



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

#INNOVCare @RareDiseasesEU @eurordis @frambu

OVERVIEW OF THE ORGANISING PROJECTS



INNOVCare

Bridging the gaps between health, social and local services to improve care of people living with rare and complex conditions

2015-2018

Project Overview

Call for proposals from EC DGEMP (2014): “Social policy innovation”

Time frame: 36 months - 01/10/2015 to 30/09/2018

Consortium: 8 partners, 6 countries

Main Applicant

MSSSI Ministry of Health and Social Affairs - Spain - Aitor Aparicio García

Co-Applicants

Finovatis – France - David Koubi

IER Inštitut za Ekonomska Raziskovanja – Slovenia – Valentina Rupel

EURORDIS – France – Raquel Castro

APWR RPWA Asociatia Prader Willi din Romania (NoRo) – Romania – Dorica Dan

CJSJ Regional County Sălaj – Romania - Monica Avram

ZSI Zentrum für Soziale Innovation – Austria - Ursula Holtgrewe

KI Karolinska Institutet – Sweden - Peter Lindgren



www.creenfermedadesraras.es



www.cjsj.ro



www.apwromania.ro



www.eurordis.org



www.finovatis.com



www.ier.si



www.ki.se

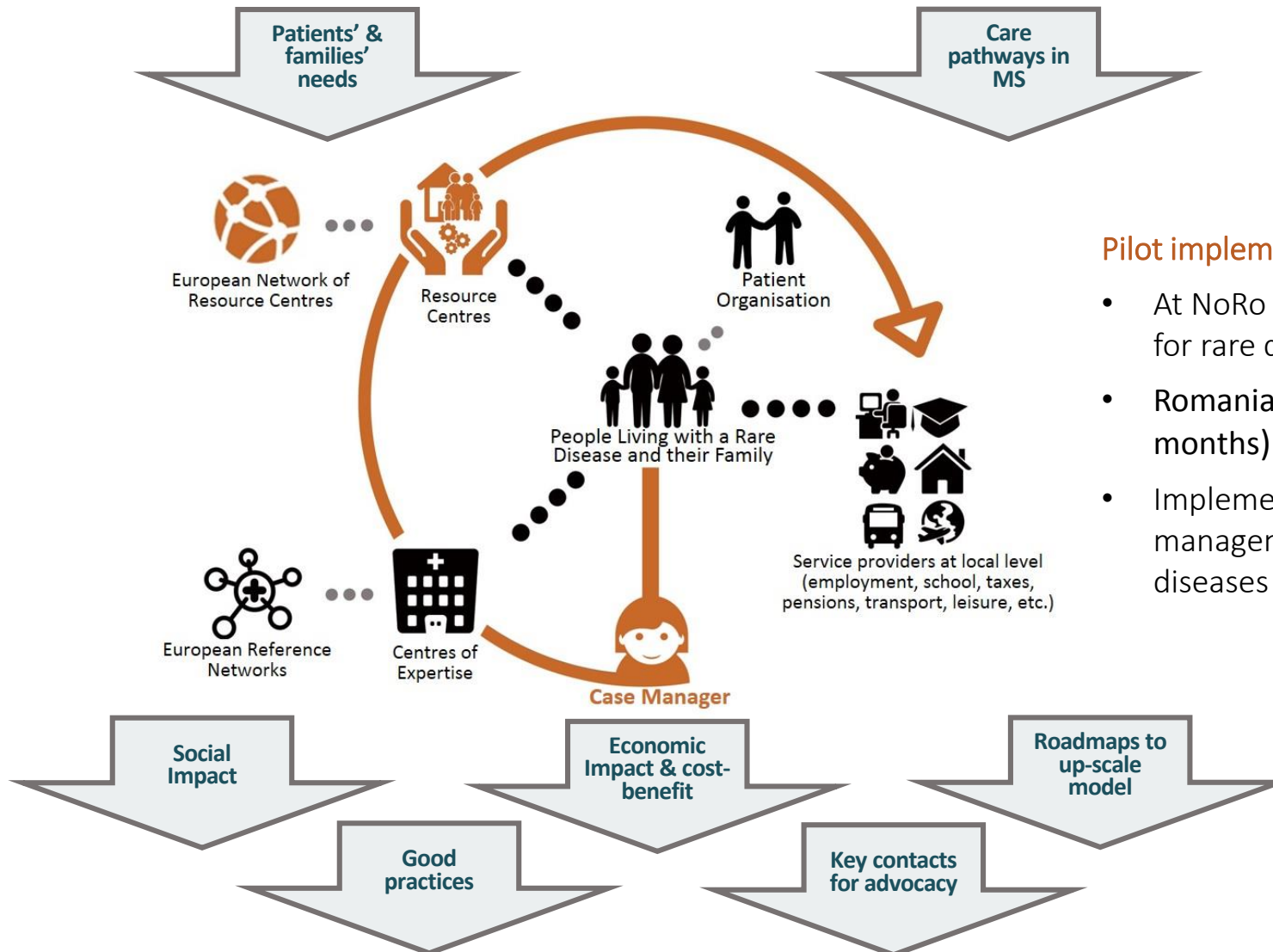


www.zsi.at



This project is co-funded by the European Union

Project Concept



Pilot implementation

- At NoRo Resource Centre for rare diseases
- Romania, 2017-2018 (18 months)
- Implementation of case management for rare diseases

Project Resources

- **1st European survey on the social and everyday impact of RD**
- **Case managers role & training outline**
- **Social and economic impact of the pilot of case management**
- **Findings on the key aspects for the implementation of integrated care for RD - results of project research and multi-stakeholder workshops**
- **Roadmaps to support the upscaling of the INNOVCare pilot**
- **Launch of European Network of Resource Centres for Rare Diseases, RareResourceNet**

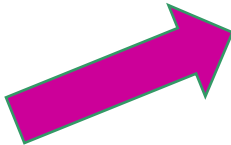
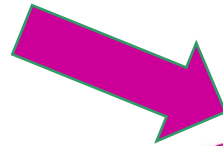
More information and all resources available at:
<http://innovcare.eu/>

RD-ACTION

2015-2018



RD-ACTION



- **RD-ACTION Key Stats**
- 1st June 2015 - 31st July 2018
- 34 beneficiaries (APs)
- 30 collaborating partners
- 40 countries incl. Argentina and Australia
- Total Budget: €8,344,079.80



Goals of RD-ACTION

‘Promoting the implementation of Recommendations on policy, information and data for RD’

