

# INNOVCare

Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions

## INNOVCare project

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

Raquel Castro, EURORDIS-Rare Diseases Europe

INNOVCare Workshop on Advancing holistic and innovative care for rare diseases and complex conditions, 1<sup>st</sup> June 2017

[www.innovcare.eu](http://www.innovcare.eu)



[www.creenfermedadesraras.es](http://www.creenfermedadesraras.es)



[www.cjsj.ro](http://www.cjsj.ro)



[www.apwromania.ro](http://www.apwromania.ro)



[www.eurordis.org](http://www.eurordis.org)



[www.finovatis.com](http://www.finovatis.com)



[www.ier.si](http://www.ier.si)



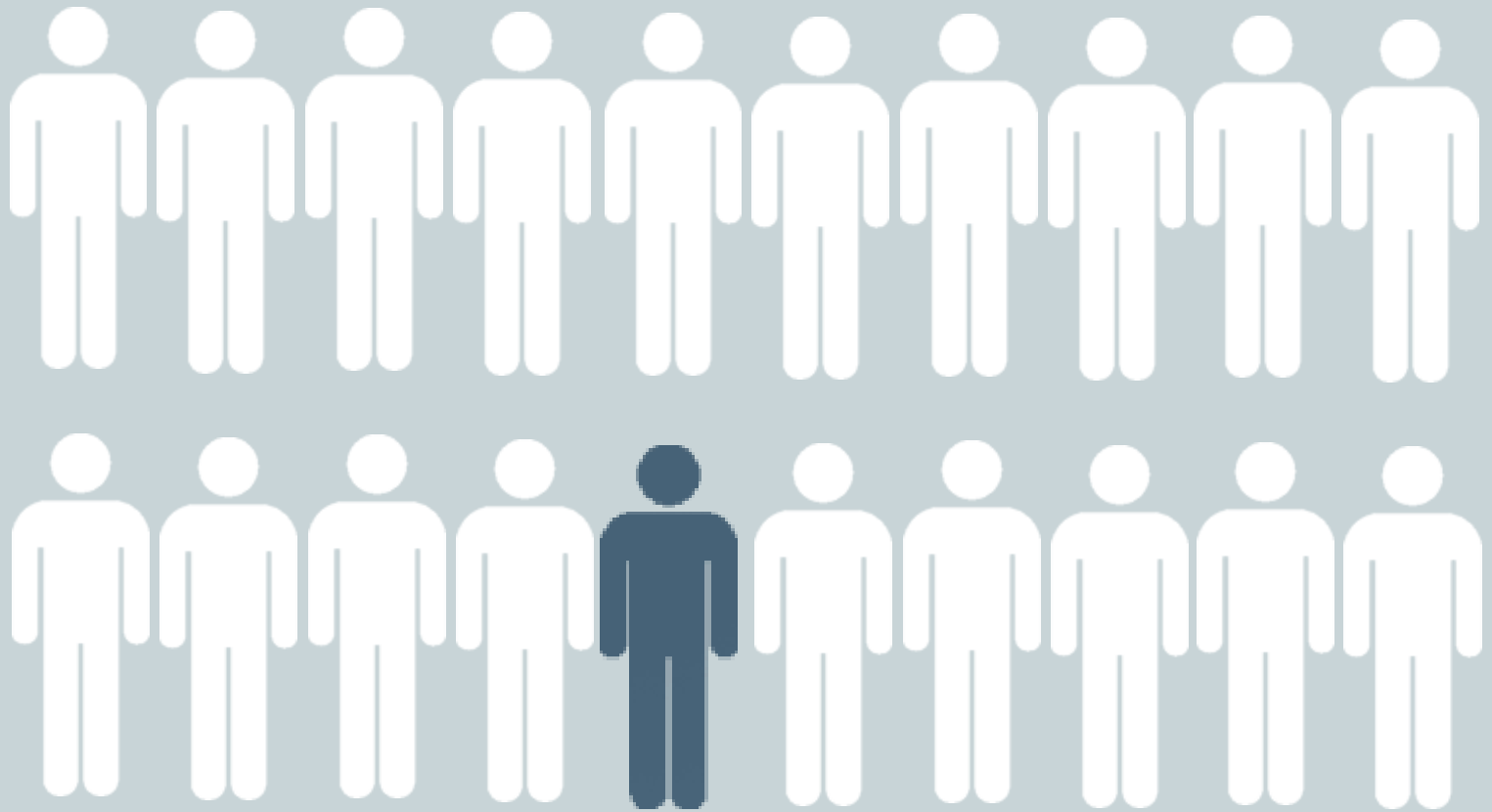
[www.ki.se](http://www.ki.se)



