



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

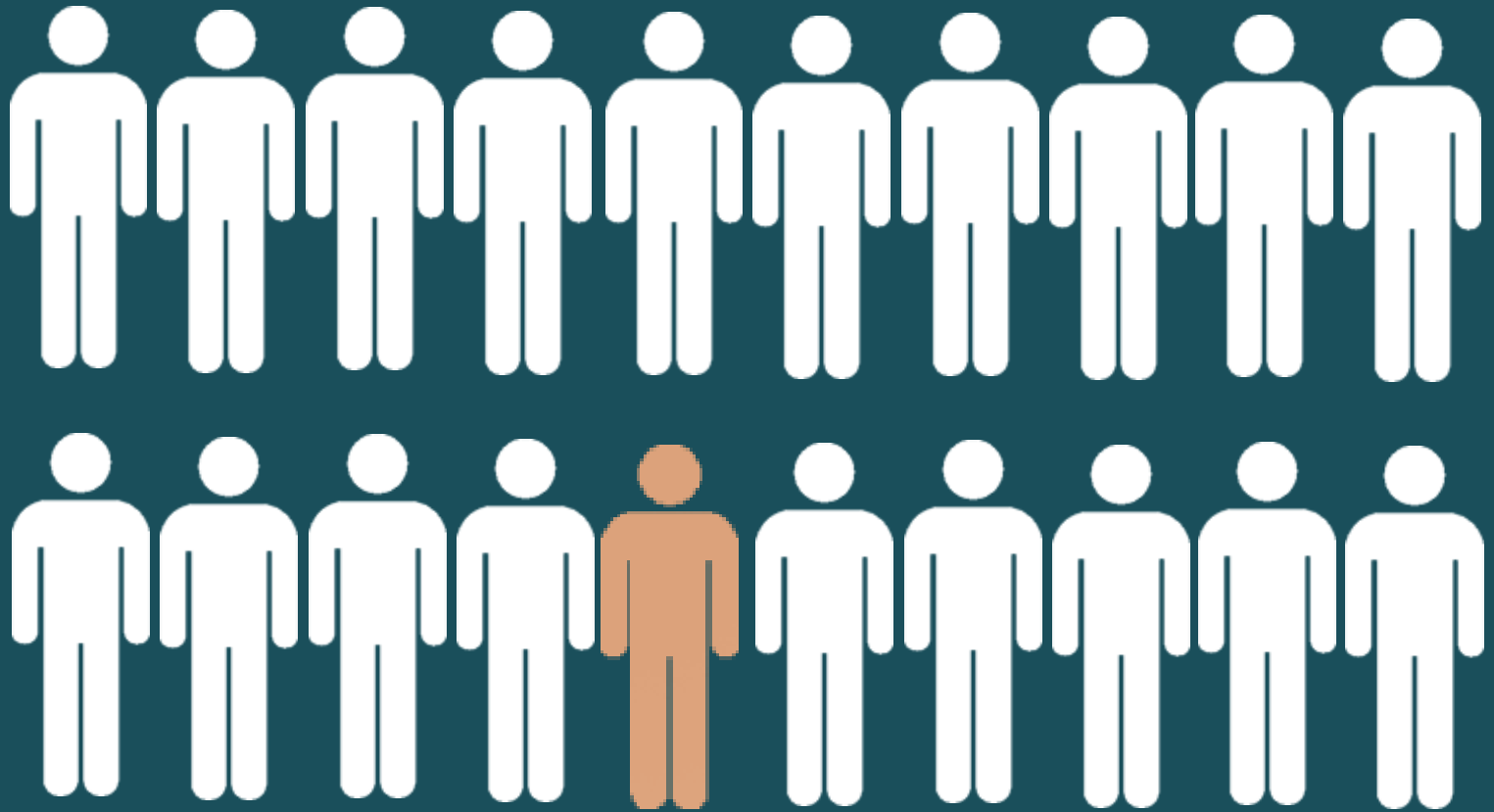
INNOVCare Workshop on Scaling Innovative Care Delivery for Rare Diseases and Complex Conditions
Vienna, 6-7 October 2016

