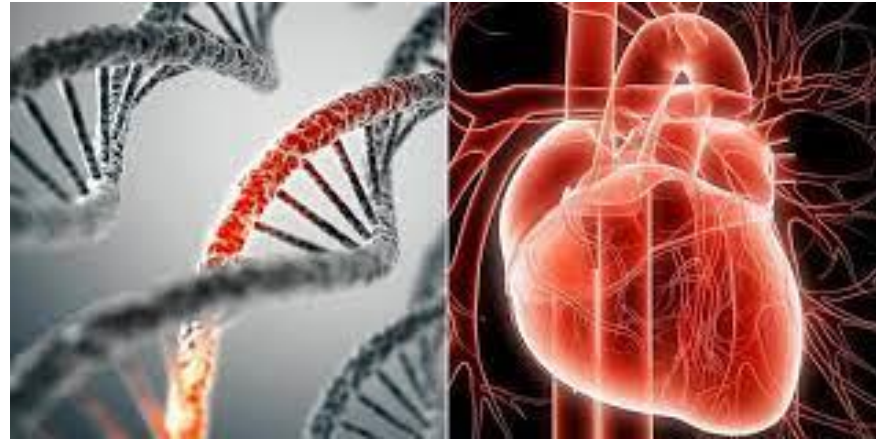


PRIMARY CARE AND INHERITED CARDIAC CONDITIONS



Dr Rachel Bastiaenen- Consultant Cardiologist and Clinical Lead for ICC

Liam Tobin- Lead Clinical Nurse Specialist for ICC

Liz Wilson- Clinical Nurse Specialist for ICC

Housekeeping

- Please keep your microphone on mute until Q&A.
- Questions / comments can be added to the chat box.
We will attempt to address these during the Q&A.
- This session is being recorded for on demand viewing later. If you are not comfortable with your camera on, you are welcome to turn it off.
- An email link to the feedback form will be sent after the session.
- Attendance certificates will be issued on completion of the feedback.
- ODN news and upcoming sessions: slcn.nhs.uk/publications.



[@slcardiovascularnetworks](https://www.youtube.com/@slcardiovascularnetworks)

Objectives

- Introduction- Who and what are we?!
- What conditions do we look after?
- How can we support you and your patients and why is it important to refer?
- How can you refer to ICC at GSTT/KCH/SGH?
- How can you contact us?
- Discussion

ICC- An introduction

The Inherited Cardiac Conditions (ICC) Service provides integrated care for patients with Inherited Cardiac Conditions. This includes family screening, patient management, risk assessment and genetic testing. We work closely with our colleagues in Cardiovascular Genetics and across other Cardiology services (including heart failure, electrophysiology and cardiac surgery).



Guy's and St Thomas'
NHS Foundation Trust



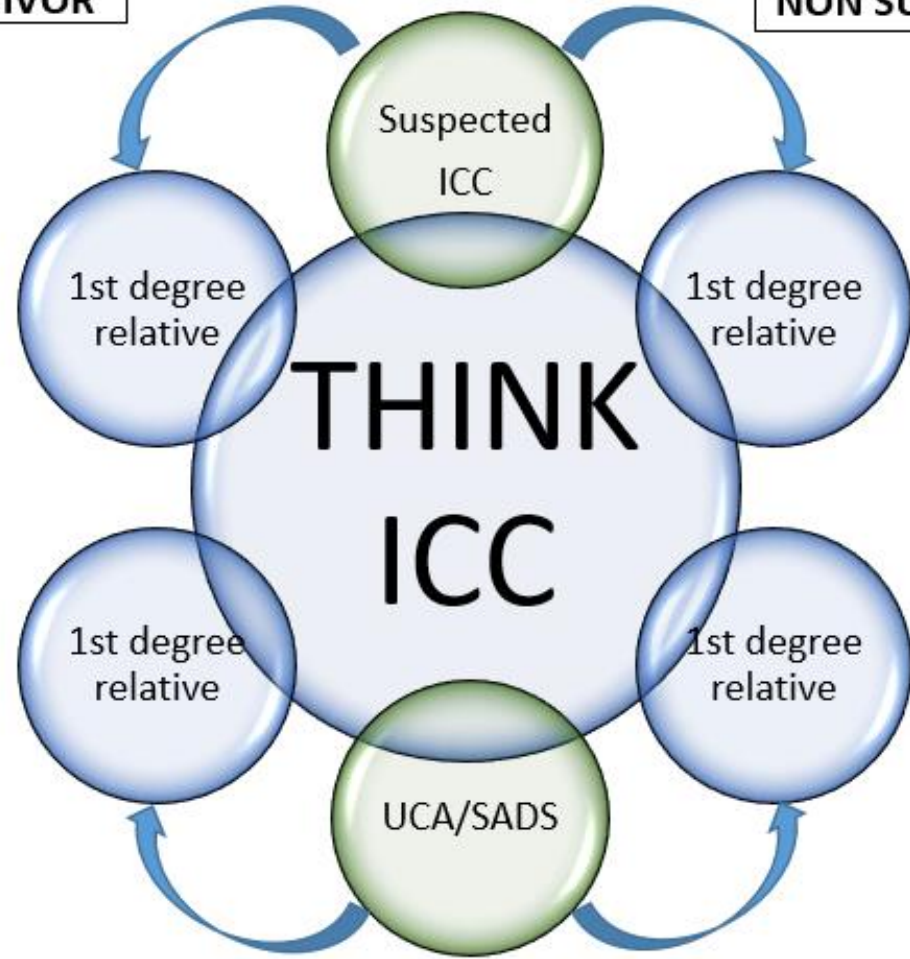
King's College Hospital
NHS Foundation Trust