[www.zsi.at](http://www.zsi.at)

 This project is co-funded by the European Union

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



**1 in 20 people is affected  
by a rare disease**



There are over 6000 Rare Diseases

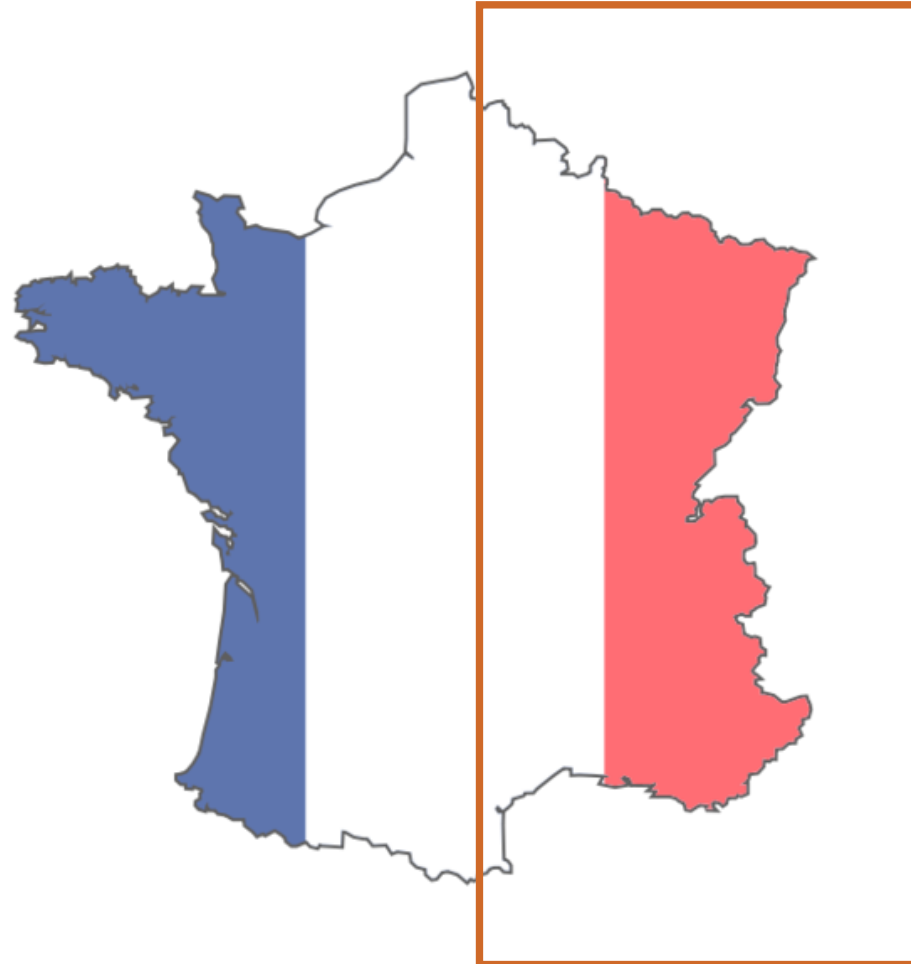


Each rare disease  
affects few patients

*A rare disease in Europe is a disease affecting less than 1 in 2,000 citizens*

# But collectively rare diseases affect:

30 million people in Europe  
~½ of the population of France



# What is a rare disease

- Rare, highly complex, chronic, severely disabling
- **Lack of treatment**
- **Scarcity of information**
- **Scarcity and scattering of experts and resources**
- **Fragmented & lack of good practices**



*The serious unmet social needs of people with a rare disease and their families affect their dignity, autonomy and other **fundamental human rights** expressed in the Universal Declaration of Human Rights and in the UN Convention of the Rights of Persons with Disabilities*

The needs of people living with rare require coordinated multidisciplinary care

In most countries the care pathways are not structured



Image used for illustration purposes. Source: [Nationella Funktionen Sällsynta Diagnoser](#), Sweden



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.»***

**Unanimously adopted by representatives of all EU Member States**

[http://ec.europa.eu/health/rare\\_diseases/docs/recommendations\\_socialservices\\_policies\\_en.pdf](http://ec.europa.eu/health/rare_diseases/docs/recommendations_socialservices_policies_en.pdf)

