



Public Final Technical Report

MERITA PROJECT: A METADATA REGISTRY FOR THE ERN RITA	
<i>CHAFEA Grant Nr</i>	947180
<i>Acronym</i>	<i>MeRITA</i>

The general objective of the “Metadata registry for the ERN RITA” (MeRITA) project is promoting the interoperability of the registries of diseases covered by the ERN RITA and, potentially, with the other ERNs. In order to achieve this, the adherence of RITA members to the ERDRI platform and to the European Commission’s Joint Research Centre (JRC) standards is of foremost importance.

The main goal of the project is the set-up and maintenance of a new registry for sharing clinical metadata provided by RITA registries according to the European Commission’s Joint Research Centre (JRC) standards.

The project has been developed in two main branches:

Common Data Elements questionnaire and ERDRI registration

A questionnaire containing the information collected by ERDRI.dor has been shared among the coordinators of the 47 registries identified to cooperate within the project. The questionnaires have been completed by 26 Registry owners and entered into the ERDRI.dor by the partners of the related working party (WP4).

The MeRITA website

The MeRITA website is online, and it has been divided into a public area and a member-only area, dedicated to registries’ owners.

On the public part of the website, every user can see information and details on the MeRITA project such as the list of partners, the common data elements collected and used, and the project updates. A general search feature is also publicly available, allowing users to perform complex queries on MeRITA dataset and view statistical data about it.

In case any public user has an interest in obtaining more details in the search results, there is a registration form (including an e-mail verification), that will allow making contact with the owner of the specific data to forward a request for access to the data.

Registry owners, on the other hand, access a member-only area, where they can manage their registry’s details, add new collaborators to the registry, upload new subjects’ data and manage the requests of access to data they might receive.



All the public web pages are freely accessible. Every user can ask to each registry owner about other patient's data, after a registration to the MeRITA platform and email verification.

Currently, 15 Registries have transferred data of 42.546 subjects.

Coordination with other projects or activities

From the beginning, the project has been conceived and carried out in close collaboration with already existing PRINTO and ESID Registries and the PReS society.

In parallel, the MeRITA project has a deep connection with European initiatives such as the ERDRI tools, in order to align all initiatives to a common and recognised practice and standard that follows the Joint Commission recommendations on the specific issue. All WP4 partners have followed a EU training on the use of ERDRI and the pre-requisite for the participation into MeRITA is the use and registration of Common Data Elements.

Both at national and international level, the project coordinators have maintained a constant link with other ERN initiatives in the context of common registries.

Further use and longterm sustainability

MeRITA tools have fully shown the potential benefits both for research and patients' everyday life, with the possibility to have an overview of the data contained in each registry and to be able to link the data necessary for a specific project to their source.

Our final objective is to help and support achieving earlier, faster and more accurate diagnosis of rare diseases through better and more consistent use of harmonised standards and programmes across Europe.

The MeRITA project will potentially bring benefit to the quality of life of all the patients with RID across Europe and beyond.

Currently operational, the MeRITA registry only needs minimal financial resources for technical operation of the registry. MeRITA receives data from existing ERN RITA affiliated registries. These ERN RITA affiliated registries are established registries with their own funding. Therefore, MeRITA can operate with a minimum of costs, which makes it sustainable.