www.innovcare.eu

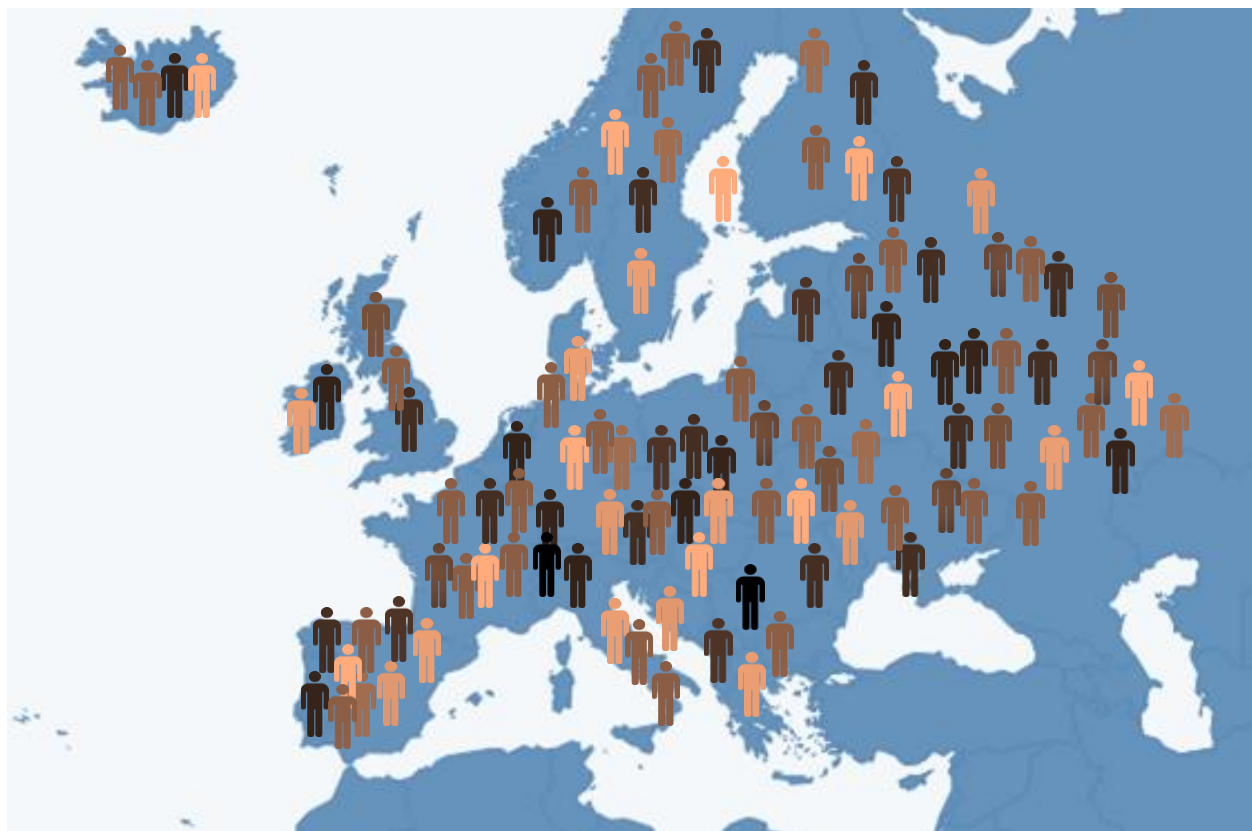


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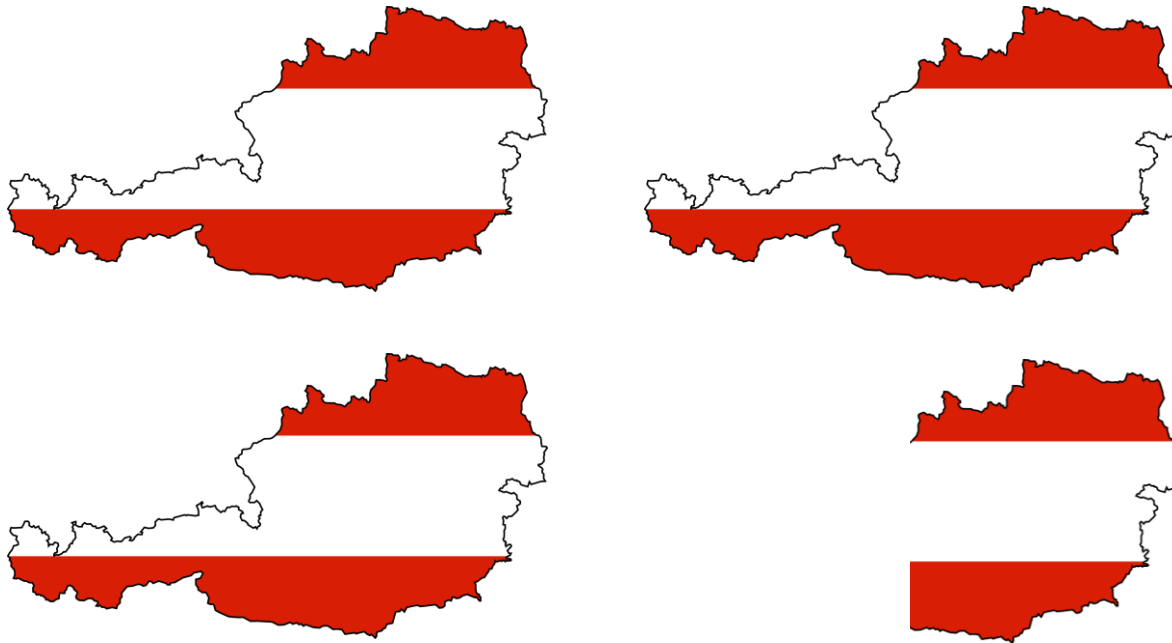
**1 in each 20 persons is affected by a
rare disease**



