

### DAY 0: Wednesday 31<sup>st</sup> May

11:00-19:30 RareResourceNet Meetings: Steering Group (SG) and Working Group (WG)

### DAY 1: Thursday, 1 June

11:00-15:00 Improving holistic care for rare diseases (reserved to social services)

15:30 Welcome to the meeting (15') *Olah Emese, Vice Mayor of Cluj-Napoca, Lidia Onofrei, Ministry of Health Dorica Dan, NoRo resource centre & Lavinia Ghilea, County of Salaj, Romania*

15:45 Introduction to the meeting: context, programme & expected outcomes (10') *Raquel Castro, EURORDIS*

15:55 Update on INNOVCare: bridging the gap between health, social & local care for rare diseases (10') *Raquel Castro, EURORDIS*

#### Session 1: State of the art of social care provision to rare diseases & complex undiagnosed conditions

16:05 Juggling care and daily life: The balancing act of the rare disease community - results of INNOVCare/EURORDIS Rare Barometer survey on the impact of rare diseases on daily life (20') *Raquel Castro, EURORDIS*

#### Session 2: Advancing holistic & innovative care for rare diseases & complex conditions: INNOVCare case management pilot

16:25 Progress on INNOVCare pilot of case management for rare diseases (30' w/ Q&A) *Dorica Dan, NoRo resource centre*

17:00-18:30 *Bus transport to NoRo resource centre for rare diseases (Zalau)*

#### 18:30-20:30 Open house at NoRo resource centre:

Welcome to NoRo *Dr. Ligia Marincas, Director of the Health Care Department Salaj, Dorina Babos, Director of Social Assistance Department, Zalau, Lisen Julie Mohr, Frambu & Dorica Dan, NoRo resource centre*

Visit to the centre & meeting the NoRo team

Networking & poster session by participants

19:00-20:30 *Dinner at NoRo*

20:30-22:00 *Transport from NoRo to hotel in Cluj-Napoca & end of the day*

### DAY 2: Friday, 2 June

#### Session 2 (Cont.): Advancing holistic & innovative care for rare diseases & complex conditions: INNOVCare case management pilot

09:00 Evaluation of the social impact of the INNOVCare pilot (30' w/ Q&A) *Juliet Tschank, Zentrum für Soziale Innovation (ZSI)*

09:30 Evaluation of the economic impact of the INNOVCare pilot (30' w/ Q&A) *Vibeke Sparring, Karolinska Institutet*

#### Session 3: Implementing innovative care for rare diseases and complex conditions in European countries

10:00 Ways to take the next steps towards holistic care (30' with Q&A), *Nicol Gruber, Irina Vana, Zentrum für Soziale Innovation (ZSI)*

10:30 *Comfort break (30')*

#### Breakout sessions: Taking the next step towards integrated holistic care for rare diseases

11:00 Introduction to the exercise (10')

11:10 Discussions (parallel sessions): (60')

- Building the case of rare diseases, *Chair: Raquel Castro, EURORDIS*
- Steps to implement holistic care for rare diseases, *Chair: Ester Sarquella Casellas, Generalitat de Catalunya*
- Evaluation of social and economic impact, *Chairs: Juliet Tschank, Zentrum für Soziale Innovation (ZSI), Vibeke Sparring, Karolinska Institutet*
- Case management role and training, *Chair: Dorica Dan, NoRo resource centre*

12:10 Converting the discussion outcomes into tools (20')

12:30 *lunch (60')*

#### Breakout sessions (Cont.)

13:30 Converting the discussion outcomes into tools (50') – *themes & chairs as above; coffee in rooms*

14:20 Recap of breakout sessions (15' per group - 60')

15:20 Next Steps & Take home messages (10')

15:30 *End of the meeting*



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