AGENDA

20th June 2018

13:00 **Registration**

13:30 **Welcome address**

I. Introduction

13:45 **Introduction and scope of the meeting**

PAOLA FACCHIN

13:50 **The importance of the traceability of RD patients: the role of the Orphanet classification**

ANA RATH

14:20 **Presentation of the WP5 activities and resources developed so far**

STEFANIE WEBER

II. Testing activities and results

14:40 **Testing activities in different settings (1st phase and 2nd phase): results, feedback on the tools, problems encountered**

PAOLA FACCHIN /MONICA MAZZUCATO
OSCAR ZURRIAGA

15:30 **Questions and future perspectives**

ALL

16:00 **End of the meeting**

21st June 2018

09:00 **Welcome address**

09:20 **RD codification: interoperability with research activities and exploitation needs at EU level**

ANA RATH

09:50 **Representation of RD in ICD: state of the art and future perspectives**

ROBERT JAKOB

10:20 **Orphacodes and the European Reference Networks**

MAURIZIO SCARPA

10:40 **JRC - EU Platform for Rare Diseases Registration: state of the art and future perspectives**

ALEXANDER BINDER

11:00 ***Coffee break***

11:20 **Orphacodes adoption at national level: future perspectives**

DEBORAH LAMBERT

11:40 **Orphacodes' use at national level: the Rare Disease Card Implementation in Portugal**

MIGUEL DIAS

12.00 **Traceability of RD in electronic health records: opportunities and challenges**

CLAUDIO SACCAVINI

12:20 **The case of undiagnosed RD patients: tools and how "expert systems" can help: a practical experience**

PAOLA FACCHIN/MONICA MAZZUCATO

12:40 **Questions and discussion**

ALL

13:10 **Conclusions anf future perspectives**

ALL

13:30 **End of the meeting**

FACULTY

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REGIONE DEL VENETO

RD-ACTION
DATA AND POLICIES FOR RARE DISEASES

WP5 Final Workshop

20th-21st June 2018

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SS. Giovanni e Paolo Hospital
Venice, Italy