There are over 6000 Rare Diseases
30 million people affected in Europe



30 million people in Europe





**Each rare disease
affects few patients**

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

What is a rare disease

- Many are of genetic origin
- Main groups: metabolic, neuro-muscular, autoimmune, developmental anomalies, bleeding disorders, cardiovascular, respiratory, skin diseases, rare cancers...
- **Rare, highly complex, chronic, severely disabling**
- A high percentage of people with a RD is affected by motor or intellectual impairments
- They influence the person's health conditions and daily life in a disabling way
- **Lack of treatment** (4000+ without treatment; treatments are too expensive)
- **Scarcity of information** on diseases & consequences on daily life
- **Scarcity and scattering of experts and resources**
- **Research is fragmented**
- **Lack of good practices**
- People living with a rare disease **struggle to connect to peers and experts**

Complexity is not easy to grasp

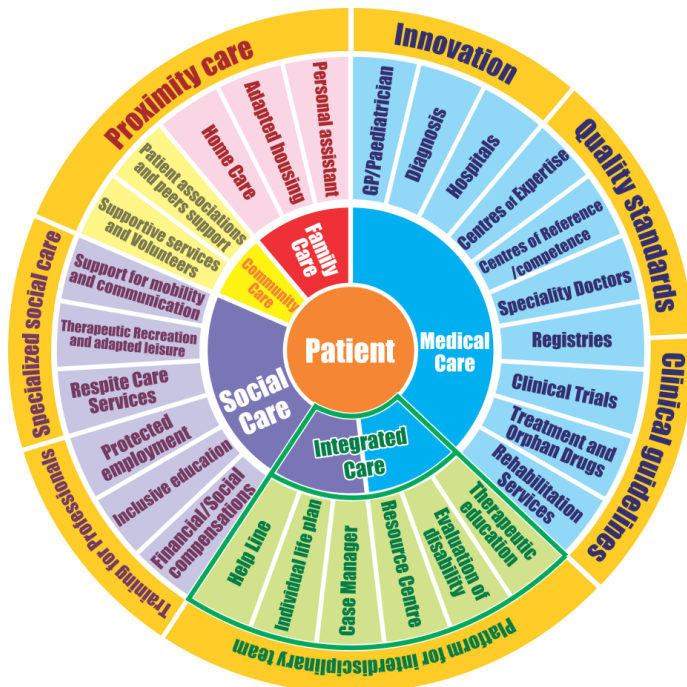


EURORDIS Photo Contest, 2014



*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, complex diseases are many and require coordinated multidisciplinary care



In most countries the care pathways are not structured and patients often struggle to access the services and the support they need



Holistic care provision to rare diseases: Recent activities at European level

Understanding the needs of
people living with a rare disease
and their families



Promoting the integration of rare diseases
into social services and policies

Specialised Services



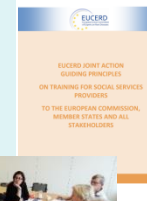
Mainstream Services



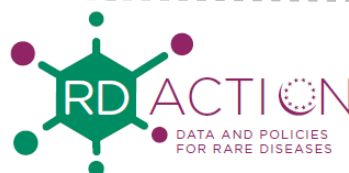
Rare Barometer

A EURORDIS INITIATIVE

Studies & surveys to patients and families



Recommendations to Member States & good practices



EU-funded projects



Holistic care provision to rare diseases: Commission Expert Group on Rare Diseases Recommendations



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

Advising EU **Member States** and the European Commission on issues that should be considered when organising holistic care for people living with a rare disease within national health and social care systems