St George's University Hospitals
NHS Foundation Trust

SURVIVOR

NON SURVIVOR



ADULT SERVICE- OVER 16 YEARS

Patients with suspected inherited cardiac conditions

Inherited cardiomyopathies:

Conditions: Hypertrophic cardiomyopathy (HCM), dilated cardiomyopathy (DCM), arrhythmogenic cardiomyopathy (ACM/ARVC/ALVC), left ventricular non-compaction cardiomyopathy (LVNC).

Inherited arrhythmia syndromes/channelopathies:

Conditions: Long QT syndrome (LQTS), Brugada syndrome (BrS), catecholaminergic polymorphic ventricular tachycardia (CPVT), short QT syndrome (SQTS), short coupled ventricular fibrillation, arrhythmogenic mitral valve prolapse.

Aortopathies:

Conditions: Marfan syndrome, Loeys-Dietz syndrome, Vascular Ehlers-Danlos syndrome (vEDS), aortic dilatation in association with a bicuspid aortic valve.

Unexplained cardiac arrest/sudden cardiac death

Mitochondrial

Directory of service

Section 9 - Service Specific Booking Guidance

Patients suspected to have, affected by or have a family history of: Inherited cardiomyopathies-dilated, hypertrophic, restrictive, arrhythmogenic right ventricular cardiomyopathy. Inherited neuromuscular disease with associated cardiac involvement-myotonic, limb girdle, emery dreyfuss, becker muscle dystrophy Inherited heart rhythm disorders-long QT Syndrome. Catecholaminergic Polymorphic Ventricular Tachycardia, Brugada Syndrome. Sudden Arrhythmic Death Syndrome, Idiopathic VF arrest. Inherited heart disease. Fabry Disease, Mitochondrial disorders. Aortopathies eg Marfan Disease.

Procedures Performed:

Procedures performed at outpatient clinic may include: Ajmaline provocation test 12 lead ECG Signal Average ECG Echocardiogram Genetic testing and counselling

Exclusions:

Children under the age of 16 years. Refer to the Evelina Children's Hospital. Patients with familial hypercholesterolemia – refer to the Lipid Clinic.

Suggested Investigations:

Please include any relevant family history information-clinic letters of relatives, death certificates or post-mortem reports with referral.

Administrative Requirements :

For Urgent referrals please ensure that all clinical letters are attached within 24hrs of the appointment request. For Routine referrals please ensure that all clinical letters are attached within 3 working days of the appointment request. Please include details of current condition and all relevant medical and past surgical history including all current medications and suggested investigation results. Please ensure that the patient's demographics are up to date and complete including correct full name, address, contact numbers including mobile, failure to do so will result in slowing the vetting process. Please note that transport for the first appointment is assessed according to medical need. Patients for appointments at Denmark Hill need to call 020 3299 8000 no earlier than five days and no later than 24 hrs. before their appointment. Interpreter – Foreign Language translation – please specify if an interpreter service is required and language/dialect spoken in the body of the referral letter. Interpreter – Sign Language – Please Indicate on the referral letter if sign language services are needed.

How can we support you?

- We can provide **long term follow up** for patients with an ICC if not in place already/patient has moved area/patient requests.
- We can **clinically screen patients** with a family history of an **ICC in a first degree relative** (parent, sibling, child) inc. confirmation via post mortem.
- We can **clinically screen patients** with a family history of **unexplained cardiac arrest/ sudden cardiac death**.

REF:

INHERITED CARDIAC CONDITIONS

Hambleton Wing
Denmark Hill
London
SE5 9RS

Date:

To Whom It May Concern

Dear Relative,

I am writing to you as one of your family members has been diagnosed with a condition known as hypertrophic cardiomyopathy (HCM). The main feature of HCM is thickening of the heart muscle in the absence of an apparent cause. This condition can be inherited and we would recommend that first-degree relatives have a detailed cardiac assessment by a cardiologist. This should include an electrocardiogram (ECG) and an echocardiogram (echo).

