



European  
Commission

## Agenda

# EU Rare Diseases (RD) Platform: Training workshop on the European RD Registry Infrastructure (ERDRI) tools

Milan-Malpensa Airport, Italy

8-9 March 2018

**The European Commission's  
science and knowledge service**

Joint Research Centre

Joint  
Research  
Centre

### JRC Mission

As the science and knowledge service of the European Commission, the Joint Research Centre's mission is to support EU policies with independent evidence throughout the whole policy cycle.



**EU Science Hub**  
[ec.europa.eu/jrc](http://ec.europa.eu/jrc)



@EU\_ScienceHub



EU Science Hub - Joint Research Centre



Joint Research Centre



EU Science Hub

**EU Rare Diseases (RD) Platform: Second training workshop on the European RD Registry Infrastructure (ERDRI) tools**

**8 - 9 March, 2018**

**Sheraton Hotel, Malpensa airport, Italy**

---

***Day 1 – Thursday, 8 March***

**12:00 - 13:00 – Workshop Registration**

**13:00 - 14:00 – Welcome lunch**

***14:00 – 16:00 – Session 1***

**14:00 – Introduction**

- Welcome from the JRC – C. Nicholl
- EU RD Platform update – S. Martin

**14:45 – EUPID – the Pseudonymisation Tool – M. Nitzlader**

- Overview pseudonymisation
- EUPID background
- EUPID integration into ERDRI
- Use of EUPID by the registries in the EU RD Platform

**16:00 – Coffee break**

***16:30 – 18:30 – Session 2***

**16:30 – EUPID: ERDRI's Pseudonimisation Tool Practical Use – M. Falgenhauer**

**17:00 – Discussion – Q & A session**

**18:30 – End of day 1**

**19:30 – Dinner**

**EU Rare Diseases (RD) Platform: Second training workshop on the European RD Registry Infrastructure (ERDRI) tools**

**8 - 9 March, 2018**

**Sheraton Hotel, Malpensa airport, Italy**

---

***Day 2 – Friday, 9 March***

***09:00 – 13:00 – Session 3***

**09:00 – Linking ERDRI.mdr (The Central Metadata Repository) with ERDRI.dor (The European Directory of Registries) – H. Storf, D. Kadioglu**

**10:30 – Coffee break**

**11:00 – ERDRI Search Broker – H. Storf , D. Kadioglu**

**12:00 – Procedures for setting up a Registry – S. Martin, H. Storf, D. Kadioglu**

**12:30 – Discussion – Q & A session**

**13:00 – 14:00 Lunch**

**14:00 – End of the meeting and departures**