

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

INNOVCare Workshop on Improving Integrated Care for People Living with Rare Diseases and Complex Conditions—Gothenburg—8-9 September 2016

www.innovcare.eu

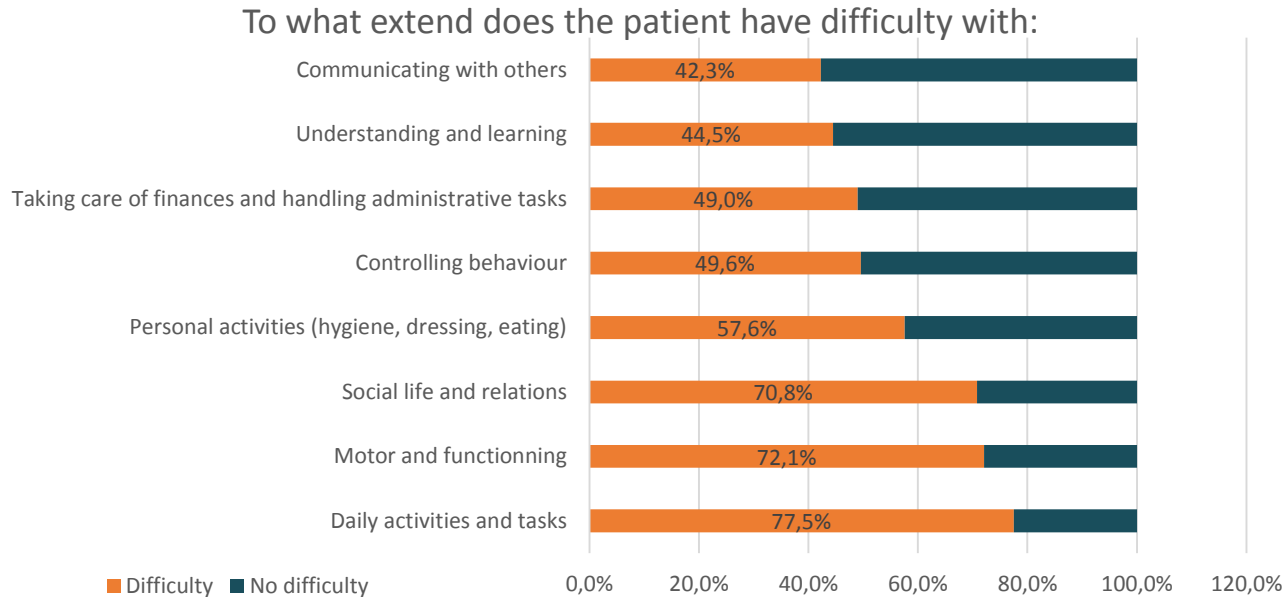


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*The serious unmet social needs of people with a rare disease and their families affect their dignity, autonomy and other **fundamental human rights** expressed in the Universal Declaration of Human Rights and in the UN Convention of the Rights of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