Unanimously adopted by representatives of all EU Member States

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

Next Step

Moving from the recommendations to the implementation

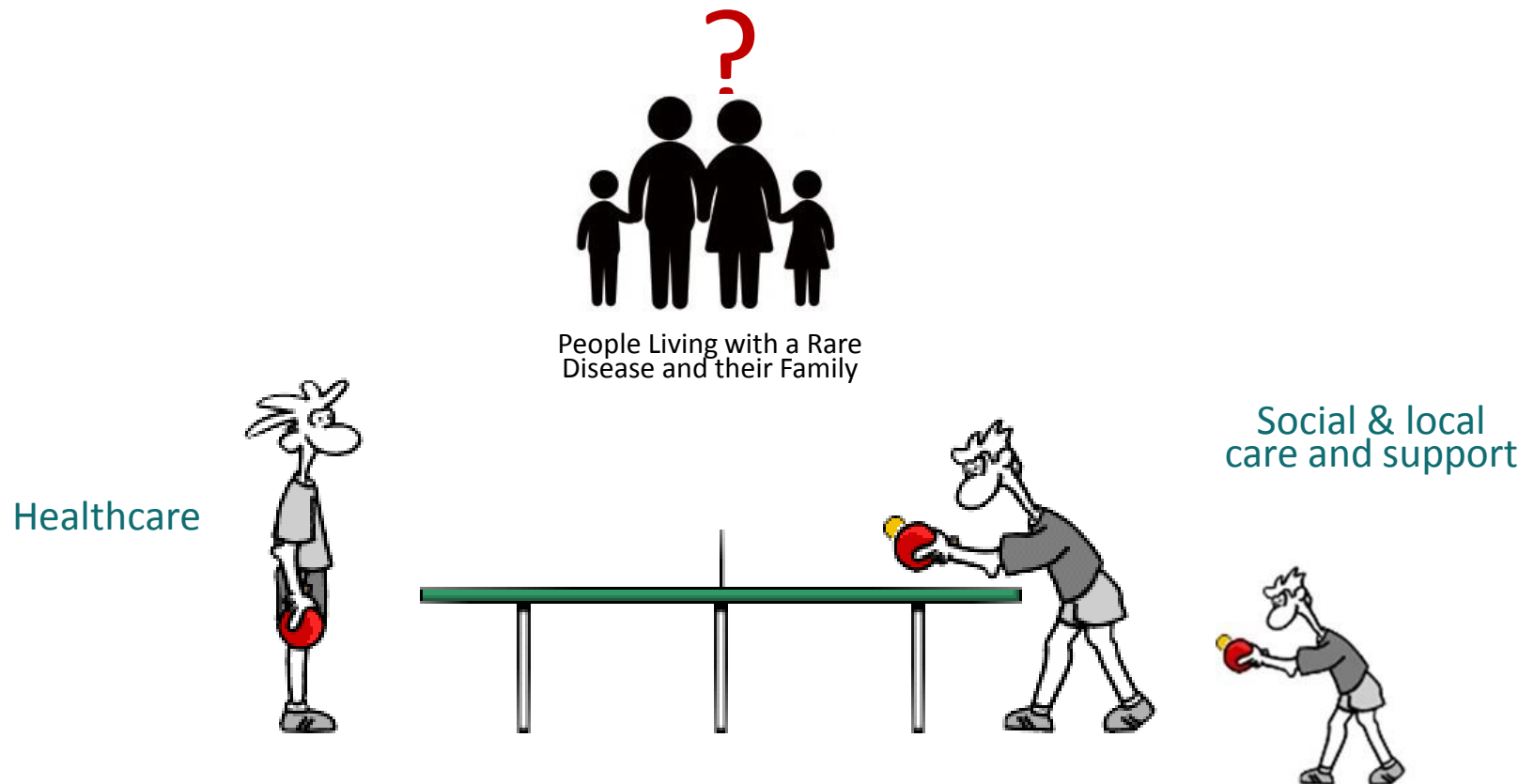
INNOVCare

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

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



The dilemma



Call for proposals

- Call for proposals from EC-DG Employment, Social Affairs and Inclusion (2014)
- Call on “social policy innovation supporting reforms in social services” - specific focus on “one stop shop services” and “case handlers”
- Not specific to health/disability – open to all vulnerable populations
- Over 200 projects submitted - 7 selected
- INNOVCare is the only project on health/disability and with European scope

Project Overview

Time frame:

- 36 months
- 01/10/2015 to 30/09/2018

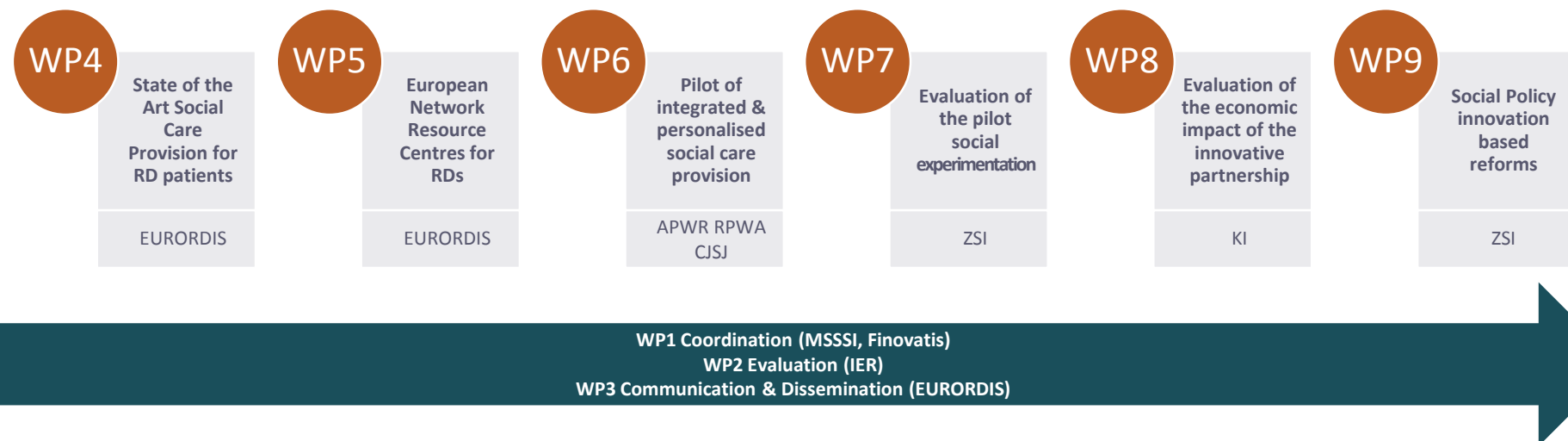
Consortium:

