

Agenda

The meeting is in English. All presentations to include 5'-10' reserved for discussion.

DAY 1: Thursday, 8 September

10:00-13:00 Closed session with Steering Group & Working Group of future network of resource centres (transport from hotel to Agrenska at 9:30)

14:00 Transport from hotel to Agrenska

14:30 Welcome to the meeting (10') *Robert Hejdenberg, Agrenska*

14:40 Introduction to the meeting: context, programme & expected outcomes (15') *Raquel Castro, EURORDIS*

14:55 INNOVCare project: bridging the gap between health, social & local care for rare diseases (20') *Raquel Castro, EURORDIS*

15:15 European Recommendations Support the Incorporation of Rare Diseases into Social Policies and Services (20') *Gerhard Steffes, Policy Officer, Programme Management and Diseases, Directorate-General for Health and Food Safety, European Commission*

15:35 Coffee break (25')

16:00 Improving holistic and integrated care provision to people living with a rare disease

Presentations by case study resource centres for rare diseases (15' each)

16:10 Ågrenska (Sweden) *Anders Olauson*

16:40 NoRo (Romania) *Dorica Dan*

16:25 Frambu (Norway) *Lisen Julie Mohr*

16:55 CREER (Spain) *Marta Fonfría*

17:10-19:00 Visit to Ågrenska (divided in alternating groups, while others stretch their legs, enjoy the island and the sun)

18:00-19:00 Closed session with INNOVCare partners'

19:00 Networking dinner at Agrenska (90')

20:30 End of the day – transport back to hotel

DAY 2: Friday, 9 September

09:00 Transport from hotel to Agrenska

Improving holistic and integrated care provision to people living with a rare disease

09:30 Integrated health and social care – what matters (20'), *Anne Hendry, Clinical Lead for Integrated Care, Scotland & Senior Fellow, International Foundation for Integrated Care*

Presentations by case study case management services for rare diseases (20' each)

09:50 Project "FAC" Train, Support, Coordinate *Christine de Kalbermatten, ProRaris, Switzerland*

10:10 "Navigators project" *Stephanie Jøker Nielsen, Rare Diseases Denmark*

10:30 INNOVCare's pilot implementation in Romania (20') *Dorica Dan, NoRo resource centre*

10:50 Coffee break (10')

11:00 Discussions on INNOVCare's pilot - Breakout sessions (90')

What matters to patients and their family, *Chair: Raquel Castro, EURORDIS*

Design of the intervention: regional case managers for rare diseases in Romania, *Chair: Dorica Dan, NoRo resource centre*

Creating the enabling environment, *Chair: Anne Hendry, Scottish Government & International Foundation for Integrated Care*

Evaluation of the impact of the intervention, *Chair: Juliet Tschank, Centre for Social Innovation (ZSI)*

Making it happen in other countries, *Chair: Ursula Holtgrewe, Centre for Social Innovation (ZSI)*

12:30 Plenary session, reporting back from breakout sessions (20')

12:50 Next Steps & Take home messages (10')

13:00 lunch (30')

13:30 End of the meeting - transport back to city and to airport



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