

International Summer School on Rare Disease Registries and FAIRification of Data ISS, Rome, September 28 - October 2, 2020

The “International Summer School on Rare Disease Registries and FAIRification of Data” is a part of a series of training activities proposed by the European Joint Programme on Rare Diseases (EJP RD). EJP RD is a European Commission funded project (grant agreement No 825575, 2019 - 2023) with the goal to create a comprehensive, sustainable ecosystem allowing a virtuous circle between research, care and medical innovation.

This edition of the training course organized by the Istituto Superiore di Sanità (ISS) in close collaboration with EJP-RD partners will be held **ONLINE**, due to the force majeure situation associated with the COVID-19 pandemic.

Course director: Dr. Domenica Taruscio, Head of the National Centre for Rare Diseases (CNMR), ISS, Rome

Course coordinator: Dr. Claudio Carta (CNMR), ISS, Rome

This course is composed of two training modules:

- **First three days module (28 – 30 September 2020)**, participants will learn (a) what resources are needed for the establishment/maintenance of a high quality registry (b) the features of successful strategies to ensure (i) long-time sustainability of the registry, (ii) quality, (iii) legal and ethical issues in compliance with the EU General Data Protection Regulation.
- **Second two days module (1 – 2 October 2020)** “FAIRification of data”, participants will deepen their knowledge on the single steps of the FAIRification of data and will discover the potential of FAIR registries. In this part a time slot will be allocated to discuss FAIR data management and FAIR project planning.

Registration is available for:

- the first training module: “Rare Disease Registries”, 28 – 30 September 2020
- the second training module: “FAIRification of Data”, 1 – 2 October 2020
- the entire course: “Rare Disease Registries” and “FAIRification of data”, 28 September – 2 October 2020.

The online **registration form** is available at

<https://sondage.inserm.fr/index.php/257338/lang-en>

For further information, please see the following [LINK](#)

The draft of the programme and logistics are available at this [LINK](#)

If you have any question, please contact the course organizer: claudio.carta@iss.it and CC: laura.cellai@iss.it