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Finding rare disease registry data in the context of the EJP RD VP Virtual Platform, Access rights and Automation

09/02/2022 _ 15:00 – 17:30 CET

Online

This online meeting is **recorded**. If you do not wish to have your image appear, please make sure to turn off the camera before joining the sessions (see instructions below).

Registration link (to get access to connection details and event material):

<https://forms.office.com/r/K7cQF5avHW>

Table of contents

Description	2
Agenda	2
Next Workshop	3

Description

This workshop is the second of the ERN data strategy workshop series. In this workshop, different approaches to making data and cases safely findable via the VP will be described, along with a short technical overview of how this is achieved. This includes an elaboration of the difference between Resource Discovery (incorporating completely safe querying of very limited/obfuscated data fields) and far deeper Record Interrogation queries by which users can more fully understand (though still not analyse) a registry's content. An additional focus will be given to Authorisation-Authentication-Identification (AAI) as a means of further securing the discovery process, and to Common Conditions of use Elements (CCEs) as an extra information layer that may be queried. CCEs may also enable some automated triaging of data access requests. Following these presentations, a hands-on session will be held for the VP end users to test the first version of the VP, provide feedback and address any further open questions.

Agenda

Moderator: Ana Rath

- 1) Welcome & introduction – Presentation of the survey on data sharing conducted with the ERNs and scenarios envisioned by ERNs for data visiting (5 minutes)**
Speaker: Franz Schaefer
- 2) Frontend of the EJP RD Virtual Platform and opportunities offered for discovery and querying – a demonstration of the VP version 0.1 (20 minutes)**
Speaker: David Reinert
- 3) Backend of the EJP RD Virtual Platform – Technical aspects, structure of the network, and considerations for partners wishing to join the VP (15 minutes)**
Speaker: Tony Brookes

Feedback from the ERNs & discussion – the ERNs could provide feedback to the VP team (are the concepts clear, what is missing, etc) and ask questions. (20-30 minutes)

Moderator: Tony Brookes

- 4) The importance of rich metadata to increase the discoverability and reuse of the data.**

Speaker: Marc Hanauer (15 minutes)

- 5) Different levels of data harmonisation and FAIRification to support a federated discovery ecosystem in the VP, and how the tools developed by EJP RD experts can help reaching the necessary standards – An overview of the current situation and future developments (15 minutes)**

Speakers: Bruna Vieira, Clémence Le Cornec

- 6) Authentication and Authorisation Infrastructure for the EJP RD VP – Level of authentication, data security and the use of the CCEs to automatise data visiting (15 minutes)**

Speaker: Pim Kamerling

- 7) Hands on session with the VP v0.1 (20 minutes) – An example featuring the use of the VP for rare kidney disease research will be given.**

Speaker: David Reinert

Participant: all

Feedback from the ERNs & discussion – ERN researchers to provide feedback to the VP team (are the concepts clear, what is missing, etc) and ask questions. (20-30 minutes)

- 8) Conclusion and wrap-up (5 minutes)**

Speaker: Franz Schaefer

Next Workshop

A second workshop will take place at a later stage based on the outcomes of this workshop.

It is planned to discuss deeper the practical aspect of engaging with the VP and offer the various stakeholders susceptible to interact with the VP to discuss the opportunities, challenges and type of collaboration envisioned.