



EUCERD Joint Action and European Commission Workshop

Realising Rare Disease European Reference Networks: a preparatory workshop for the Rare Disease field

Aim of the Workshop:

The overall aim of the workshop is **to support the rare disease (RD) field in preparing for the first Call for ERNs, expected to be announced in December 2015 or early 2016.**

Objectives:

The specific objective is to assess and address the current 'readiness' for RD ERNs. The context for these discussions will be provided, in terms of the background to ERNs, the fundamental legal basis of ERNs, relevant RD policy documents, and examples of the first draft components of the tool-kit under preparation by the European Commission (EC) Tender generating the Assessment Manual for ERNs. Common questions relating to RD ERNs will be explored and discussed, to provide maximum detail at this stage on the opportunities afforded the RD field through these constructs. Finally, the state of the art of networking practices across the various RD or low prevalence and complex clinical 'areas' will be shared and explored, with an emphasis on ensuring the best possible applications from the RD field result from the December 2015 Call for ERNs.

Day 1: Wednesday 1st July 2015

Venue: [Albert Borschette Building on Rue Froissart 36, 1040 Brussels \(room AB/2B\)](#)

11:00: Welcome to the Workshop (Kate Bushby and Enrique Terol)

Session 1- Rare Disease ERNs – where are we?

11:20: Rare Diseases, Joint Actions and the Commission Expert Group on Rare Diseases (Jaroslaw Waligora)

11:40: EUCERD Recommendations on Rare Disease ERNs (incl. 2015 Addendum) and Centres of Expertise (Kate Bushby)

12:00: The road to ERNs (E. Terol)

12:20: Board of Member States on ERNs – roles and responsibilities (Till Voigtlander)

12:40: Timelines for ERNs (Enrique Terol)





13:00 – 14:00 – Lunch*

14:00 Patient Involvement in RD ERNs – Yann le Cam (EURORDIS)

14:30 Assessment scheme and examples of ERN applications (Charles Bruneau)

15:00 Discussion Session and FAQs (topics to include):

- Procedural aspects of establishing ERNs
- Distinction between Healthcare Providers and ERNs
- Organising ERNs by disease area and respective specialisms
- Financial Considerations
- What will be the added value of ERNs

(Moderators: Enrique Terol, Kate Bushby, Jaroslaw Waligora, Yann le Cam, Till Voigtlander, Charles Bruneau)

16:00- 16:30 Coffee Break

16:30 Discussion and FAQs cont.

18:00 Day 1 Ends

Day 2: Thursday 2nd July 2015

Venue: Brussels Office of the Instituto de Salud Carlos III (ISCIII), Rue du Trône, 62 - 1050 (Room III on 7th Floor)

09:30 Recap of Day 1 – K. Bushby

Session 2: Services for RD ERNs: where do we want to be?

09:50 Tools and services: European Commission IT Platform for ERNs and anticipated Services of RD ERNs (Enrique Terol)

10:10 Identifying good practices/successful services in existing networks, and how to go further: *providing healthcare in a network (and virtual) environment*

11:00-11:20 Coffee Break



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11:20 Identifying good practices/successful services in existing networks, and how to go further: *supporting clinical guideline development*

12:20 Identifying good practices/successful services in existing networks, and how to go further: *training within a network environment*

13:00-14:00 Lunch (please note that this will be provided for participants in the restaurant downstairs)

14:00 Identifying good practices/successful services in existing networks, and how to go further: *facilitating an environment for clinical research and data-sharing*

Discussion: **Session 3 – Next steps**

15:00 Summary and Next Steps: what needs to be done between now and October? How might disease groups collaborate and organise themselves into broader fields? How should the report and outputs of this workshop be disseminated?

16:00 Workshop Closes

****Please note – lunch for Day 1 to be purchased by participants (canteen on-site)***



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