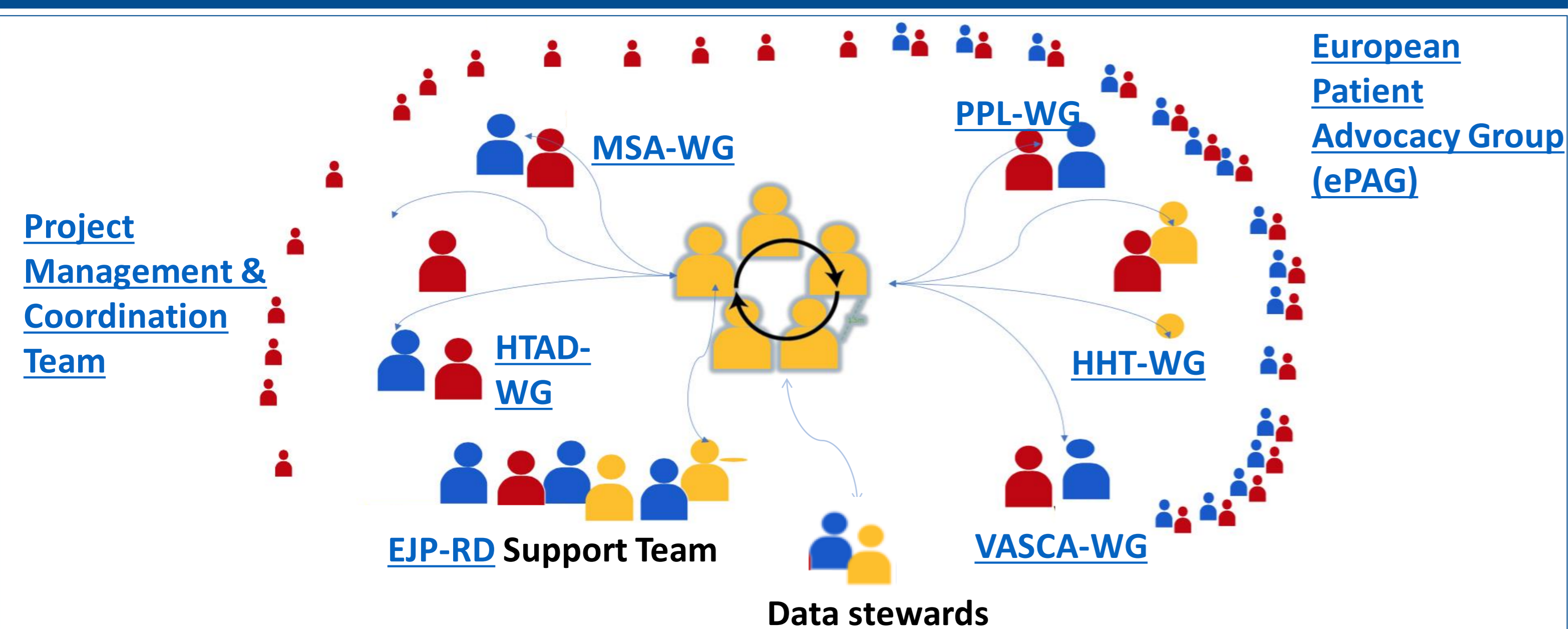




As rare diseases are rare and patient numbers are therefore often limited, sharing of data is absolutely crucial. A European-wide registry is universally recognised as beneficial for epidemiological studies, phenotypic descriptions of new diseases, natural history studies, and hopefully trials of new drugs, or of repurposed drugs, in the treatment of rare diseases. With this VASCERN Registries project, we aim to reach the objective of developing our rare disease registries in order to reinforce our research capabilities and the knowledge about rare vascular diseases. Our project can be viewed as either a unique registry, with the core data elements required for all rare vascular disease patients and the specific disease elements varying for each 5 Rare Disease Working Groups (RDWGs), or 5 different registries with a common core making interoperability and epidemiological studies on the whole population of patients seen within the ERN possible.

## The VASCERN Registries Project Team



The European FAIR HHT, HTAD and MSA vEDS registries will be built on the basis of existing French national registries.

### HHT Registry CIROCO – Hereditary Haemorrhagic Telangiectasia:

- Registry Lead and HHT-WG Co-Chair: Dr. Sophie DUPUIS-GIROD
- Registry Project Manager: Evelyne DECULLIER
- Registry Developer: Jean-Philippe ALLARD

### HTAD Registry – Heritable Thoracic Aortic Diseases:

- Registry Lead and HTAD-WG Co-Chair: Prof. Guillaume JONDEAU
- Registry Project Manager: Samira LARIBI
- Data Stewards: Marie-Capucine TELLIER and Claire BATISTA

### MSA RaDiCo Registry – Vascular Ehlers-Danlos Syndrome:

- Registry Leads: Dr. Sonia GUEGUEN and Dr. Michael FRANK (MSA-WG Co-Chair)
- Registry SEDVASC Project Manager: Eve KLISING
- Datamanager SEDVASC: Huong DANG
- ETL Expert on RaDiCo platform: Xuan-Bach NGUYEN-LE

The European FAIR VASCA and PPL registries will be designed, including the core dataset and their specific diseases datasets.