Main objectives:

- ✓ Support the development and sustainability of Orphanet database, the biggest global repository of information on RD
- ✓ Contribute to solutions to ensure the appropriate codification of rare diseases in health information systems across Europe.
- ✓ Work on priority issues for PLWRD by implementing the actions identified in *EU Council Recommendation on an action in the field of rare diseases (2009)*: Ensure the sustainability of these actions and support the work of the European Commission Expert Group on Rare Diseases.





**Recommended Practices for Data
Standardisation in the Context of the
operation of European Reference
Networks**

2017

RD-ACTION Output



<http://www.rd-action.eu/european-reference-networks-erns/>



CONTACT

INTRANET

Home

About us

Directory

Workpackages

News

Leaflet and documents



Key Outputs of RD-ACTION:

OUTPUT and LINK	DESCRIPTION	DATE PUBLISHED
Workshop Resources 'Creating a Sustainable Environment for Holistic & Innovative Care for Rare Diseases & Complex Conditions'	The dedicated webpage for our latest Workshop (12-13 Apr, 2018, Frambu, Norway) co-organised with INNOVCare, hosting the agenda, presentations and outputs	April 2018
Workshop Resources 'ERNs & Clinical Practice Guidelines'	The dedicated webpage for our Workshop (6-7 Dec 2017, Rome) co-organised with DG SANTE and the ERNs, hosting the agenda, presentations and outputs	December 2017
Summary of RD-ACTION Support for ERNs (2015-17)	Two-page overview summarising the main forms of RD-ACTION support for ERN implementation and cooperation around key policy priorities	September 2017
'Recommended Practices for Data Standardisation in the Context of the operation of ERNs'	Main Output from the Workshop 26-7th April 2017 on 'Using Standards and Embedding Good Practices to Enable Interoperable Data-Sharing in ERNs'	September 2017
Workshop Resources & Outputs on 'Indicators and Outcomes for ERNs'	The dedicated webpage for our Workshop (1-2 June, Newcastle) on Indicators and Outcomes for ERNs hosting the agendas, presentations and outputs.	June 2017
Tool-Kits on key resources, resulting from Workshop on Data & ERNs (April 2017)	'Tool-Kits summarising where to find practical information on Orphanet Nomenclature; HPO ; FAIR Data; PPRL for rare diseases	June 2017

OUR WORKSHOP!



