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# Imperial cardiac conditions registry

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|---|---|---|
| **Submission date**<br>25/07/2025 | **Recruitment status**<br>No longer recruiting | [_] Prospectively registered<br>[_] Protocol |
| **Registration date**<br>01/10/2025 | **Overall study status**<br>Ongoing | [_] Statistical analysis plan<br>[_] Results |
| **Last Edited**<br>01/10/2025 | **Condition category**<br>Circulatory System | [_] Individual participant data<br>[_] 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
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# Contact information

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Public

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Scientific

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# Additional identifiers

### 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

### Primary study design
Observational

### Study design
Retrospective observational cohort study

### 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
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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 |