## Next Step

# Moving from the recommendations to the implementation

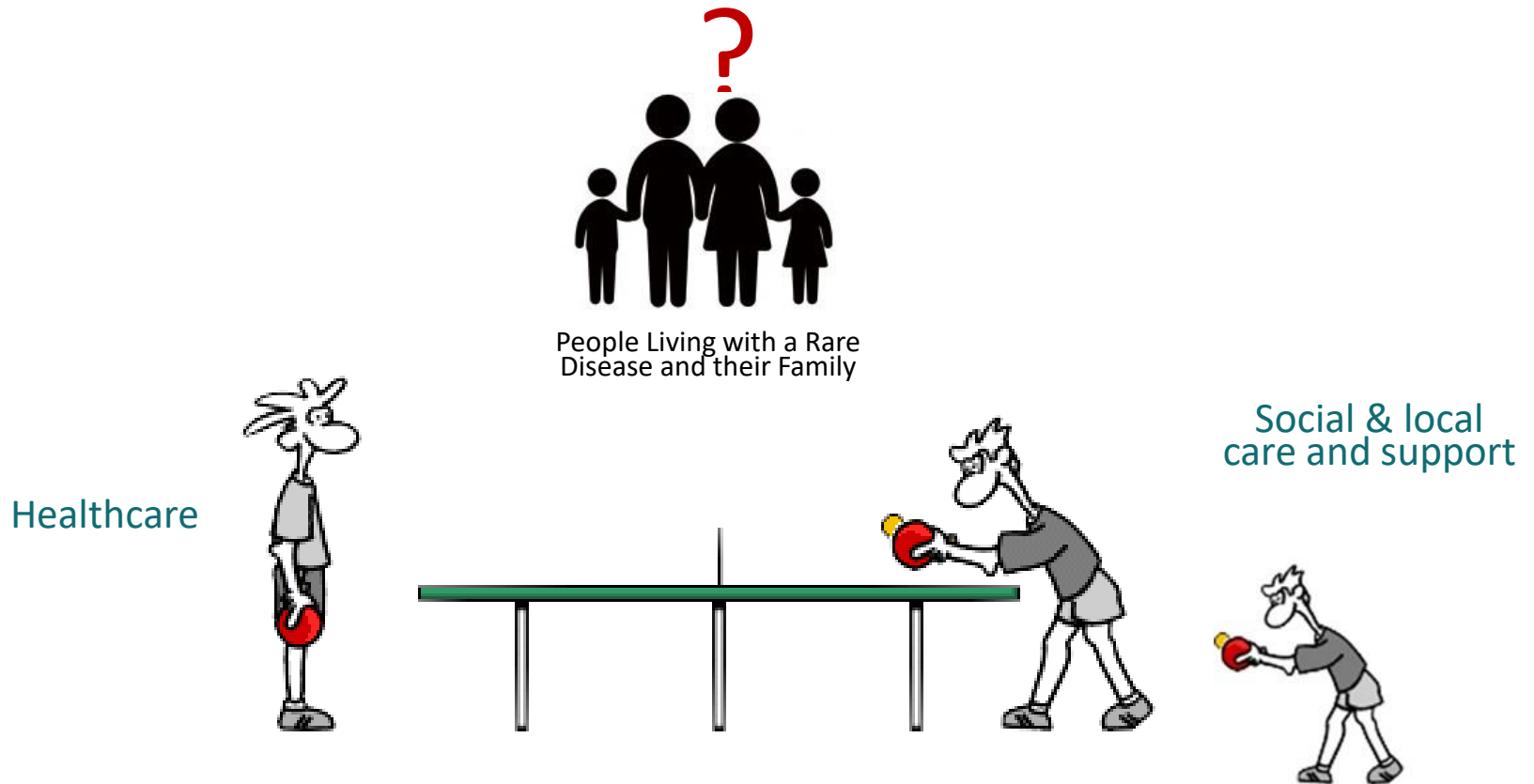
INNOVCare

2015-2018

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



# The dilemma



# Project Overview

## **Call for proposals from EC DGEMP (2014) - “Social policy innovation”**

- Focus on one stop shop services & case handlers
- Over 200 projects submitted - 7 selected
- INNOVCare is the only project on health/disability and with European scope

