OD4RD2 Kick Off Meeting

AGENDA

13-14 April

Online

Thursday 13 April from 13h30 to 17h30

N.B. This half day is only for OD4RD2 project partners & Orphanet Network

13h30 Welcome – *Orphanet Network Coordinator*

13h45 Introduction – *Orphanet Network Coordinator*

14h15 Orphanet nomenclature and classification of RD update and maintenance (WP2) : What has been done, What is planned & Discussion (including items to discuss the day after with the external stakeholder*s) – Orphanet Director - ERN collaboration Manager*

14h45 Develop Orphanet Knowledge and information base around RD in collaboration with ERNs (WP3): What has been done, What is planned & Discussion (including items to discuss the day after with the external stakeholders)- *Orphanet director-Alignement Manager*

15h15 Support to the EC in its ERN strategy including dedicated IT systems (WP5) : What has been done, What is planned & Discussion (including items to discuss the day after with the external stakeholders) – *WP5 leaders*

15h30 Break

15h45 Consolidate and Expand national Orphanet nomenclature hubs (WP4) : What has been done, What is planned & Discussion (including items to discuss the day after with the external stakeholders) – *WP4 Leaders*

16h15 Workshop: kick off of Network of National Hubs (WP4) activities – *WP4 Leaders*

17h15 Closing : tomorrow's agenda presentation and items to be adressed *Orphanet Network Coordinator*

Friday 14 April from 10h to 17h30

N.B. This meeting is open to extrenal stakeholders from 10h to 16h30.

For Orphanet members the meeting will start at 10h and end at 17h30 (the last Planning session is only for OD4RD2 project partners)

10h Welcome *–Orphanet Network and OD4RD2 Coordinator*

10h15 Introduction and brief presentation of OD4RD achievements *– Orphanet Network and OD4RD2 Coordinator*

10h45 Session 1 : OD4RD2 & ERNS *Chair: Orphanet OD4RD2 Coordinator-Orphanet National Hubs Scientific Coordinator*

- Implementation of ORPHAcodes in Hospitals: German usecase *(ERN-RND)*
- Collaboration feedback from ERNs perspective *(ERN CRANIO)*
- Orphanet database results analysis: Disease coverage by ERN centres *– (Orphanet Director)*

11h30 Break

11h45-12h30 Session 1: Connecting Ideas : brainstorming to find consensus solutions to adress the difficulties encountered by ERNs/OD4RD and discuss new ideas for implementation by the action

12h30 Lunch Break

14h00- ORPHAcodes Implementation Support *Chairs: OD4RD2 National Hubs Coordinators*

- National Hubs activity feedback from an Hospital Clinicians perspective *(Norway)*
- ORPHAcodes Implementation at National Level Hospitals Managers perspective : the Netherlands use case *(MSc -EUHA & Erasmus MC Representative; Dutch Hospital Data)*
- Interactions with the ERNs Integration Joint Action *(JARDIN Coordinator)*
- Storyline: What are the process/ tools available *(Orphanet CTO)*

15h15 Session 2: Connecting Ideas : brainstorming to find consensus solutions to adress the difficulties encountered by Hospitals/OD4RD and discuss new ideas for implementation by the action

16h00 Closing (for external partners only)

16h15 Break

16h30-17h15 [**only for project partners / wp leaders]:** Adjustement of plans according to feedback received

17h15 Closing for internal partners