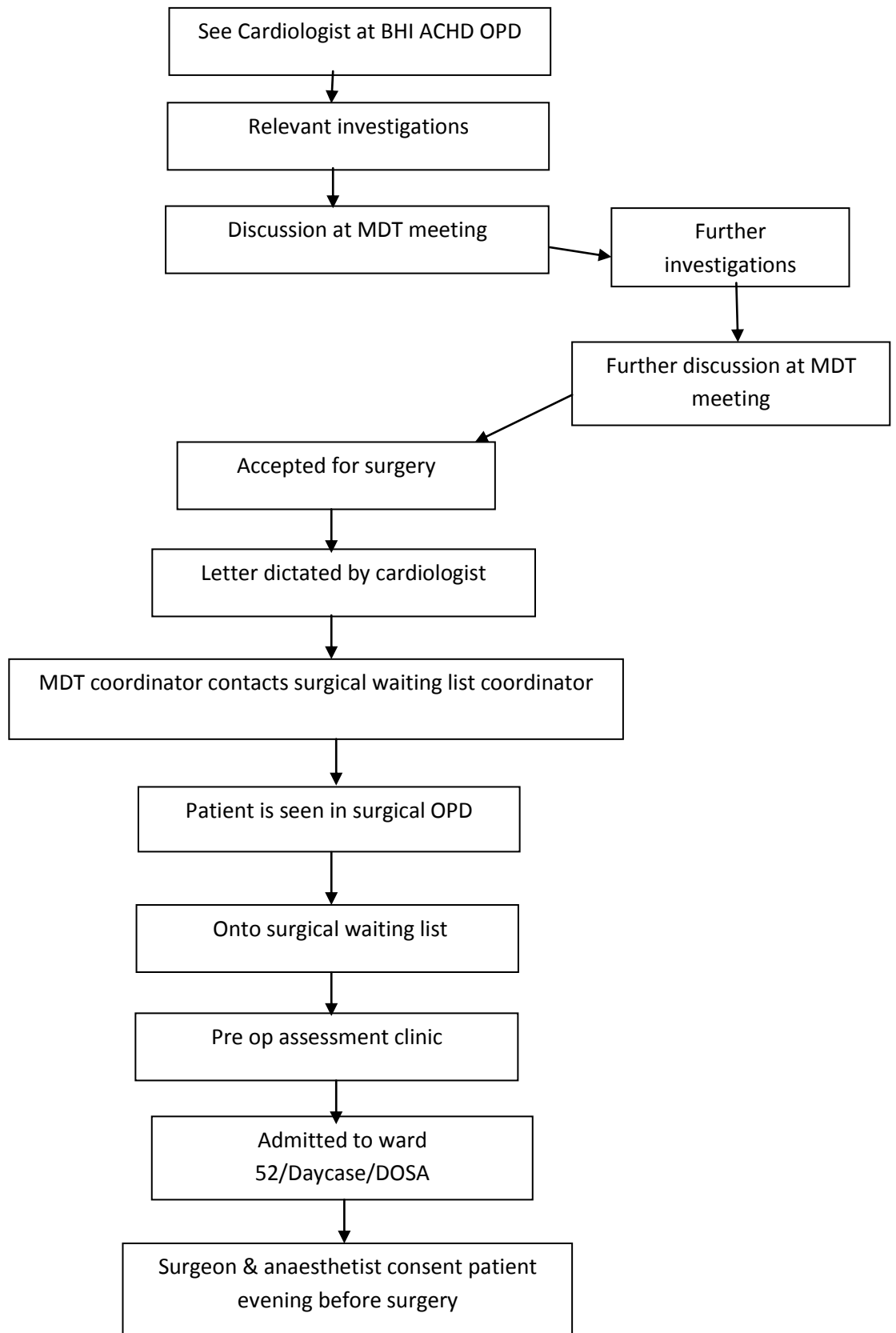
The Cardiac Society of Australia and New Zealand. Annual conference aimed at cardiologists, cardiac surgeons, senior nursing staff, anesthetists and intensivists.

