

**Workshop: Creating a Sustainable Environment for Holistic & Innovative Care for Rare Diseases & Complex Conditions**  
**Frambu Resource Centre for Rare Diseases, Oslo, 12-13 April 2018**

**Agenda**

**DAY 1: Thursday, 12<sup>th</sup> April**

08:25 Bus transport from hotel to Frambu

09:30 Welcome to the meeting (20') Kristian E. Kristoffersen & Lisen Julie Mohr, Frambu

09:50 [Introduction & expected meeting outcomes](#) (20') Raquel Castro, EURORDIS & Victoria Hedley, University of Newcastle

10:10 [Integrated care at the core of European Policy for Rare Diseases](#) (20') Victoria Hedley, University of Newcastle

10:30 Coffee break (30')

**Session 1: Promoting integrated holistic care for rare diseases**

11:00 Why does it matter? (10') Raquel Castro, EURORDIS

11:10 Learning from case study health and social care providers' successes and challenges. Case study presentations:

11:10 [INNOVCare pilot of case management for rare diseases](#) (20') Dorica Dan, NoRo resource centre for Rare Diseases

11:30 [Centre of Expertise \(CE\) example](#) (20') Eduardo Tizzano, RD Unit, Hospital Universitari Valle Hebron, Barcelona, Spain

11:50 What are the key strengths of these CEs/HCPs? What makes them such good examples? (30') QA & Discussions

12:20: Lunch Buffet (70')

**Session 1 (cont.)**

13:30 [European Reference Networks \(ERNs\) and the status quo of integrated care: Results of cross-ERN survey](#) (20') Victoria Hedley

13:50 ERN Case Studies (30'): [ERN EYE \(Hélène Dollfus\)](#): [ERN TRANSPLANT-Child \(Juan Manuel Torres Canizales\)](#): [ERN ITHACA \(Bronwyn Kerr\)](#)

14:20 Possible roles of ERNs and CEs in supporting integrated care for rare diseases (60') QA & Discussions

15:20 Coffee break (20')

**Session 2: Assessing and monitoring the impact of integrated care for rare diseases**

15:40 [Lessons learnt so far from the evaluation of social & economic impact of the INNOVCare pilot](#) (30' w/ QA) Juliet Tschank, Zentrum für Soziale Innovation & Vibeke Sparring, Karolinska Institutet

16:10 How might ERNs' data collection and/or indicators support the assessment and monitoring of patients' quality of life (QoL) and of the impact of integrated care?

16:10 [Core Indicators for ERNs: achievements to-date of the ERN Working Group on Assessment & Monitoring](#) (20') Michelle Batty, eUROGEN

16:30 Possible roles of ERNs to support the assessing/monitoring of QoL and of the impact of integrated care (30') QA & Discussions

**17:00-19:00 Open house at Frambu: visit the centre & meet the team**

19:00-21:00 Networking Dinner

21:00 End of the day; Bus transport to hotel

**DAY 2: Friday, 13<sup>th</sup>**

08:25 Bus transport from hotel to Frambu

**Session 3: Promoting integrated holistic care for rare diseases - key issues to transfer and sustain integrated care across Europe**

09:30 [Key issues for the implementation of integrated care for rare diseases: preliminary results of interviews in MS](#) (30' w/ QA)

Irina Vana & Barbara Glinsner, Zentrum für Soziale Innovation

**Breakout Sessions: Key issues for the implementation and sustainability of holistic integrated care for rare diseases**

10:00 Introduction to the exercise (10') Raquel Castro, EURORDIS

10:10 Discussions in parallel sessions ('120) *Topic briefs to be sent to participants 1 week ahead of the workshop*

*Guiding questions: What needs to happen within each of these topics, to improve the status quo for rare diseases? What might ERNs specifically do to make an impact?*

1. Health & Social Care: structural coordination & cooperation to ensure person-centred holistic care pathways
2. Patient empowerment & engagement: strategies to ensure person-centred care & meaningful patient engagement in care design
3. Knowledge sharing: effectively promoting the exchange of good practices/expertise/information to support holistic care
4. Professionalization of the coordination of care: who coordinates care? What is the role of case managers? How to train them?
5. Data collection: demonstrating the impact of the services on patients' QoL/public health & the cost-efficiency of integrated care

12:10 Recap of breakout sessions (40') *Poster session*

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

13:00 Farewell - Lunch boxes (30')

13:30 End of the meeting; Organised transport to Oslo city

This workshop is co-organised by EURORDIS and the University of Newcastle, on behalf of the EU-funded projects INNOVCare and RD-Action, respectively.



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The information contained in this publication does not necessarily reflect the official position of the European Commission.