- 8 partners
- 6 countries - Spain, France, Slovenia, Romania, Austria, Sweden

Total budget:

- 1 994 414.72€

Project Structure



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

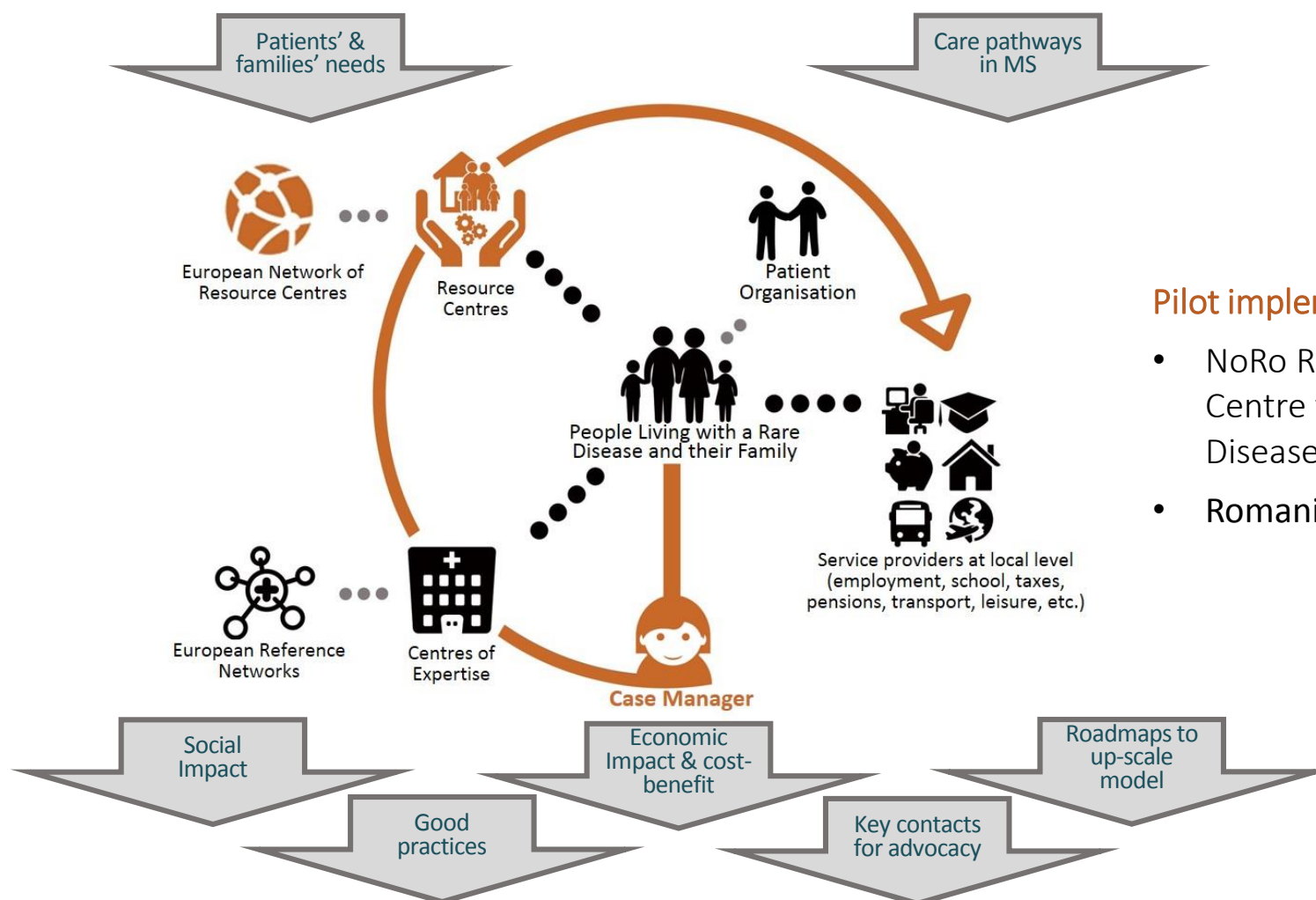
APWR RPWA Asociatia Prader Willi din Romania (NoRo) – Romania – Dorica Dan