Overview

- Co-organised by the INNOVCare project and the RD-Action
- Venue: Frambu Resource Centre
- 65 participants, 22 countries
 - Policy makers - national/regional competent authorities; former members of the Commission Expert Group on RD
 - Patient representatives - European Patient Advocacy Groups (ePAGs) and of the Social Policy Advisory Group
 - European Reference Networks and other Health Care Providers
 - Social services
 - Academics

Why this workshop?

PEOPLE LIVING WITH A RARE DISEASE AND THEIR CARERS FACE SERIOUS CARE BURDEN*

65%

have to visit different health, social and local services in a short period of time



67%

feel that these services communicate badly between each other



7in10

do not feel well informed about their rights

7in10

find that organising care is time-consuming; 6 in 10 find it hard to manage



*Juggling care and daily life: The Balancing Act of the Rare Disease Community - [see full results here](#)
First Europe-wide survey on social impact of RD, involving 3000 people with a RD & carers
Study performed via Rare Barometer Voices and within the EU-funded INNOVCare project

Why this workshop?



Rare diseases have a serious impact on everyday life



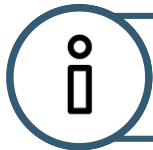
Significant time and care burden for patients and carers



Strong impact on work-life balance: absence from work, hampered professional activity, economic burden



Care pathways are complex and hard to manage e.g. need to visit different services in short time; lack of communication between providers



Patients and carers feel badly informed about their rights and feel that social services are badly prepared to support them



Rare diseases impact the mental health of patients and carers

**Juggling care and daily life: The Balancing Act of the Rare Disease Community - [see full results here](#)
First Europe-wide survey on social impact of RD, involving 3000 people with a RD & carers
Study performed via Rare Barometer Voices and within the EU-funded INNOVCare project*

Why this workshop?

European Commission Expert Group Recommendations to Support the Incorporation of Rare Diseases into Social Services and Policies (2016):

«4. MS should promote measures that facilitate multidisciplinary, holistic, continuous, person-centred and participative care provision to people living with rare diseases, supporting them in the full realisation of their fundamental human rights.»

http://ec.europa.eu/health/rare_diseases/docs/recommendations_socialservices_policies_en.pdf

Objectives

Advancing holistic care for RD across Europe

- To present case studies of Health Care Providers and of the INNOVCare pilot - demonstrating effective and innovative practices;
- To exchange and learn from ongoing good practices;
- To discuss a range of key issues to support the implementation of integrated health-social care - sharing/upscaling good practices and considering sustainability;
- To affirm the role of Centres of Expertise/ERN Healthcare Providers can play, in providing integrated and holistic care for RD;
- Explore how ERNs can add value by expanding/improving the provision of integrated care for RD - upskilling practices at constituent CEs/HCPs and as a Network.

Programme

- Session 1: Promoting integrated holistic care for rare diseases
- Session 2: Assessing and monitoring the impact of integrated care for rare diseases
- Session 3: Promoting integrated holistic care for rare diseases - key issues to transfer and sustain integrated care across Europe
- Breakout Sessions: Key issues for the implementation and sustainability of holistic integrated care for rare diseases
 1. Health & Social Care
 2. Patient empowerment & engagement
 3. Knowledge sharing
 4. Professionalization of the coordination of care
 5. Data collection

Thank you

raquel.castro@eurordis.org | victoria.hedley@newcastle.ac.uk

INNOV Care



This project is co-funded by
the European Union

*Call for Proposals VP/2014/008; EaSI PROGRESS,
DG Employment, Social Affairs and Inclusion*



Co-funded by
the Health Programme
of the European Union



This meeting is also co-funded by
Kindness for Kids Foundation
Germany

Stiftung für Kinder mit
Selteneren Erkrankungen
Foundation for Children
with Rare Diseases