

# Heart Core Registry

A Gateway to Uncommon And Rare Diseases of the Heart



AN ERN GUARD-HEART OVERARCHING REGISTRY

INFORMATION LEAFLET

## Mission

The main objective of the Heart-Core Registry is to establish an overarching registry of rare and uncommon diseases that are covered by ERN GUARD-Heart, the European Reference Network for rare, low-prevalence and complex diseases of the heart. The Heart-Core Registry will create a cost-effective and comprehensive approach of rare disease registration in the ERN GUARD-Heart, lead to increased awareness and improved reusability of currently existing and future condition-specific or gene-specific registries in the ERN GUARD-Heart, and better interaction with other rare disease registries in Europe.

## Geographical Coverage

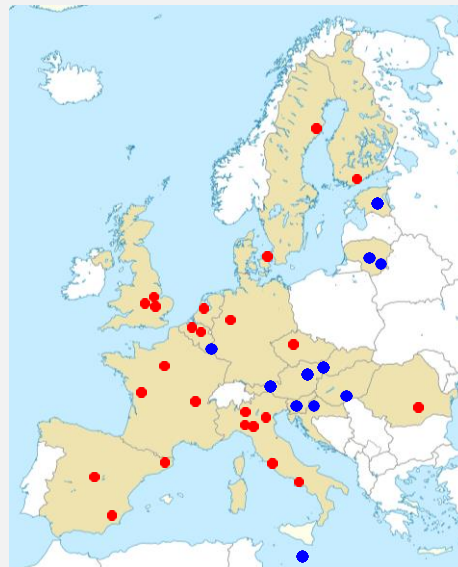
 **Coordinating centre**  
Amsterdam UMC (NL)

**Full members** ●  
(no. of centres per Member State)

BE 2	CZ 1	DK 1	DE 1	ES 3	FR 3
IT 6	NL 1	RO 1	FI 1	SE 1	UK 3

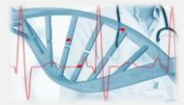
**Affiliated Partners** ●  
(no. of centres per member state)

AT 2	EE 1	HU 1	HR 1	LT 2	LU 1
MT 1	SI 1	SK 1			



## Disease Coverage

Familial electrical diseases



Familial cardiomyopathies



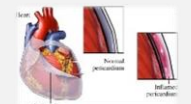
Special electrophysiology condition in children



Congenital heart diseases (from 2021)



Other rare heart diseases (from 2021)



*This leaflet is part of the project "The Heart-Core Registry: a Gateway to Uncommon & Rare Diseases of the Heart" [GUARD-Heart Registry - 946148]. The project has been funded with support from the 3<sup>rd</sup> Health Programme (2014-2020) of the European Union (EU). The document reflects only the views of the authors and the EU cannot be held responsible for any use which may be made of the information contained therein.*





## Aims

- ♥ Build the first overarching registry (*Heart-Core Registry*) of patients who are included in gene- and condition-specific registries of ERN GUARD-Heart using tools/standards of EU Rare Disease Platform.
- ♥ Collect a core dataset for all patients, including the Set of Common Data Elements for Rare Diseases Registration of the Joint Research Centre.
- ♥ Facilitate semantic interoperability between the Heart-Core Registry and other patient registries.
- ♥ Collaborate closely with the European Directory of Registries of ERDRI (ERDRI.dor) and the Central Metadata Repository of ERDRI (ERDRI.mdr).
- ♥ Signpost users to the detailed condition- or gene-specific registries of ERN GUARD-Heart registries.
- ♥ Make data in the Heart-Core Registry findable & promote their visibility/usability for stakeholders.

## Existing ERN GUARD-Heart Registries\*

- ♥ Registry of patients with a variant in *CALM* genes.
- ♥ Registry of catecholaminergic polymorphic ventricular tachycardia.
- ♥ Registry of long QT syndrome.
- ♥ Registry of short QT syndrome.
- ♥ Registry of patients with a variant in *PRKAG2* gene.
- ♥ Registry of long QT syndrome type 5 (*KCNE1* gene).#
- ♥ Registry of arrhythmogenic right ventricular cardiomyopathy. #

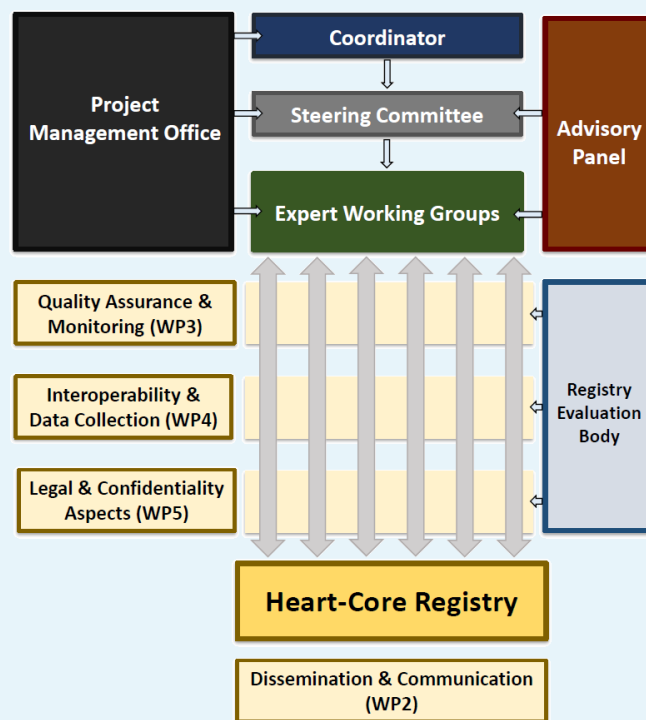
\* All registries are international.

# Registry is being led by a non-ERN centre.

## Stakeholders

- ♥ Healthcare providers.
- ♥ Patients & their families.
- ♥ Healthcare providing organizations.
- ♥ European Reference Networks (ERNs).
- ♥ Researchers & European academia entities.
- ♥ Public healthcare systems.
- ♥ Pharmaceutical & medical device companies.
- ♥ European Commission.

## Organization Structure



WP = Work Package.

WP1 = Project Management & Coordination.

Follow ERN GUARD-Heart & Heart-Core Registry on: (click on logo to proceed)



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Project  
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