I would be grateful if you would seek a referral from your GP to a local cardiologist for further evaluation. Should you wish to be seen at King's College Hospital, please ask your GP to refer you to:

Dr ~~Nabeel~~ Sheikh
Consultant Cardiologist
King's College Hospital
Denmark Hill
London
SE5 9RS

If you require any further information, please do not hesitate to contact me.

Yours sincerely

Elizabeth Wilson
Clinical Nurse Specialist
Inherited Cardiac Conditions

If you are going to take this letter to your own GP to request a referral, please complete the following information:

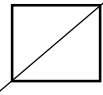
Your Name: _____ Your date of birth: _____
Your Address: _____


Family Screening

DCM= Dilated Cardiomyopathy

SCD= Sudden Cardiac Death

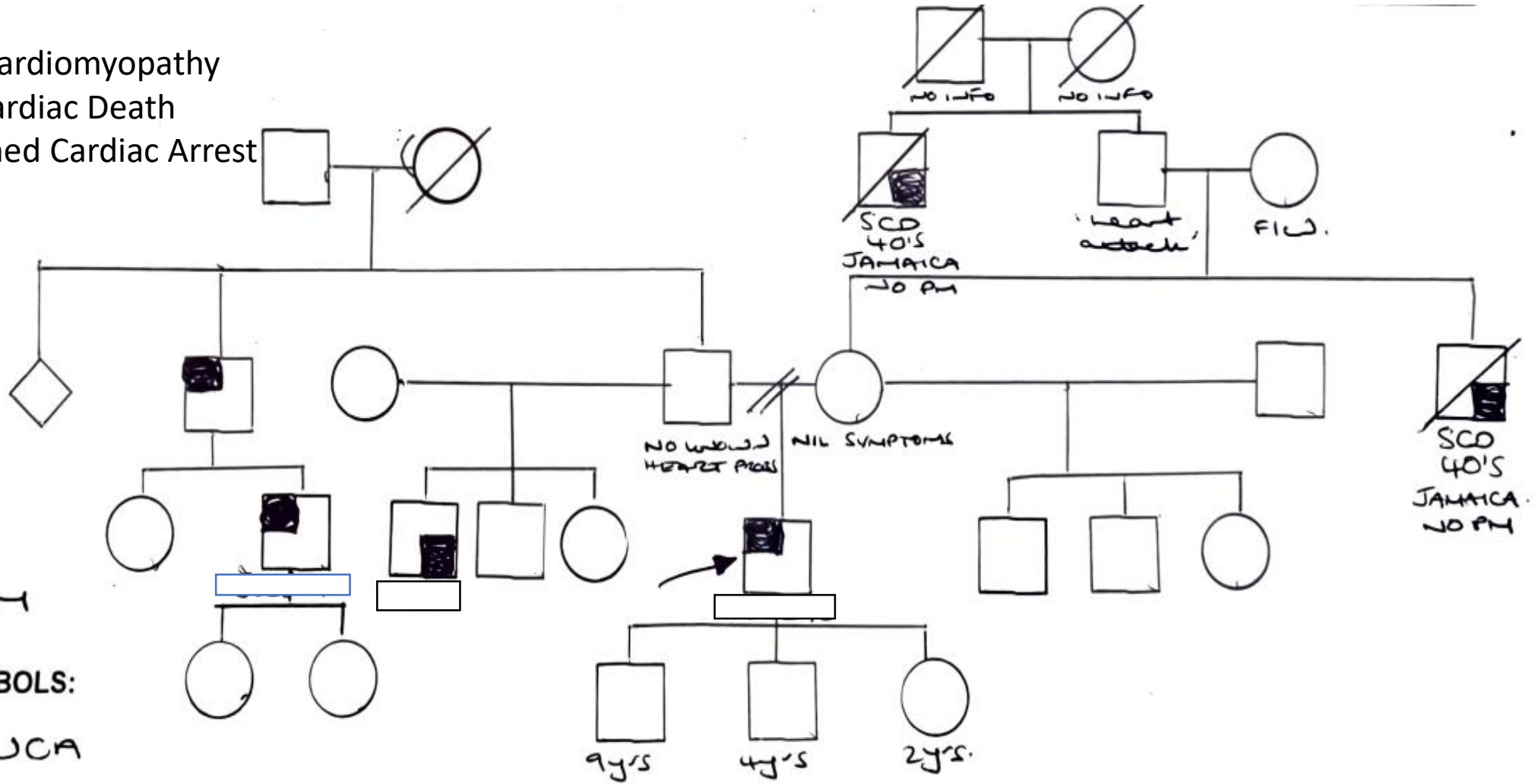
UCD= Unexplained Cardiac Arrest

 = Dead

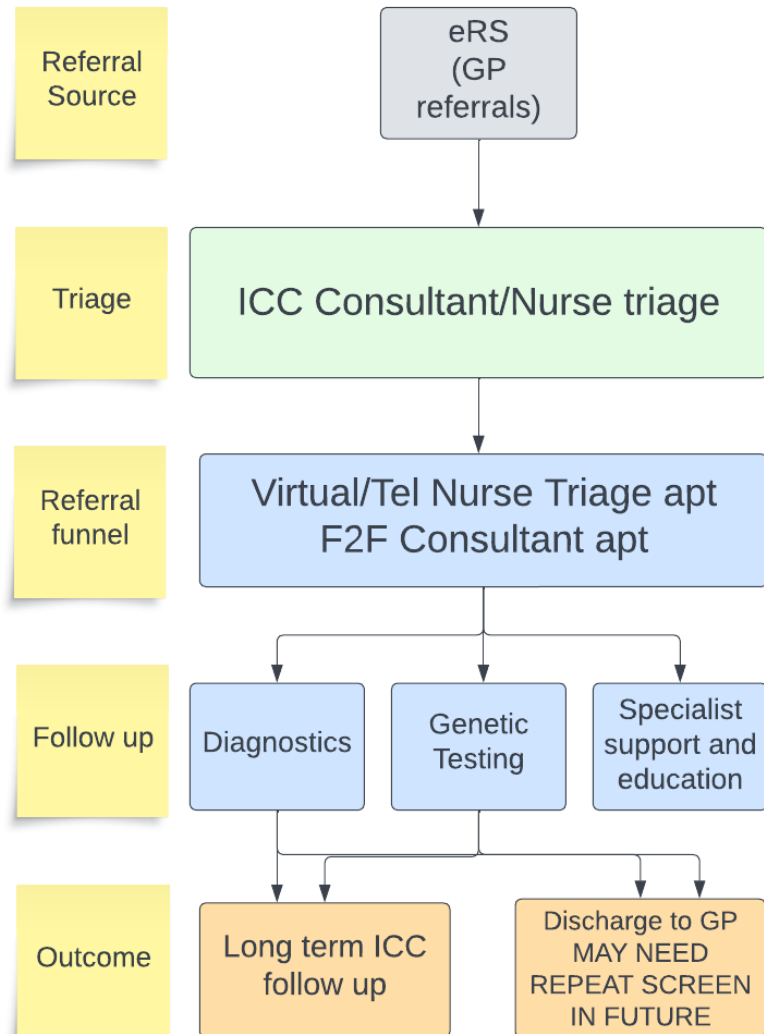
 DCM

KEY TO SYMBOLS:

 SCD/UCD



Referral Pathway- Guy's and St Thomas' and Kings College Hospital



IMPORTANT POINTS:

- ICC should assess all patients with an ICC diagnosis for a long term plan
- Sudden Cardiac Death/Unexplained Cardiac Arrest <60years are relevant
- All screening requires ICC input
- Patients do not need to have symptoms to screen
- We may ask for repeat screens in future, it's rarely ever a 'one off'

