

BYOD Directors

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BYOD Bring Your Own Data To Link Rare Disease Registries

GENERAL INFORMATION

Registries represent key resources for Rare Disease to increase timely and accurate diagnosis, improve patients management, tailor treatments, facilitate clinical trials, support healthcare planning and speed up research.

The "Bring Your Own Data, BYOD, To Link Rare Disease Registries" aims to promote the establishment of Findable, Accessible, Interoperable, Reusable (FAIR) Rare Disease (RD) registries in compliance with IRDIRC and EU Recommendations.

The BYOD is organized by the National Centre for Rare Diseases (ISS) in collaboration with Office for External Relations and Centre for International Affairs (ISS), RD-Connect, ELIXIR, RD-Action, EURORDIS, EpiRare, European Reference Networks, and ICORD.

The BYOD 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.

PARTICIPANTS AND REGISTRATION

The BYOD is open to health professionals, researchers, medical specialists, registry curators, database managers and representatives of patients associations who are involved in or intend to establish a rare disease registry, mainly inside a European Reference Network [priority will be given to Registry Curators and IT support staff, ePAG members (or a patients/patient representatives linked with ePAGs)].

The BYOD will accept max 27 participants. A selection process will be applied based on the participant's background, role with reference to registry activities, and involvement in ERNs.

Important dates and further information at www.iss.it/cnmr.

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 event.

ASSESSMENT OF THE ACHIEVEMENT OF THE LEARNING OBJECTIVES The participants' performance will be mainly evaluated on the basis of the group work written solutions.

ATTENDANCE CERTIFICATES At the end of the BYOD a certificate of attendance will be handed to the participants who attended 100% of the program. No credits of Continuing Education in Medicine will be issued.

OFFICIAL LANGUAGE English.

VENUE Aula Marotta, Istituto Superiore di Sanità, Viale Regina Elena, 299 – 00161 Rome, Italy.

September 21-22, 2017

Rome, Italy

organised by



National Centre for Rare Diseases, Istituto Superiore di Sanità

in collaboration with

Office for External Relations and Centre for International Affairs, Istituto Superiore di Sanità



European
Reference
Networks



Day 1

Thursday, Sept. 21

- 08:30** *Participants registration for BYOD*
- 09:00** *Welcome address (D. Taruscio)*
- 09:15** *Introduction of the BYOD (M. Roos, C. Carta)*
- 09:30** Session "FAIR data and related tools"
Introduction to FAIRification workflow and tools
- 09:50** *Five minute presentations for FAIR data trainers to introduce their special expertise*
- 10:10** *Document ontologies and clinical ontologies. What they are and where to look (R. Cornet)*
- 10:30** *Use Case Introduction and work group division (M. Roos, M. Hanauer, C. Carta)*
- 11:00** Coffee break
- 11:30** *Working in small groups with FAIR data -Trainers*
- 13:00** Lunch
- 14:00** *Working in small groups with FAIR data Trainers*
- 16:30** *Self-sketching the FAIRification workflow*
- 17:00** *First impressions / progress report (M. Roos, C. Carta and D. Taruscio)*
- 17:30** *End of the day*

Day 2

Friday, Sept. 22

- 09:00** *Day 1 Recap*
- 09:30** *Working in small groups with FAIR data Trainers*
- 10:45** Coffee break
- 11:00** *Use case presentations & discussion (Attendees and FAIR data Trainers)*
- *FAIRification workflow sketch*
 - *Implications for registry managers*
- 13:00** Lunch
- 14:00** *FAIR project planning (M. Roos, D. van Enckevort and C. Carta)*
- 15:00** *Future challenges*
- 15:30** *Evaluation of the BYOD*
- 16:00** *Remarks and Conclusion (M. Roos, D. Taruscio)*
- 16:30** *End of the BYOD*

OBJECTIVES

The BYOD will show practically how a rare disease registry can be a FAIR Resource. At the end of the BYOD the participants will be able to:

- Describe a FAIRification workflow for a rare disease registry
- Describe the resources needed to make a registry FAIR
- Describe some tools in order to FAIRifier a registry

LEARNING METHOD

The BYOD will consist of brief plenary introductions and practical working groups where participants see how to make selected sample data FAIR and see how easy it becomes to answer difficult queries when a registry is FAIR.

SPEAKERS/TRAINERS

The teaching staff will include:

Claudio Carta, National Centre For Rare Diseases, Istituto Superiore di Sanità, Italy

Ronald Cornet, Academic Medical Center, Universiteit van Amsterdam, The Netherlands

Nuno Miguel da Silva Nunes, Dutch Techcentre for Life Sciences, DTL, The Netherlands

Marc Hanauer, Directeur technique Orphanet, Inserm, France

Annika Jacobsen, BioSemantics group, Leiden University Medical Centre

Rajaram Kaliyaperumal, BioSemantics group, Leiden University Medical Centre

Marco Roos, BioSemantics group, Leiden University Medical Centre, The Netherlands

Domenica Taruscio, National Centre For Rare Diseases, Istituto Superiore di Sanità, Italy

David van Enckevort, University Medical Centre Groningen, The Netherlands

Andra Waagmeester, Micelio, Belgium

Mark Wilkinson, Centro de Biotecnología y Genómica de Plantas UPM-INIA (CBGP), Spain

OBSERVERS

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