### VASCA Registry – Vascular Anomalies:

- Registry Lead, VASCA-WG Co-Chair and Registry-WG Chair: Prof. Leo SCHULTZE KOOL
- Registry Project Manager & Data Steward: Pim KAMERLING
- Data Steward: Bruna DOS SANTOS VIEIRA

### PPL Registry – Pediatric and Primary Lymphedema:

- Registry Lead and PPL-WG Chair: Dr. Robert DAMSTRA
- Registry Project Manager & Data Steward: Pim KAMERLING

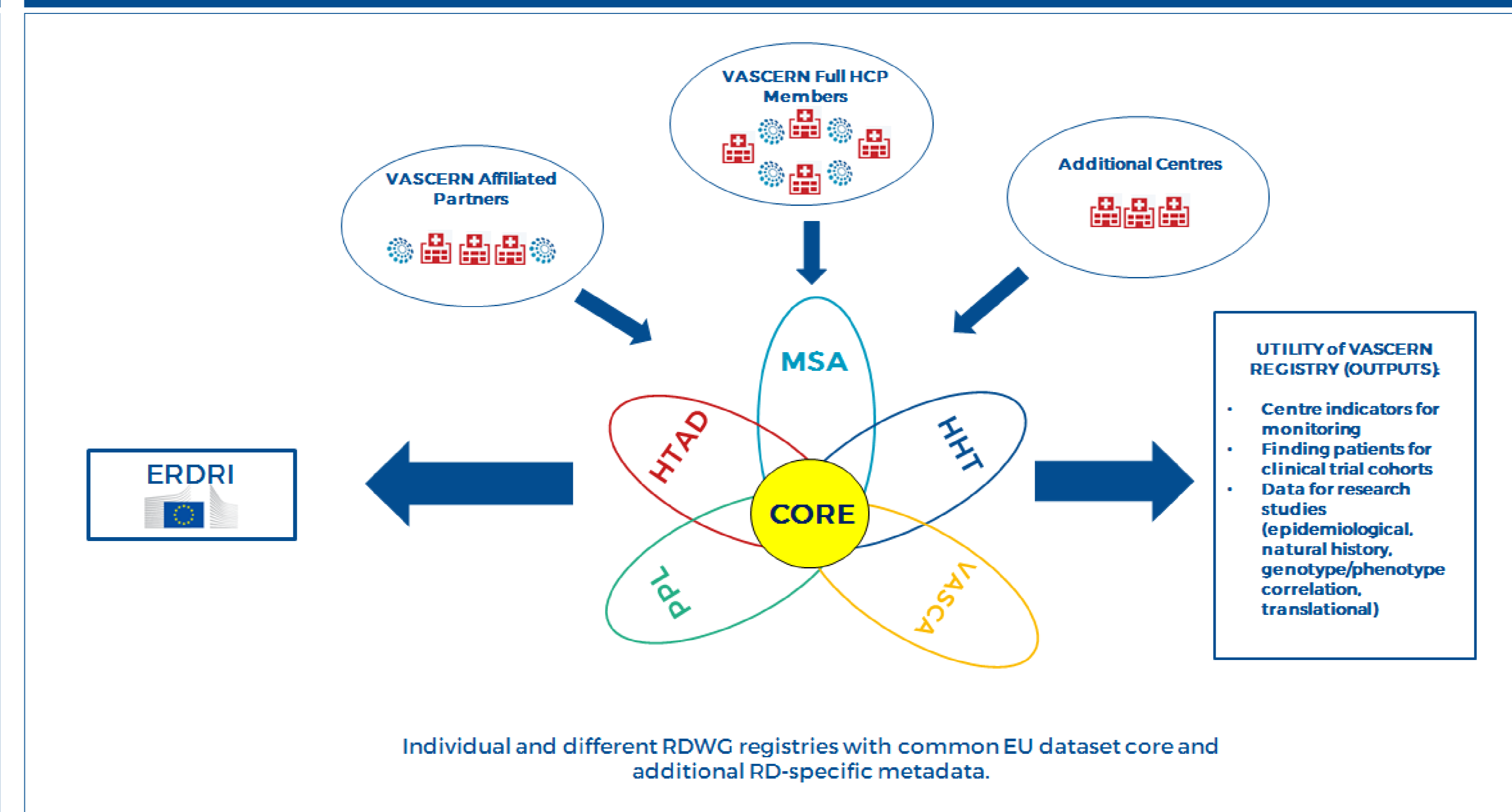
### VASCERN ePAG (European Patient Advocacy Group):

