



The **two events** intend to promote the establishment of Findable, Accessible, Interoperable and Reusable (FAIR) Rare Disease (RD) registries in compliance with the IRDiRC and EU Recommendations and to support cooperation among different registry stakeholders and coordination with registries that are developed within National Plans in the EU in the field of rare diseases.

Patient registries represent key resources for RD to increase the chances of a timely and accurate diagnosis, improve patient management, tailor treatments, facilitate clinical trials and stimulate research towards new treatments and diagnosis. The establishment and the governance of a disease registry towards these aims remains a challenge.

The **4th International Summer School on Rare Disease and Orphan Drug Registries**, endorsed by ICORD - International Conference on Rare Diseases & Orphan Drugs, will consist of plenary presentations and interactive small-group exercises, according to the Problem-Based Learning methodology. The course will provide participants with useful tools and methodologies to establish, manage and plan the activities of a patient registry with an overview of new approaches.

The **RD-Connect BYOD (Bring Your Data) Workshop to Link Rare Disease Registries** will be a hands-on experience, where the attendees work with FAIR data experts to make their (sample) data FAIR and linked to other data that has been made FAIR before. The workshop will consist of preparatory webinars (one as a presentation at the Summer School), brief plenary introductions and practical working groups where participants see practically how to make their data FAIR and linkable, link it other linkable data and see how easy it becomes to answer difficult queries.

Both events are open to **health professionals, researchers, medical specialists, medical students, registries curators, database managers and representatives of patient associations, who are involved in or intend to establish a rare disease patient registry.**

A selection process will be applied based on the participant's background and role with reference to registry activities.

- **VENUE:** National Centre for Rare Diseases, Istituto Superiore di Sanità, via Giano della Bella, 34 - Rome, Italy.
- **LANGUAGE** English.
- **FEES AND COSTS** Registration is free of charge. ISS does not cover any travel, subsistence and other costs incurred by the participants to attend the two events.
- **REGISTRATION** It can be carried out for either one or both events. Registration is carried out by filling the on-line form at the following link: https://it.surveymonkey.com/r/4th_Sum_School_and_RD-BYOD

IMPORTANT DATES

Deadline for registration: July 10, 2016. Due to organizational constraints, registration after this date cannot not be guaranteed.

Notification of acceptance: July 15, 2016.

Accepted participants will be informed by e-mail. For additional information, clarifications, or questions, please contact the Secretariat at rareregistries-school@iss.it

Please check periodically on the CNMR-ISS website www.iss.it/cnmr any updates on the events.

Warmest Regards

Domenica Taruscio

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