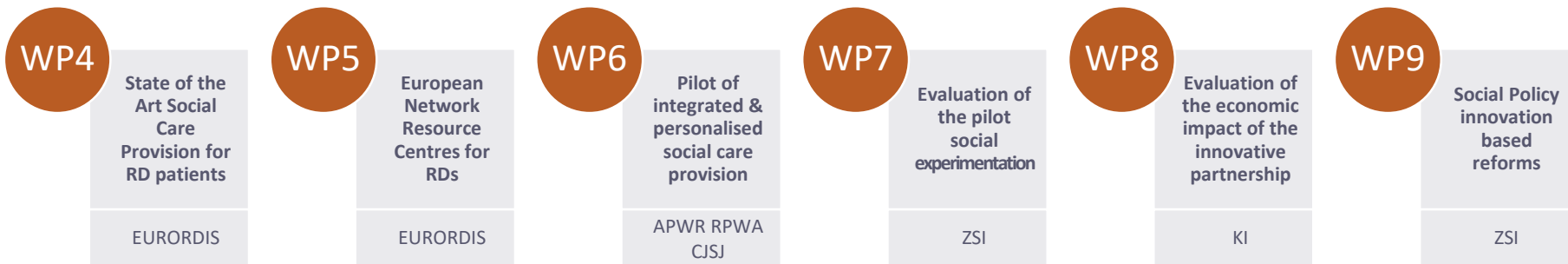
**Time frame:** 36 months - 01/10/2015 to 30/09/2018 -> **half way!**

## **Consortium:**

- **8 partners, 6 countries** - Spain, France, Slovenia, Romania, Austria, Sweden
- Main Applicant: MSSSI Ministry of Health and Social Affairs – Spain

**Total budget:** 1 994 414.72€ (EC co-funding 80%)

# Project Structure



WP1 Coordination (MSSSI, Finovatis)  
 WP2 Evaluation (IER)  
 WP3 Communication & Dissemination (EURORDIS)

## 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

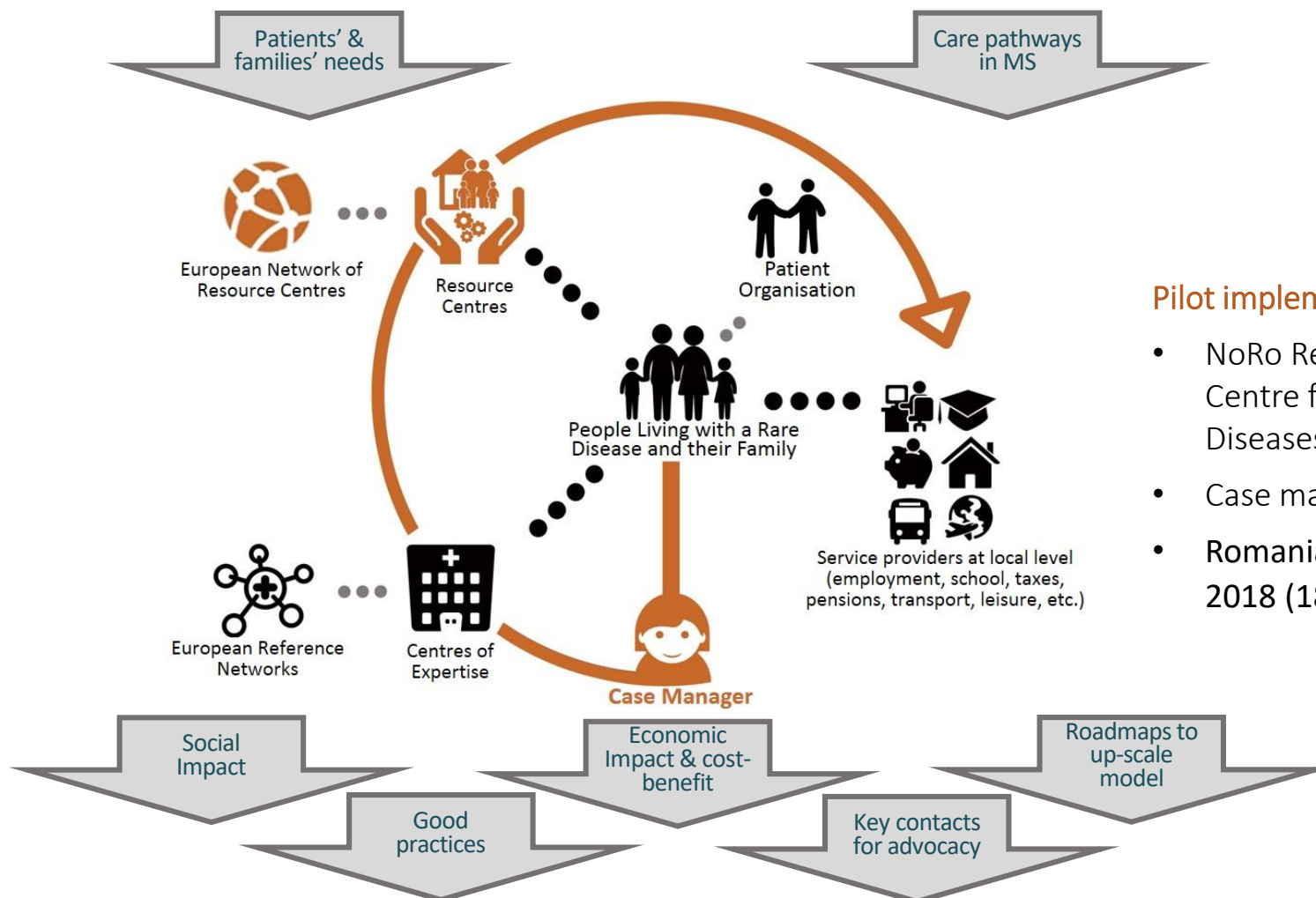
**APWR RPWA** Asociatia Prader Willi din Romania (NoRo) – Romania – Dorica Dan