- ePAG advocate for the Registry-WG and ePAG Deputy Co-Chair for the VASCA-WG: Maria BAREA

### VASCERN Project Management & Coordination Team:

- Project Manager: Marine HURARD
- Project Officer: Natasha BARR
- Project Assistant: Karen DAOUD

## The VASCERN Registries



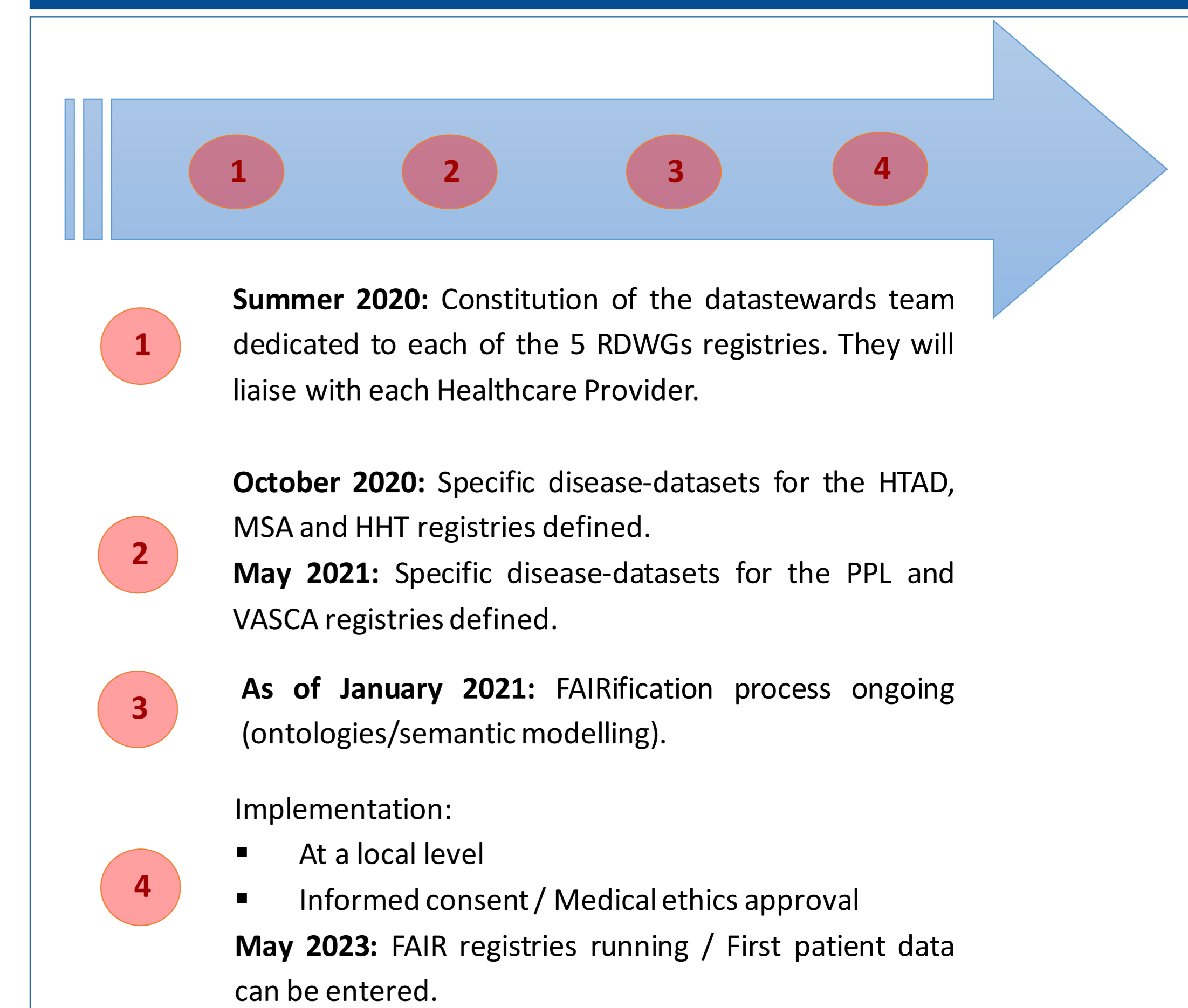
## Goals of our Registries

- Adhere to the FAIR principles
- Be linked to ERDRI (the European Platform of Rare Diseases)
- Start with optimizing links eHR to registries

## What is a FAIR database?

The FAIR data principles are a set of principles used to make data **Findable, Accessible, Interoperable and Reusable (FAIR)**. They also provide the guidelines for good scientific data management and stewardship in order to maximize the use of valuable research data by the scientific community.

## Timeline



## Our 5 Work Packages

- Project Management and Coordination (horizontal)
- Dissemination and communication (horizontal)
- Evaluation (horizontal)
- Creating new registries: Core dataset, VASCA and PPL registries (core)
- Adaptation of existing registries (HTAD, MSA, HHT) (core)