Weekly Team Activities

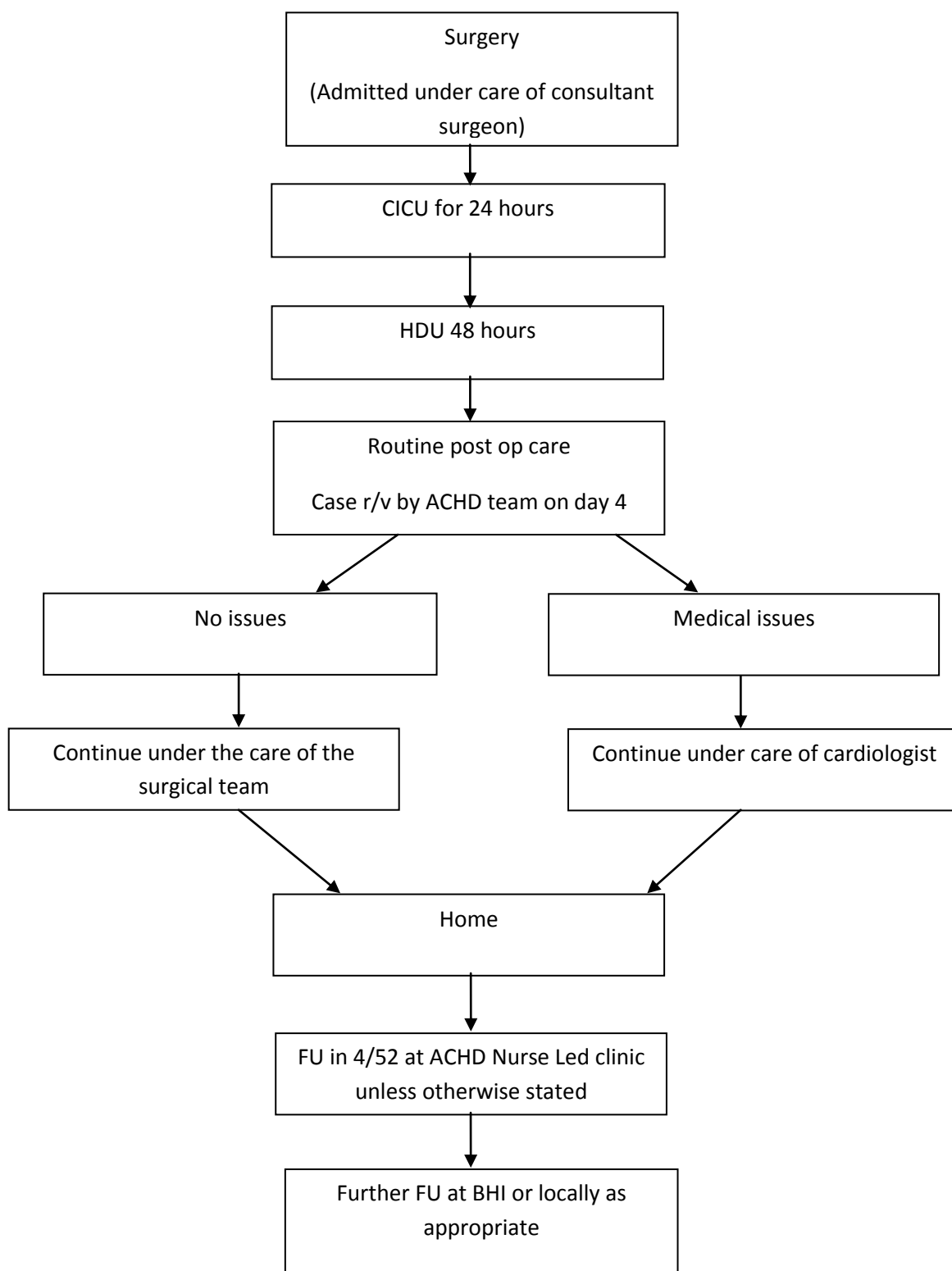
Ward Rounds – The Consultant of the week will do a weekly ward round. Registrar/fellow will complete daily ward rounds with an allocated CNS. A handover sheet may be found on the *Workspaces* under *Teams then Bristol Congenital Cardiac Centre*.

