

# MERITA

the METadata registry of the ERN RITA

## PROJECT ORGANIZATION

**GOVERNANCE BODY**  
RITA Network Board

**MERITA STEERING COMMITTEE**  
IGG, UMCU, HUS

**ERDRI TEAM (WP4)**  
AUT, UKC, UL,  
PCZD, LSMU

**IT TEAM (WP5)**  
IGG, CCI,  
GUH

**IMPLEMENTATION GROUP**  
MERITA members & RIPAG

## PROJECT APPLICANTS

NAME	ORGANIZATION	CITY	COUNTRY
IGG	Istituto Giannina Gaslini	Genoa	Italy
UMCU	University Medical Centrum	Utrecht	Netherlands
GUH	General University Hospital	Prague	Czech Republic
AUTH	Hippokraton General Hospital	Tessaloniki	Greece
UKCL	University Medical Centrum	Ljubljana	Slovenia
IPCZD	Children's Memorial Health Institute	Warsaw	Poland
LSMU	Lithuanian University of Health Sciences	Kaunas	Lithuania
CCI	Centre of Chronic Immunodeficiency	Freiburg	Germany



Promote the interoperability of the RITA network registries so far identified<sup>1</sup> and potentially with other ERNs.

## CHARACTERISTICS

Duration: 40 months

Budget: 250.000 €

Supporting RITA registries: 31 and beyond  
Stakeholders: health professionals working in the field of immune disorders, patients and family organisations, other ERNs, academia, international organizations and industries.

## COORDINATOR GROUP

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## references

- 1) Papa, R., Cant, A., Klein, C. et al. Towards European harmonisation of healthcare for patients with rare immune disorders: outcome from the ERN RITA registries survey. Orphanet J Rare Dis 15, 33 (2020).
- 2) [https://eu-rd-platform.jrc.ec.europa.eu/\\_en](https://eu-rd-platform.jrc.ec.europa.eu/_en)
- 3) [http://www.erare.eu/sites/default/files/SetCommonData-EU%20RD%20Platform\\_CDS%20\\_final.pdf](http://www.erare.eu/sites/default/files/SetCommonData-EU%20RD%20Platform_CDS%20_final.pdf)
- 4) [www.printo.org](http://www.printo.org)
- 5) <https://esid.org/>
- 6) <https://cpms.ern-net.eu/login/>



## EXPECTED OUTCOMES

- All RITA registries will be enrolled in the European Rare Disease Registry Infrastructure (ERDRI)<sup>2</sup>;
- The new RITA registry will collect the common data elements (CDE) from all the RITA registries that participate in the project, according to the European Commission Joint Research Centre's standards;
- A set of domain specific CDE regarding immune disorders will be proposed to the RITA members and other ERNs.



## METHODS

- 1) Maximize the adherence of RITA members to the ERDRI platform;
- 2) Set-up of a new registry for sharing common data elements provided by RITA registries according to the European Commission's Joint Research Centre (JRC) standards<sup>3</sup> and the unique expertise gained mainly by:
  - PRINTO<sup>4</sup> registry
  - ESID<sup>5</sup> registry
  - CPMS<sup>6</sup> platform
- 3) Define a set of common data elements specific for immune disorders to be share with all the other metaregistries of the ERNs.

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