

Finding Rare Disease Data in the EJP RD Virtual Platform

**A Joint Online Workshop of the European Joint Programme
on Rare Diseases (EJP RD) and the European Rare Disease
Research and Support Action (ERICA)**

24/03/2022, 10:00 – 12:00 CET

Registration link (to connection details and event material):

<https://forms.office.com/r/D60Jf7Njbi>

Description

This workshop is the third of the ERN data strategy workshop series. It is dedicated to the various stakeholders expected to interact with the EJP RD Virtual Platform.

In this workshop, the feedback received from the ERN registries on the level of discovery that should be authorised for either anonymous or authenticated users of the Virtual Platform will be discussed first. The practical use of the VP will be presented in a **Demo** session. Subsequently, a **hands-on session** will allow participants to test the Virtual Platform and provide their feedback. **Researchers** as well as stakeholders **from industry, the member states and the European Medicines Agency** are invited to present their thoughts about the Virtual Platform and discuss the type of collaboration they envision with the ERNs.

Furthermore, **patient representatives** will discuss the opportunities for rare disease patients created by enabling the discovery of patient data with increasingly automated online solutions. They will present any wishes, concerns, and drawbacks they foresee.

Following these presentations, any further open questions will be addressed in **an open discussion and a Q&A session**.

Preliminary agenda

1) Welcome & introduction (5 minutes)

Speaker: Franz Schaefer

2) What would you like to discover with the VP?

**Overview of the feedback received from Workshop 1 and
Discussion of technical aspects of the VP. (15 minutes).**

Speaker: Tony Brookes

3) Practical aspects of engaging with the VP and hands-on session (25 minutes). After a short demo, the participants will be asked to test the VP with user accounts and provide feedback via a survey form.

Speaker: David Reinert

4) Researchers - Opportunities offered by the VP, type of collaboration envisioned, challenges and potential concerns. (15 minutes – 3 minutes per speaker, 2 slides max per speaker)

Speakers: TBC

5) Other Stakeholders - Opportunities offered by the VP, type of collaboration envisioned, challenges and potential concerns. (15 minutes – 3 minutes per speaker, 2 slides max per speaker)

Speakers: TBC

6) Patients – Opportunities offered by the VP, guidelines, wishes, concerns and feedback from patient representatives and patient organisations (10 minutes)

Speakers: Nawel Lalout, Inés Hernando (TBC)

7) Question & Answers session

Speakers: all

8) Conclusion and wrap-up

Speaker: Franz Schaefer