ISRCTN17200091 https://doi.org/10.1186/ISRCTN17200091

Imperial cardiac conditions registry

Submission date 25/07/2025	**Recruitment status** No longer recruiting	[_] Prospectively registered [_] Protocol
Registration date 01/10/2025	**Overall study status** Ongoing	[_] Statistical analysis plan [_] Results
Last Edited 01/10/2025	**Condition category** Circulatory System	[_] Individual participant data [X] Record updated in last year

Plain English summary of protocol

Background and study aims
This study is part of a larger research programme called AIMM (Artificial Intelligence for Multimorbidity). The specific part we're talking about is called the Imperial Cardiac Conditions Registry (ICC Registry). It focuses on people with inherited or structural heart conditions. The goal is to use artificial intelligence (AI) to study heart test results—like ECGs, pacemaker data, and heart scans—to better understand how these conditions develop and change over time. This could help doctors diagnose these conditions earlier and provide more personalised care.

Who can participate?
The study includes NHS patients who:
-Are over 18 years old
-Have had heart tests as part of their NHS care
-Have a known or suspected inherited heart condition

What does the study involve?
This is a retrospective study, which means it uses information that has already been collected during routine NHS care. There are no new tests or appointments, and patients will not be contacted.

What are the possible benefits and risks of participating?
There are no direct benefits or risks to participants, as the study only uses existing data. However, the findings could help improve care for people with inherited heart conditions in the future.

Where is the study run from?
Imperial College London (UK)

When is the study starting and how long is it expected to run for?
The study is already underway and is expected to continue as part of the ongoing AIMM research programme. There is no fixed end date yet.

Who is funding the study?
British Heart Foundation (UK)

Who is the main contact?
Dr Amanda Varnava, amanda.varnava@nhs.net
Dr Joseph Barker, joseph.barker@imperial.ac.uk
Dr Fu Siong Ng, f.ng@imperial.ac.uk

Contact information

Type(s)
Public

Contact name
Dr Amanda Varnava

Contact details
Head of Department
Department of Cardiology
Hammersmith Hospital
London
United Kingdom
W12 0HS
+44 20 3313 1000
amanda.varnava@nhs.net

Type(s)
Principal investigator

Contact name
Dr Fu Siong Ng

Contact details
Reader in Cardiac Electrophysiology
Hammersmith Hospital
London
United Kingdom
W4 3ET
+44 20 3313 1000
f.ng@imperial.ac.uk

Type(s)
Scientific

Contact name
Dr Joseph Barker

ORCID ID
https://orcid.org/0000-0002-5483-9608

Contact details
Clinical Research Fellow
Hammersmith Hospital

London
United Kingdom
W12 0HS
+44 20 3313 1000
joseph.barker@imperial.ac.uk

Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

Integrated Research Application System (IRAS)
338595

Protocol serial number
Nil known

Study information

Scientific Title
Imperial Inherited Cardiac Conditions Registry

Acronym
ICC Registry

Study objectives
A subregistry of patients with inherited and structural cardiac phenotypes curated from the "Artificial Intelligence for Multimorbidity (AIMM)" database for deep phenotyping and AI-enabled cardiac disease discovery.

Ethics approval required
Ethics approval required

Ethics approval(s)
approved 06/07/2025, Health Research Authority (2 Redman Place, Stratford, London, E20 1JQ, United Kingdom; +44 207 104 8000; contact@hra.nhs.uk), ref: 24/HRA/2562

Study design
Retrospective observational cohort study

Primary study design
Observational

Study type(s)
Other

Health condition(s) or problem(s) studied
Inherited cardiac conditions

Interventions

Participants enrolled in this study will receive standard medical care through a tertiary inherited cardiac conditions clinic. Following referral, patients undergo routine assessment and management as per clinical guidelines, including clinical evaluation, genetic counselling, diagnostic testing, and ongoing follow-up. Observation begins at the point of referral and continues until death, representing a lifelong follow-up period.

Intervention Type
Other

Primary outcome(s)
Incident disease diagnoses will be recorded using International Classification of Diseases (ICD-10) codes, as compiled by the Imperial College Healthcare Trust Coding Department through systematic review of electronic health records and clinical documentation. Procedure data will be obtained using OPCS codes, collected through the same methodology.

Key secondary outcome(s))
There are no secondary outcome measures

Completion date
01/07/2033

Eligibility

Key inclusion criteria
>18 years attending tertiary care for suspected inherited cardiac conditions

Participant type(s)
Patient

Healthy volunteers allowed
No

Age group
Adult

Lower age limit
18 years

Upper age limit
120 years

Sex
All

Total final enrolment
10000

Key exclusion criteria
<18 years

Date of first enrolment
01/01/2000

Date of final enrolment
01/01/2025

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
Imperial College Healthcare NHS Trust
Hammersmith Hospital
Hammersmith Campus
Du Cane Rd
London
United Kingdom
W12 0HS

Sponsor information

Organisation
Imperial College London

ROR
https://ror.org/041kmwe10

Funder(s)

Funder type
Charity

Funder Name
British Heart Foundation

Alternative Name(s)
The British Heart Foundation, the_bhf, BHF

Funding Body Type

Private sector organisation

Funding Body Subtype
Trusts, charities, foundations (both public and private)

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan
Individual participant data cannot be shared owing to ethical restrictions without enrollment to the AIMM study

IPD sharing plan summary
Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Study website	Study website	11/11/2025	11/11/2025	No	Yes