RD-CODE Multistakeholder Workshop

22nd-23rd June 2020, Prague, Czech Republic

Venue (Ministry of Health, teleconferencing platform)

Draft Agenda

Training day   **15th June 2020 14:00 – 16:00   Connection testing**

Day one

12:00   Preparations (connection of participants)

Session 1 (12:30-14:00) (*chair* Francesc Palau)

Objective: *to learn about the RD-CODE project and Country specific activities*

12:30 – 12:35   Welcome (Miroslav Zvolský)

12:35 – 12:50   Introduction, RD-CODE Project Overview (**INSERM**)

12:50 – 13:30   Presentations from implementing countries on implementation progress and problems and opportunities encountered I

> Spain (25 minutes)

> Czech Republic (15 minutes)

13:30 – 13:40 Break

Session 2 (13:40-15:00) (*chair* Monica Mazzucato)

Objective: *to learn about Country specific activities*

> *to discuss country specific experiences and challenges*

13:40 – 14:10   Presentations from implementing countries on implementation progress and problems and opportunities encountered II

> Romania (15 minutes)

> Malta (15 minutes)

14:10 – 14:30   Discussion, Q&A

14:30 – 15:00   Break

Session 3 (15:00-16:15) (*chair Deborah Lambert*)

Objective: *to discuss country specific experiences and challenges*

                   questions and answers from experts and WP5 team

15:00 – 16:00   Roundtable discussion of implementation barriers and solutions, commonalities and differences between implementation projects, with advice from WP5 team (common template)

16:00 – 16:15   Break

Session 4 (16:15-17:00) (*chair Sylvie Maiella*)

Objective: *to disseminate project results*

16:15 – 16:35   Presentation of Orpha codes webpage/helpdesk

16:35 – 16:50   Presentation from WP5 team about documentation produced

16:50 – 17:00   Closing remarks of Day one

17:20   Prague virtual tour

Day two

10:00 – 12:00   *Time reserved for discussion topics that emerged during the first day or small groups chat*

12:00   Preparations (connection of participants)

Session 5 (13:00-14:10) (*chair Stefanie Weber*)

Objective: *to disseminate project results*

13:00 – 14:00   Roundtable on use of documents team's developed resources based on the ongoing implementation

14:00 – 14:10   Break

Session 6 (14:10-15:05) (*chair Miroslav Zvolsky*)

Objective: *to learn about available training programs and resources*

14:10 – 14:50   Orpha codes coding – overview of training programs + discussion

14:50 – 15:20   Break

Session 7 (15:20-16:25) *(chair Gulcin Gumus)*

Objective: *to present recent advance and to discuss and finalize the documents*

15:20 – 16:20   Roundtable discussion for finalizing documentation on codification of suspected/undiagnosed rare diseases, with SOLVE-RD experts

16:20 – 16:30   Break

Session 8 (16:30-17:30) *(chair Ana Rath)*

Objective: *to discuss dissemination plan and other projects in the context of eHealth*

16:30 – 16:50   Dissemination plan update

16:50 – 17:05   Integration with other eHealth activities and projects

17:05 – 17:20   AOB

17:20 – 17:30   Closing remarks

Czech participants will be present at the Ministry of Health meeting room, other participants will be connected remotely using teleconferencing platform (to be chosen).