**CJSJ** Regional County Sălaj – Romania - Monica Avram

**ZSI** Zentrum für Soziale Innovation – Austria - Ursula Holtgrewe

**KI** Karolinska Institutet – Sweden - Peter Lindgren

# Project Concept



## Pilot implementation

- NoRo Resource Centre for Rare Diseases
- Case management
- Romania, 2017-2018 (18 months)

# Project Events

Date	Duration	Place	Event	Nr of people	Partner responsible
8-9 Sept 2016	2 days	Goteborg	<b>Workshop on Improving Integrated Care for People Living with Rare Diseases and Complex Conditions</b> Including Meeting of RareResourceNet	45	EURORDIS
6-7 Oct 2016	1 day	Vienna	<b>Workshop: Social Policy Innovation and sustainability &amp; EU structural funds</b> Including Meeting of RareResourceNet	40	ZSI & EURORDIS
1-2 June	2 days	Cluj-Napoca	<b>Workshop on Improving Integrated Care for People Living with Rare Diseases and Complex Conditions</b> Including Meeting of RareResourceNet	47	EURORDIS
12-13 April 2018	2 days	Oslo	<b>Workshop with stakeholders and advisory group</b> Including Meeting of RareResourceNet	40	EURORDIS
Sept 2018	1 day	Brussels	<b>Final conference with Advisory Group and EU policy makers &amp; RD stakeholders</b>	100	EURORDIS

Details and presentations available at:  
<http://innovcare.eu/events/>

# Engaging with policy makers

- ✓ INNOVCare [Advisory Group](#)
- **19 representatives from 15 European countries**
- **National/regional competent authorities - mix of health and social**
- **Goal:**
  - Promote better **dissemination of the project to policy makers**
  - Engage on **up-scaling the pilot/similar model to their countries**
  - Advisory group will attend 3 workshops of the project
  
- ✓ Link to [Commission Expert Group on Rare Diseases](#)
- ✓ Link to [RD-Action project \(2015-2018\)](#), policy work package



# Find out more at innovcare.eu

The screenshot shows the INNOVCare website homepage. At the top left is the INNOVCare logo. To its right is the tagline: "Bridging the gaps between health, social and local services to improve care of people living with rare and complex conditions". Further right is a "Select Language" dropdown menu. Below this is a dark navigation bar with links: Home, Who we are, What we do, Why we do it, Social Services, Events, Resources. The main content area features a large image of a smiling woman in a green shirt interacting with a young girl. To the left of the image is a text block: "INNOVCare gives a voice to the social and everyday needs of people living with a rare disease and addresses the need for coordination between service providers in European Union Member States." Below this text are two buttons: "Who We Are" and "What We Do". At the bottom of the page is a dark teal banner with four circular statistics, each containing "33%":

- 1/3 of families see one member reduce or stop professional activity
- 1/3 of families see one member reduce or stop professional activity
- 1/3 of patients and families require assistance from a social worker
- 1/3 of patients and families have difficulties to meet a social worker

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## Thank you

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