| | am | pm |
|------------------|--|---|
| Monday | JCC – (MDT meeting) Cardiac surgery Pre-assessment clinic (CNS) | Cardiac surgery RB clinic Nurse-led clinic TOE list (SLC) |
| Tuesday | Clinic (RB) | Clinic (SLC) EP Cath lab list (AGS) |
| Wednesday | Clinic (SLC) Nurse led clinic Surgical clinic Cath lab list (MST) | Clinic (AGS) Cath lab list |
| Thursday | Cardiac surgery Pulmonary Hypertension clinic (Once a month) | Clinic (MST) Cardiac surgery Pulmonary Hypertension clinic (Once a month) |
| Friday | 8am consultant meeting Pre-assessment clinic (CNS) Cath lab list Cardiac antenatal clinic 1 st and 3 rd of month (SLC, St Michael's Hospital) Cardiac surgery Pulmonary Hypertension clinic (Once a month) | YP clinic (once a month) Cath lab list Cardiac antenatal clinic 1 st and 3 rd of month (SLC) Cardiac surgery Pulmonary Hypertension clinic (Once a month) |

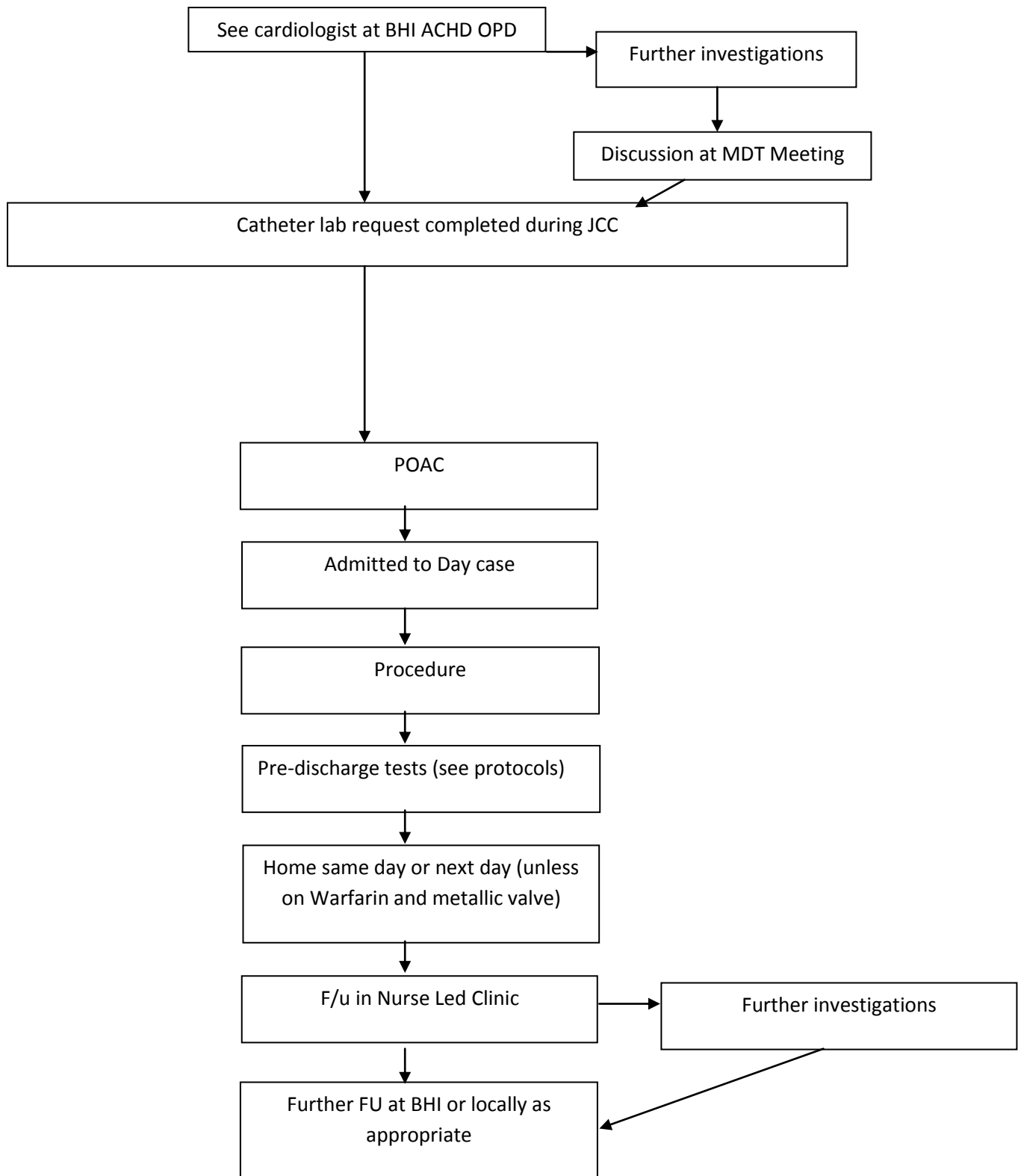
Patient Pathway for ACHD Patient for Surgery Pre op