CJSJ Regional County Sălaj – Romania - Monica Avram

ZSI Zentrum für Soziale Innovation – Austria - Anette Scoppetta

KI Karolinska Institutet – Sweden - Peter Lindgren

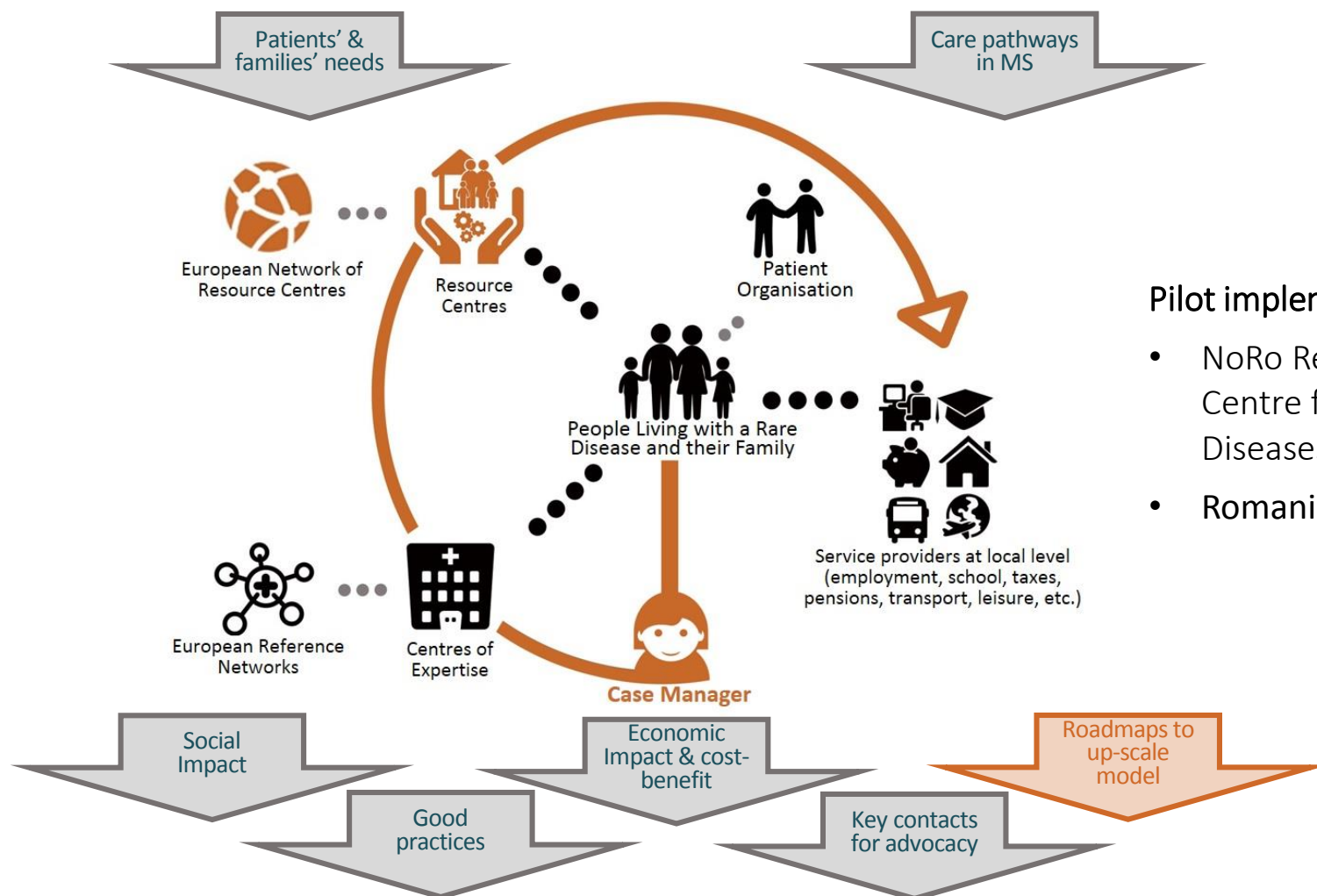
Project Concept



Pilot implementation

- NoRo Resource Centre for Rare Diseases
- Romania, 2017

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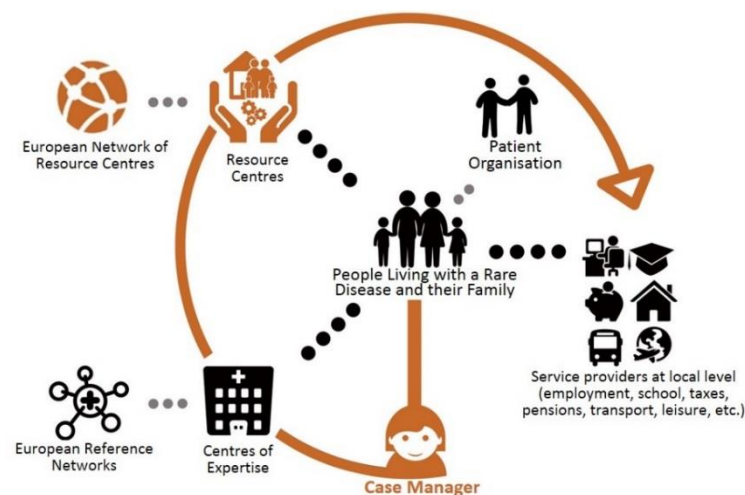
Project Objectives

- Assessment social unmet needs of people with a RD and their family
- Analysis of existing social care models in MS
- Exchange of expertise/good practices between national one-stop-shop services (resource centres)
- Proposition of a model of optimised patient social care pathway, integrating the national one-stop-shop service with regional case managers:
 - Implementation and evaluation of a pilot (Romania)
 - Assessment of the social, economic impact & cost-benefit of the care model
 - Analysis of scaling opportunities - beyond RDs (to other diseases, disabilities) and to other MS
- Strengthening partnerships between public, private and civil society organisations providing social services to RD patients/families