Needs of people living with a rare disease

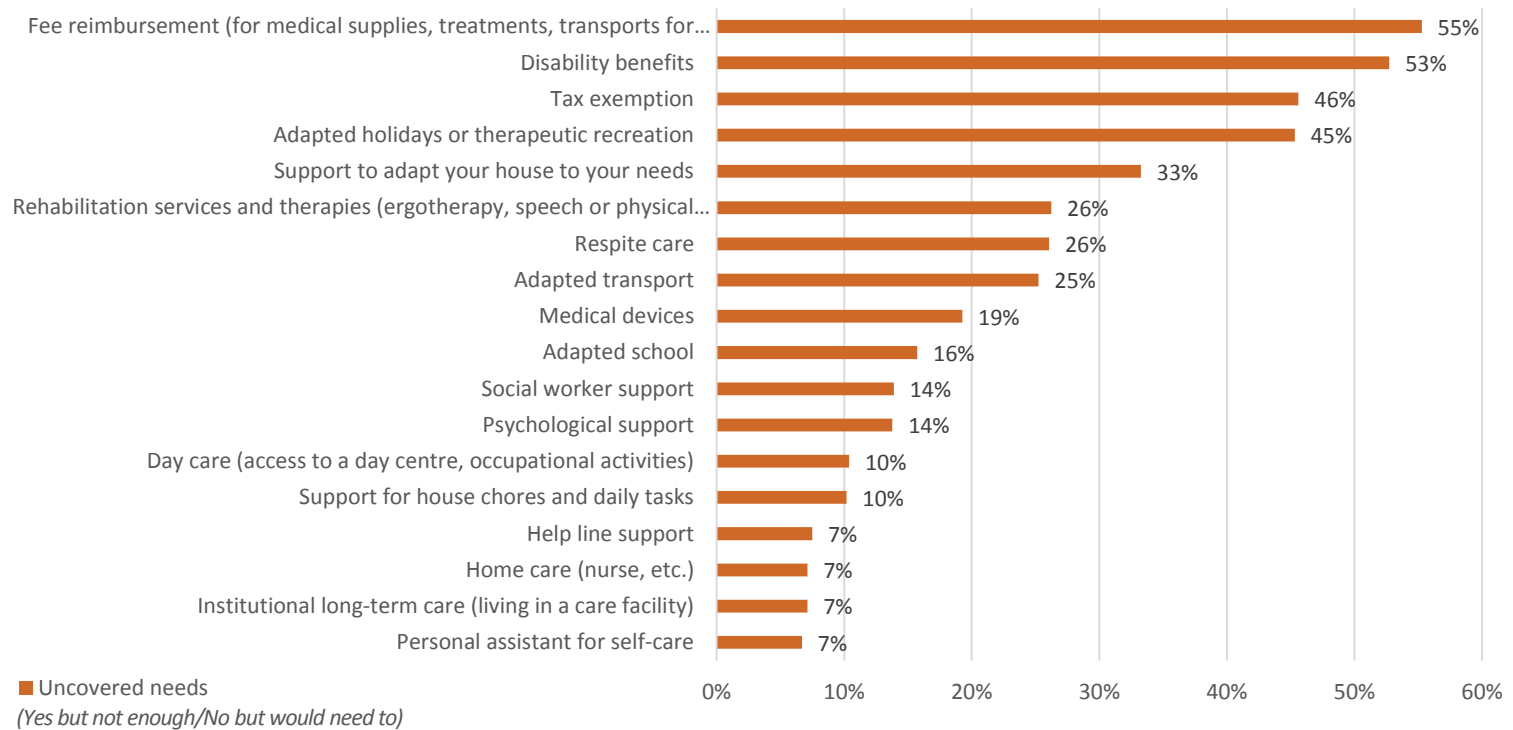


- ✓ **Rare diseases have significant impact on the daily life of 86% of patients & families** (*fairly/a lot*)
- ✓ **43% of patients/families invest over 4h/day on illness related tasks; 18.3% spend over 6h/day;**

Preliminary results of ongoing study conducted by EURORDIS, via [Rare Barometer Voices](#), in European Countries:
1200+ respondents across Europe and diseases - 63% patients, 35% parents, 2% spouses, 2% grand-parents

