

What is RADeep?

RADeep is a European patients registry on Rare Anaemia Disorders (RADs) collecting data from both new and already existing registries across the European Union, as well as from individual Healthcare providers. RADeep stores patients' data in a secure way, in line with the General Data Protection Regulation (GDPR).

It aims to map at the European level the **diagnostic methods, demography, survival rate, main clinical features and treatments of RADs patients**. In the future, the collected data aims at **providing better care to patients affected by these rare diseases**.

RADeep is led by a Consortium formed by:

- Vall d'Hebron University Hospital Foundation - Research Institute (VHIR) / Vall d'Hebron University Hospital (HUVH), Spain - Principal Investigator: [Maria del Mar Mañú Pereira](#), Team members: Victoria Gutierrez, [Martin Solorzano](#), [Sara Reidel](#), [Claire Diot-Lefebvre](#).
- Hôpital Erasme (ERASME), Belgium - Principal Investigator: [Béatrice Gulbis](#), Team members : [Ines Labidi](#)
- The Cyprus Foundation for muscular dystrophy research (CING), Cyprus - Principal Investigator: [Marina Kleanthous](#), Team members: [Petros Kountouris](#), [Stella Tamana](#).

RADeep, a Registry conceived in line with the European Strategy:

RADeep will contribute to the [European Rare Blood Disorders Platform \(ENROL\)](#), the [ERN-EuroBloodNet's](#) registry for rare blood disorders, following the European Commission's strategy for rare diseases common to the 24 European Reference Networks (ERNs).

RADeep encourages its contributors to follow the **European interoperability standards**, an essential step in the context of the upcoming [European Health Data Space \(EHDS\)](#) which will regulate the future of Data Sharing at European level: The EHDS will start in **2025** with the goal to ensure a consistent framework for the use of individuals' health data for research, innovation, policy-making and regulatory activities.

Thanks to its modular structure, the platform can also support specific research projects such as the [Genomics For Next Generation Healthcare \(GenoMed4all\)](#), the European initiative to transform the response to Haematological Diseases by seizing the power of Artificial Intelligence. The team behind GenoMed4all is working on two use cases; Myelodysplastic syndrome (MDS) and Sickle Cell Disease (SCD). The team in charge of the SCD use case is collecting clinical data through the RADeep platform, developed to include specific modules related to rare anaemia such as SCD.

On the 10th of November 2022, the Rare Anaemia Disorders European Epidemiological Platform (RADeep) held its first Data Access Committee meeting in Barcelona.

Representatives from **10 European Member States** (Belgium, Cyprus, Denmark, France, Germany, Greece, Italy, Portugal, Spain and Sweden), all providing data to RADeep, met in Barcelona on the campus of the Vall d'Hebron Hospital for the first **Data Access Committee (DAC) meeting** of RADeep.

What is expected from the DAC?

The RADeep Data Access Committee has been established in order to review the content of the requests for accessing RADeep data coming from third parties (other researchers from both public and private institutions, patients associations...).

It will also review and approve the protocol for data processing by the RADeep Consortium in order to obtain anonymized data for annual publications and for the website.

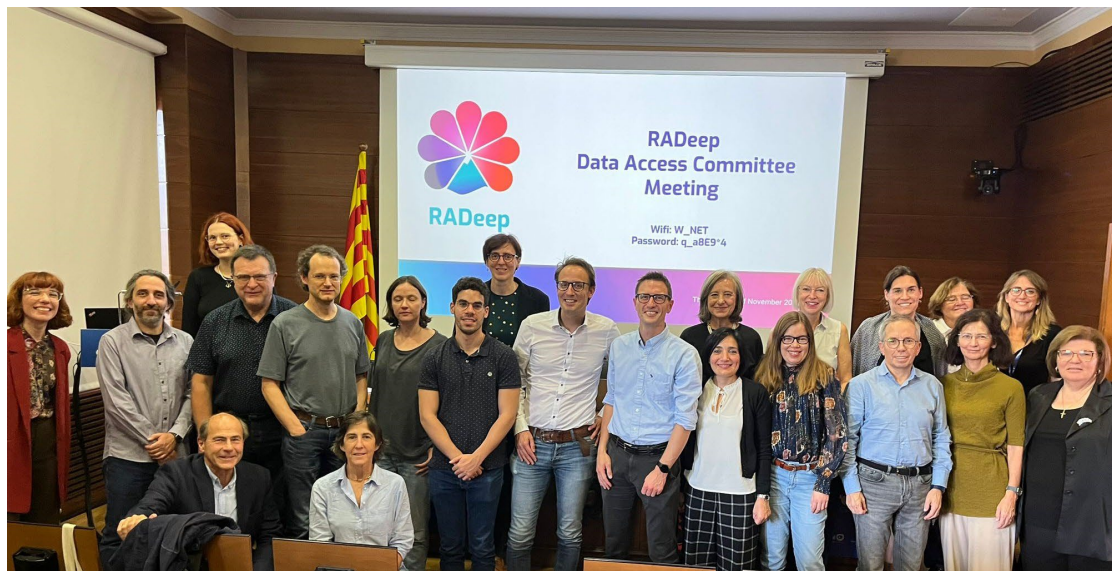
The Data Access Committee is formed by:

- The Steering Committee of the RADeep project (RADeep's Coordinators / [Eduard J. van Beers](#), Haematologist / [Raffaella Colombatti](#), Paediatrician / [Paola Bianchi](#), Lab specialist / [Dore Peerboom](#) and Loris Brunetta, Patients' representatives)
- An ethical expert, [Alexis Rodriguez Gallego](#)
- A Biostatistician, [Sara Reidel](#)
- Data providers at national / local level who are in direct or indirect link with patients and provide data to RADeep.

In its first meeting, the Data Access Committee agreed on the principles of a **Data Access Policy**, as well as of a **Publication Policy** for RADeep.

It was also the occasion for all professionals involved, many of them administering a registry at National level, to get to better know each other, exchange best practices and plan next steps for their participation in RADeep.

The members of the Data Access Committee will meet every 2 months, starting on 8th of March 2023, virtually. In their next meeting they will discuss the protocol for data processing by the RADeep Consortium for its first publication planned for June 2023.



From left to right: Victoria Gutierrez, [Petros Kountouris](#), [Ulf Tedgård](#), [Frédéric Galactéros](#), [Ines Labidi](#), Joachim Kunz, [Celeste Bento](#), [Ilona Binenbaum](#), Jose Marco, Laurence Dedeken, [Eduard J. van Beers](#), [Andreas Glenthøj](#), Giovanna Russo, [Raffaella Colombatti](#), [Dore Peerboom](#), [Béatrice Gulbis](#), Loris Brunetta, [Claire Diot Lefebvre](#), Elena Cela, [Paola Bianchi](#), Soteroula Christou & [Mar Manu Pereira](#).