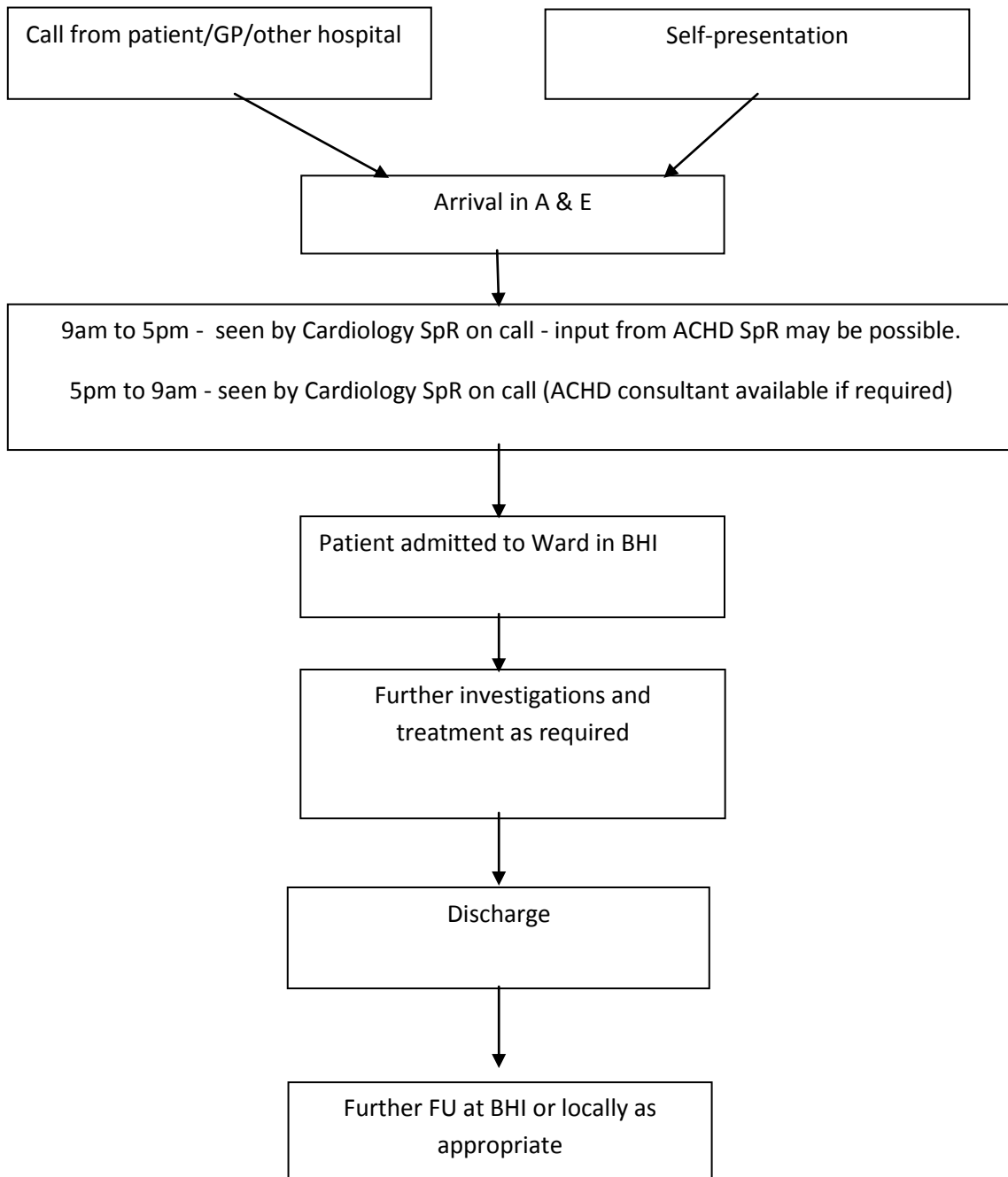
Patient Pathway for ACHD for Surgery Post op