Needs of people living with a rare disease

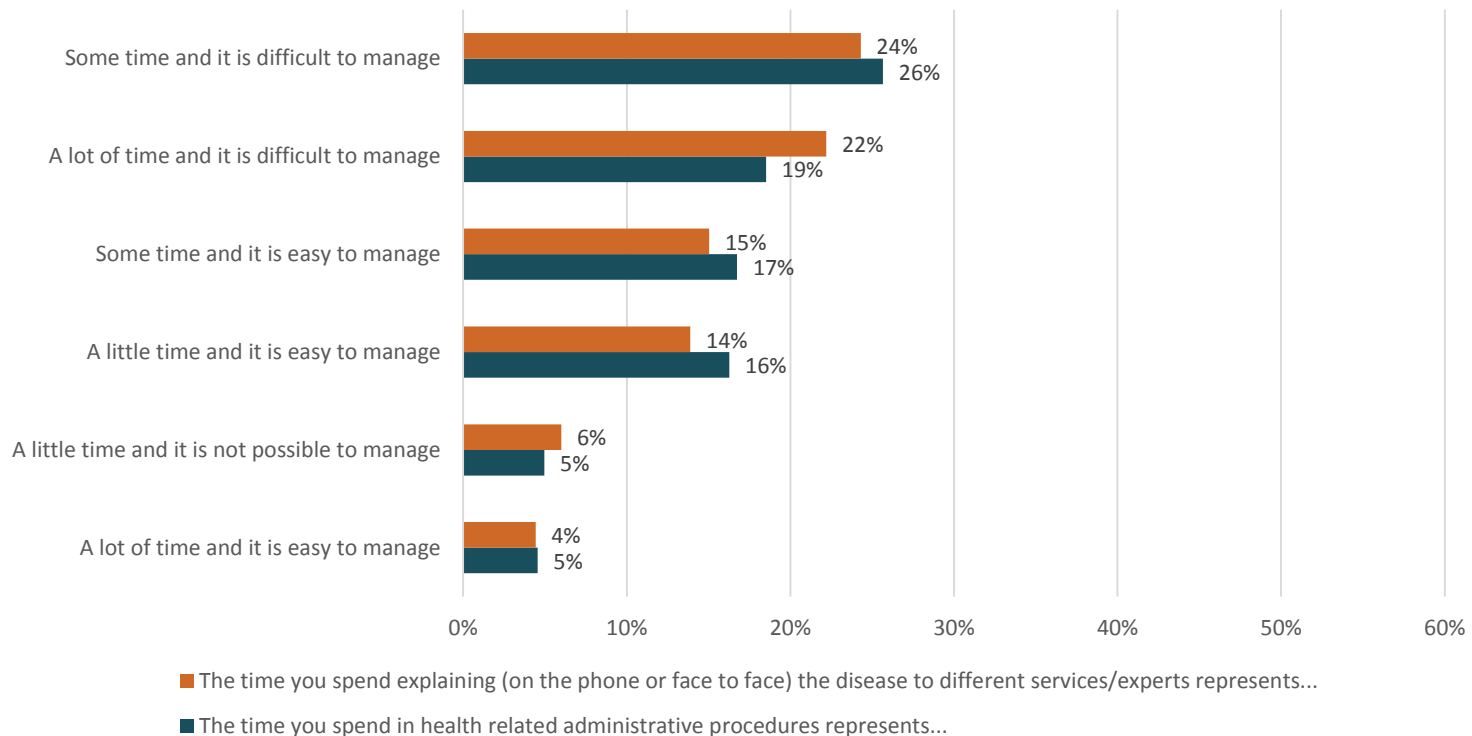
Does your family has access to...



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Needs of people living with a rare disease

Do you spend time organising care?



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Needs of people living with a rare disease

- ✓ **65% of patients/families find difficult to manage the time that they spend organising care**
- ✓ **49% of patients/families have difficulties managing their health related administrative procedures**
- ✓ **53% of patients/families have difficulties with managing the time spent explaining the disease to different experts and professionals**
- ✓ **47% of patients/families find hard to handle their visits to health and social support services/specialists in a short period of time**