INNOVCare pilot - Summary

Regional case managers to be hired by NoRo resource centre for rare diseases (Romania):

- To bridge the gaps in coordination between health, social and local services
 - To reduce care burden for patients and families
-
- Time frame: 18 months, 01/2017-06/2018
 - Target population:
 - Patients with rare/complex conditions (children and adults) and their families;
 - Current beneficiaries of NoRo and new ones;
 - 120 cases; each case includes patient + family;
 - Each case has access to the service for 9 months;
 - Geographical scope: region of Salaj, Romania;
 - Number of case managers employed: 2;
 - Nr. of simultaneous “cases” per case manager: 30;
 - Profile of case managers: social worker and lawyer;
 - Service provision should be focused on a few key areas in order to have more meaningful results.

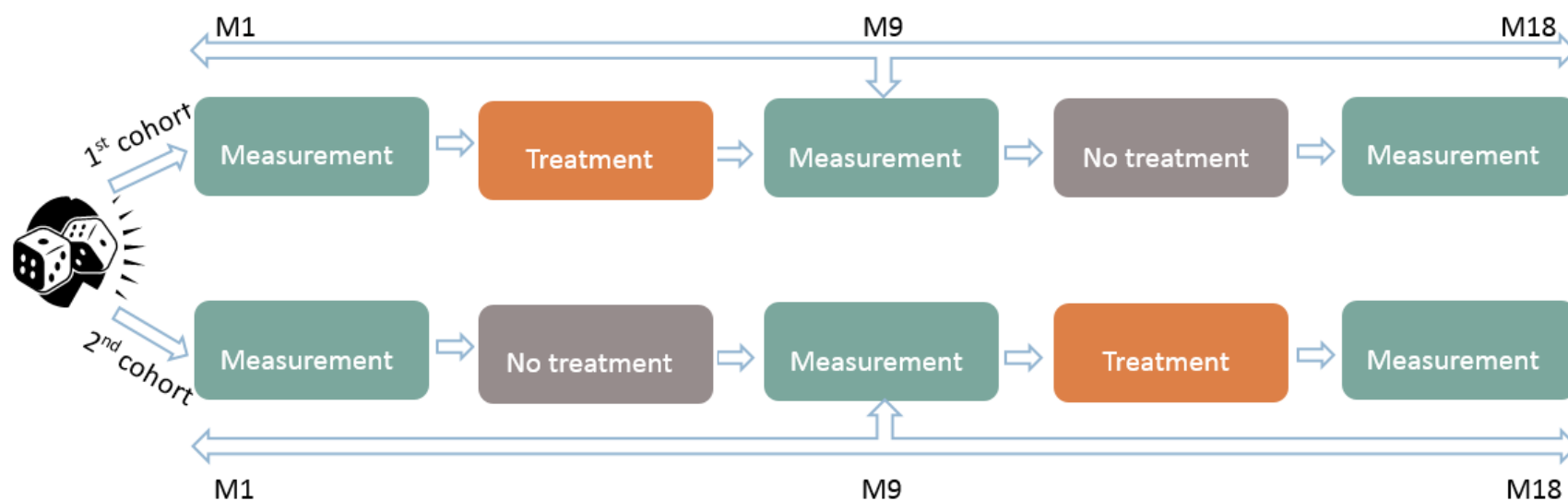


INNOVCare pilot – Possible roles of the case manager

- **Single and stable point of contact**
- **Listen, inform, support and empower patients and families**
 - Providing knowledge/tools & informing about existing resources
 - Encourage health literacy and compliance to treatments
 - Relief the burden of care provision for patients and families
- **Assessment/monitoring of needs & being an observatory of those needs**
- **Holistic and patient-centred care planning and care co-ordination:**
 - Identify resources available in the territory - services and support
 - Referral to and speed up access to services and support
 - Simplify care pathways, ensure continuous support, support navigation for patients/families and professionals
- **Hub of information and knowledge**
- **Inform, support and empower professionals involved in care provision**
- **Facilitating coordination between services and networks of service providers**
- **Prevention of avoidable high risk situations & limit over-use of health services if not needed**
- **Develop working methods that support empowerment of patients and families**



INNOVCare pilot – Evaluation



A two-condition repeated-measures design

European Network of Resource Centres for Rare Diseases



Resource Centres for rare diseases

- **One-stop-shop style** of service, specifically designed for people living with a rare disease
- **Create a bridge between patients/families and various stakeholders involved in patient care**
- Resource Centre services include:
 - Information and guidance services
 - Training courses
 - Provision of information concerning social benefits
 - Documentation and research services
 - Therapies
 - Medical/psychological consultations
 - Therapeutic recreation activities
 - Respite



Fact sheet on Resource Centres for rare diseases

Resource Centres across Europe – potential members of the network



European Network of Resource Centres

Governance

Steering Group:

- Agrenska, Sweden: Anders Olauson
- Frambu, Norway: Lisen Julie Mohr
- NoRo, Romania: Dorica Dan



Working group appointed by the Steering Group:

