

Imperial cardiac conditions registry

Submission date 25/07/2025	Recruitment status No longer recruiting	<input type="checkbox"/> Prospectively registered <input type="checkbox"/> Protocol
Registration date 01/10/2025	Overall study status Ongoing	<input type="checkbox"/> Statistical analysis plan <input type="checkbox"/> Results
Last Edited 01/10/2025	Condition category Circulatory System	<input type="checkbox"/> Individual participant data <input checked="" type="checkbox"/> 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

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Contact information

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Public

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Integrated Research Application System (IRAS)
338595

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

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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