How to refer

- ERS referral
- Advice and Guidance via ERS

QUERIES ONLY

- Guys and St Thomas- gst-tr.iccnurses@nhs.net
- Kings College Hospital- kch-tr.iccreferrals@nhs.net
- St Georges Hospital- stgh-tr.icc.clinic@nhs.net

Service Definition

Service: Cardiology - Inherited Cardiac Conditions - @
Denmark Hill for King's College Hospital - RJZ

Section 1 - Service Details

Service ID:	7579596
Service Comments:	Suite 6 Golden Jubilee Wing
Referrer Alert:	-
Service Location:	KING'S COLLEGE HOSPITAL (DENMARK HILL)
Specialty:	CARDIOLOGY
Appointment Type:	First outpatient
Genders Treated:	Male and Female
Directly Bookable:	Yes
Service Transition Date	-
Service Effective Date Range	05/11/2013 to -
Age Range Treated	16 years and over
Request Types Supported:	
Appointment Request:	Yes
Advice Request:	Yes
Triage Request:	No
Publish:	Yes
Available on Secondary Care Menu:	Yes

Discussion

- Any questions re. presentation?
- What are your experiences with referral to ICC?
- What is working?
- What isn't working?
- Forward steps...



Further information

GUYS AND ST THOMAS/KINGS COLLEGE HOSPITAL

- <https://www.guysandstthomas.nhs.uk/our-services/inherited-heart-cardiac-conditions>

ST GEORGES HOSPITAL

- <https://www.stgeorges.nhs.uk/service/cardiovascular/cardiology/inherited-heart-problems/>