- CREER, Spain: Aitor Aparicio García and Marta Fonfría
- DEBRA Centre, Croatia: Vlasta Zmazek
- Eesti Agrenska, Estonia: Tiina Stelmach
- Raríssimas, Portugal: Maria João Freitas & Sónia Fertuzinhos



Time-frame

- Governance & membership documents preparation ongoing
- Recruitment of members from early 2017

Project Events

Date	Duration	Place	Event	Target	Nr of people	WP	Partner responsible
8-9 Sept 2016	2 days	Goteborg	Workshop on Improving Integrated Care for People Living with Rare Diseases and Complex Conditions Including Working Meeting of European Network Resource Centres	Social services Stakeholders	50	WP5	EURORDIS
6-7 Oct 2016	1 day	Vienna	Workshop: Social Policy Innovation and sustainability & EU structural funds Advisory Group	Consortium; patient reps; MS health/social	15 20	WP9 WP5	ZSI EURORDIS
			Meeting European Network of Resource Centres Advisory Group	Social services MS health/social	20 20	WP5 WP3	EURORDIS
May 2017	2 days	Cluj-Napoca	Meeting European Network of Resource Centres Advisory Group	Social services MS health/social	20 20	WP5 WP3	EURORDIS
April 2018	2 days	Oslo	Meeting European Network of Resource Centres Advisory Group	Social services MS health/social	20 20	WP5 WP3	EURORDIS
Sept 2018	1 day	Brussels	Final conference	Policy makers, stakeholders & general public	50 + 50 on site	WP3	EURORDIS

Workshop: Improving Integrated Care for People Living with Rare Diseases and Complex Conditions

- At Ågrenska [Resource Centre](#), Gothenburg, Sweden
- 8-9 September 2016
- Organised by EURORDIS
- 45 participants, 20 countries
 - Social services, patient representatives (SPAG, NA), public bodies, healthcare providers, social workers & academics.
 - [*List of participants here*](#)



Workshop: Improving Integrated Care for People Living with Rare Diseases and Complex Conditions - Goals

- First steps of the future **European Network of Resource Centres for Rare Diseases** (*closed session*)
- Exchange **good practices** to **improve social and integrated health-social care** for people living with a rare disease and their families
- Contribute to **design of the INNOVCare pilot (Romania, 2017)** the & **support the development of the pilot's impact assessment model**

Workshop: Improving Integrated Care for People Living with Rare Diseases and Complex Conditions - Presentations

The workshop [agenda can be accessed here](#).

Presentations

- [INNOVCare project: bridging the gap between health, social & local care for rare diseases](#), Raquel Castro, EURORDIS – including preliminary results from ongoing Rare Barometer Survey
- [European Recommendations Support the Incorporation of Rare Diseases into Social Policies and Services](#), Gerhard Steffes, Directorate-General for Health and Food Safety, European Commission
- **Presentations by case study resource centres for rare diseases:**
 - [Ågrenska](#) (Sweden), Anders Olauson
 - [Frambu](#) (Norway), Lisen Julie Mohr
 - [NoRo](#) (Romania), Dorica Dan
 - [CREER](#) (Spain), Marta Fonfría
- [Integrated health and social care – what matters](#), Anne Hendry, Scottish Government & International Foundation for Integrated Care
- **Presentations by case study case management services for rare diseases:**
 - [Project “FAC” Train, Support, Coordinate](#), Christine de Kalbermatten, ProRaris, Switzerland
 - [“Navigators” project, Stephanie Jøker Nielsen](#), Rare Diseases Denmark
- [INNOVCare’s pilot implementation in Romania](#), Dorica Dan, NoRo resource centre

Workshop: Improving Integrated Care for People Living with Rare Diseases and Complex Conditions – Breakout Sessions

1. What matters to patients and their family

Chair: Raquel Castro, EURORDIS; Rapporteur: Sandra Courbier, EURORDIS

2. Design of the intervention: regional case managers for rare diseases, Romania

Chair: Dorica Dan, NoRo resource centre; Rapporteur: Zsuzsa Almasi, NoRo

3. Creating the enabling environment

Chair: Anne Hendry, Scottish Government; Rapporteur: Ildiko Vajda, Dutch Genetic Alliance & EURORDIS Social Policy Advisory Group

4. Evaluation of the impact of the intervention


Chair: Juliet Tschank, Centre for Social Innovation (ZSI); Rapporteur: Juliette Senecat, EURORDIS

5. Making it happen in other countries

Chair: Ursula Holtgrewe, ZSI; Rapporteur: Vlasta Zmazek, DEBRA Croatia & EURORDIS Social Policy Advisory Group

[Notes from the breakout sessions](#)

Find out more at innovcare.eu




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

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[Why we do it](#)
[Social Services](#)
[Events](#)
[Resources](#)

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.

[Who We Are](#)
[What We Do](#)



33%

1/3 of families see one member reduce or stop professional activity

33%

1/3 of families see one member reduce or stop professional activity

33%

1/3 of patients and families require assistance from a social worker

33%

1/3 of patients and families have difficulties to meet a social worker



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Thank you

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