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FIRST ANNOUNCEMENT
International Summer School on FAIRification of Rare Disease Registries and Data

18-20 September 2024

Organised by

ISTITUTO SUPERIORE DI SANITÀ
National Centre for Rare Diseases

Relevance

Registries are key resources for increasing timely and accurate diagnosis, improving patient management, tailoring treatments, facilitating clinical trials, supporting healthcare planning and speeding up research for the benefit of rare disease patients. In rare disease registries, the data need to be collected following the 15 FAIR principles (FAIR-Findable, Accessible, Interoperable, Reusable for Humans and Computers) that have been recognized and approved in 2017 by the IRDiRC-International Rare Disease Research Consortium as a fundamental resource.

ISS has gained vast experience by organizing numerous courses focused on rare disease registries with the support of key partners. In particular, since 2013 to 2018, ISS has organized and hosted the International Summer School on Rare Disease and Orphan Drug Registries and since 2014 the "Bring Your Own Data To Link Rare Disease Registries".

Since 2019 to 2023 in the framework of the European Joint Programme on Rare Diseases, EJP RD (Grant Agreement No 825575, 2019 – 2023), "The International Summer School on Rare Disease Registries and FAIRification of Data"

Learning Objectives

The course focuses on the importance of high-quality FAIR rare disease registries and data as key resources to increase timely and accurate diagnosis, improve patient management, tailor treatments, facilitate clinical trials, support healthcare professionals and speed up research.

Specific Aims

- explain the importance of having Findable, Accessible, Interoperable, and Reusable (FAIR) data and metadata
- outline the process of making data FAIR
- propose a FAIRification process for their registry and data
- describe the steps of conceptual modelling and conversion of data to machine-readable
- identify the stakeholders of a multi-disciplinary FAIRification team, and their required skills.

Training method

There will be plenary presentations with interactive question & answer sessions between speakers and participants, work in small groups and hands-on experience (Bring Your Own Data, BYOD).

Course Director

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General information

Venue

Online, Ms Teams Platform

Target audience

The training course is open to the international research community, to clinicians, medical specialists, registry curators, database managers, healthcare professionals and rare disease patients' representatives. To ensure active participation and exchange between teaching staff and participants, a maximum of 24 attendees will be admitted

ECM (CME)

No CME credits will be issued.

The online registration form is available at the following link: **ONLINE REGISTRATION** until August 26, 2024.

For additional information please check the programme