Patient pathway for ACHD Patient for intervention



Patient Pathway for ACHD Emergency in-patient



Protocols for ACHD Patients Undergoing Procedures

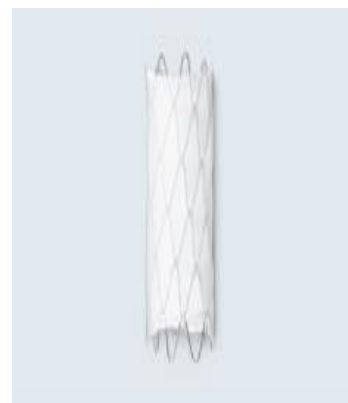
| | PFO Closure | ASD Closure | Coarctation Stent |
|------------------------------|---|--|---|
| Pre-procedure | Should be on Aspirin 300mg od | Should be on Aspirin 300mg od | |
| Post- procedure drugs | Aspirin 300mg od for 6m Clopidogrel 300mg stat, then 75mg od for 3 m | Aspirin 300mg od for 12m, then stop if no other indication Clopidogrel 300mg stat, then 75mg od for 3 m | Aspirin 75-300mg (dose /duration directed by interventionist) |
| Post-Procedure | Echo CXR (lateral) if Premere or device not well seen on echo | Echo | CXR (lateral and PA) |
| Follow-up | 6/52 Device Clinic 6/12 bubble echo (organised by MN) Reduce Aspirin to 75mg od when closed 3 years Device Clinic, discharge if closed | 6/52 Device Clinic Longer term F/U at BHI or locally as appropriate | 6/52 interventionist clinic CT 3/12 and 2 years |



Amplatzer device



Gore Helix device



Coarctation stent

On call rota:

There is a separate rota for ACHD consultants and registrars to be on call in the evenings and weekends. Team of the week is displayed on the activity board.

Bleep:

You will be given a bleep to carry with you at all times.

ACHD SpR Bleep: 6563

Useful websites:

European Society of Cardiology Guidelines on the management of ACHD (2010)

<https://www.escardio.org/Guidelines/Clinical-Practice-Guidelines/Grown-Up-Congenital-Heart-Disease-Management-of>

ACC/AHA Guidelines for the Management of ACHD (2008)

<http://circ.ahajournals.org/cgi/reprint/CIRCULATIONAHA.108.190811>

Support groups and information

We have a website dedicated to ACHD at the BHI:

<http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-heart-institute-clinical-services/adult-congenital-heart-disease/>

Information on heart disease for young people

www.yheart.net

www.hearts4teens.org.uk

British Heart Foundation www.bhf.org.uk

The Somerville Foundation <http://www.thesf.org.uk/>

American Heart Association www.heart.org

Canadian Adult Congenital Heart Network www.cachnet.org

