

Conference: Advancing person-centred and integrated care for rare diseases and complex conditions across Europe

Final Conference of the EU-funded INNOVCare project | innovcare.eu | #INNOVCare

5th September 2018, 09:00 – 13:30

Résidence Palace, 155 Rue de la Loi, 1040 Brussels

The event will also be livestreamed at <https://innovcare.eu/live/>

Agenda

The meeting is in English

08:30 – 09:00 Registration

Moderator: John Bowis, Former Member of British Parliament, UK Health Minister and Member of the European Parliament

09:00 Opening session (15')

Ana Carla Pereira, Head of Unit Modernisation of Social Protection Systems, European Commission, Directorate-General for Employment, Social Affairs and Inclusion

Terkel Andersen, President, EURORDIS-Rare Diseases Europe

09:15 Session 1: Importance and impact of integrated care for rare diseases and complex conditions

09:15 What are the challenges & how did INNOVCare approach them (15') Raquel Castro, Social Policy Director, EURORDIS-Rare Diseases Europe

09:30 The impact of integrated care for rare diseases and other complex conditions (60')

Presentations on results of the INNOVCare project (40' - presentation time of each speaker indicated in front of respective name) & panel debate (20') on key elements for the implementation and impact assessment of person-centred care models

Dorica Dan, President, Romanian Prader Willi Association, NoRo Resource Centre for Rare Diseases (10')

Juliet Tschank, Researcher on Work and Equal Opportunities, ZSI – Zentrum für Soziale Innovation (10')

Peter Lindgren, Professor of Health Economics, Karolinska Institutet (10')

Encarna Guillen-Navarro, Clinical Geneticist, Hospital Clínico Universitario Virgen de la Arrixaca; Region of Murcia Representative in the National Rare Diseases Strategy; Former Minister of Health of Murcia Region (5')

Anders Olauson, Chairman, Agrenska; Chair, RareResourceNet-European Network of Resource Centres for Rare Diseases (5')

10:30 – 11:00 Coffee Break

11:00 Session 2: From pilots of care delivery social innovation to mainstream services

11:00 Up-scaling challenges & opportunities: findings of INNOVCare's work to develop up-scaling road-maps for selected MS (15') Irina Vana, Researcher on Work and Equal Opportunities & Ursula Holtgrewe, Head of Work and Equal Opportunities, ZSI – Zentrum für Soziale Innovation

11:15 Going from pilots to mainstream: ensuring sustainability & sharing of good practices across European countries and care areas (75') Panel debate with introduction 3' statement by each panellist

Ana Carla Pereira, European Commission, Directorate-General for Employment, Social Affairs and Inclusion

Brando Benifei, Member of the European Parliament

Ana Rath, Director, Orphanet; coordinator of European Joint-Action on Rare Diseases (RD-ACTION)

Victoria Hedley, RD-ACTION-European Joint Action for Rare Diseases Policy Manager, University of Newcastle

Birutė Tumienė, Clinical geneticist, Vilnius University Hospital; Representative of Lithuania on the European Reference Network Board of Member States

Raquel Castro, Social Policy Director, EURORDIS-Rare Diseases Europe

Ursula Holtgrewe, Head of Work & Equal Opportunities, ZSI – Zentrum für Soziale Innovation

12:30 Closing session (10')

John Bowis, Former Member of British Parliament, UK Health Minister and Member of the European Parliament

Terkel Andersen, President, EURORDIS-Rare Diseases Europe

12:40 - 13:30 Networking Lunch Buffet

13:30 End of Conference



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