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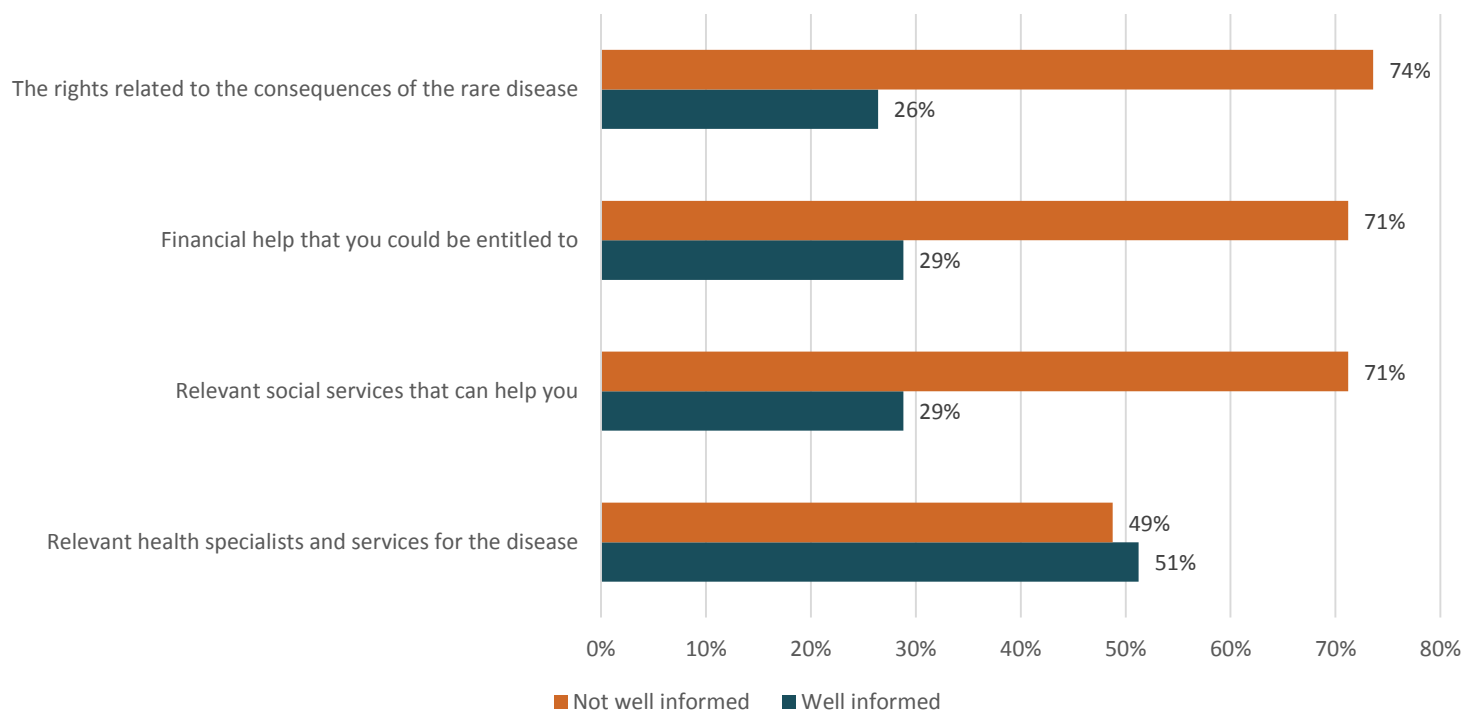
Needs of people living with a rare disease

- ✓ **69% feel that the communication/exchange between different service providers is not good** (*fairly bad/very bad*);
- ✓ **75% consider that professionals from social, local and support services don't know the consequences of their disease** (*fairly badly/very badly*);
- ✓ **70% consider that professionals from social, local and support services are not prepared to support them in dealing with the consequences of the rare disease** (*fairly badly/very badly*);

Preliminary results of ongoing study conducted by EURORDIS, via [Rare Barometer Voices](#), in European Countries:
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Needs of people living with a rare disease

How well informed do you feel about...



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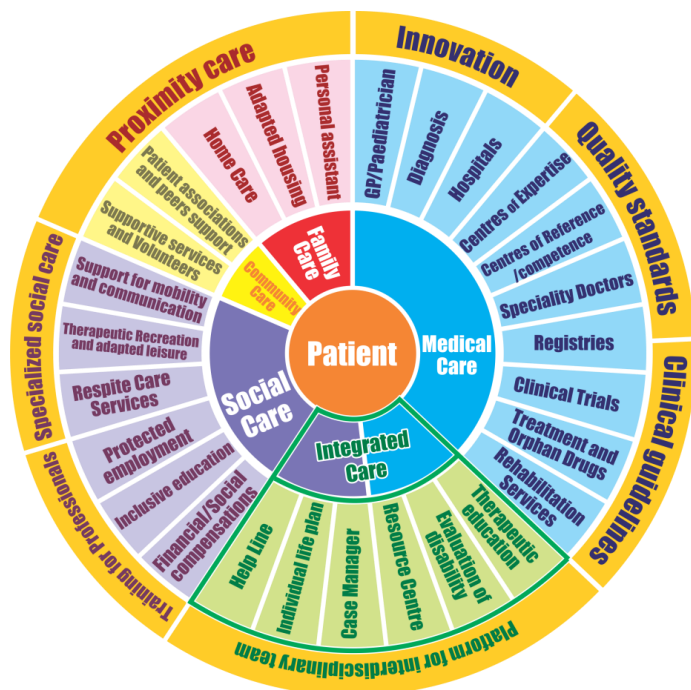
Care pathways in European Countries

- ✓ **Separation between social and health sector is common**
- ✓ **Lack of connection/coordination between different services**
- ✓ **Different funding systems affect services' capacity to work together**
 - ✓ **Fragmented care pathways**
- ✓ **Patients, patient organisations often have to coordinate care**

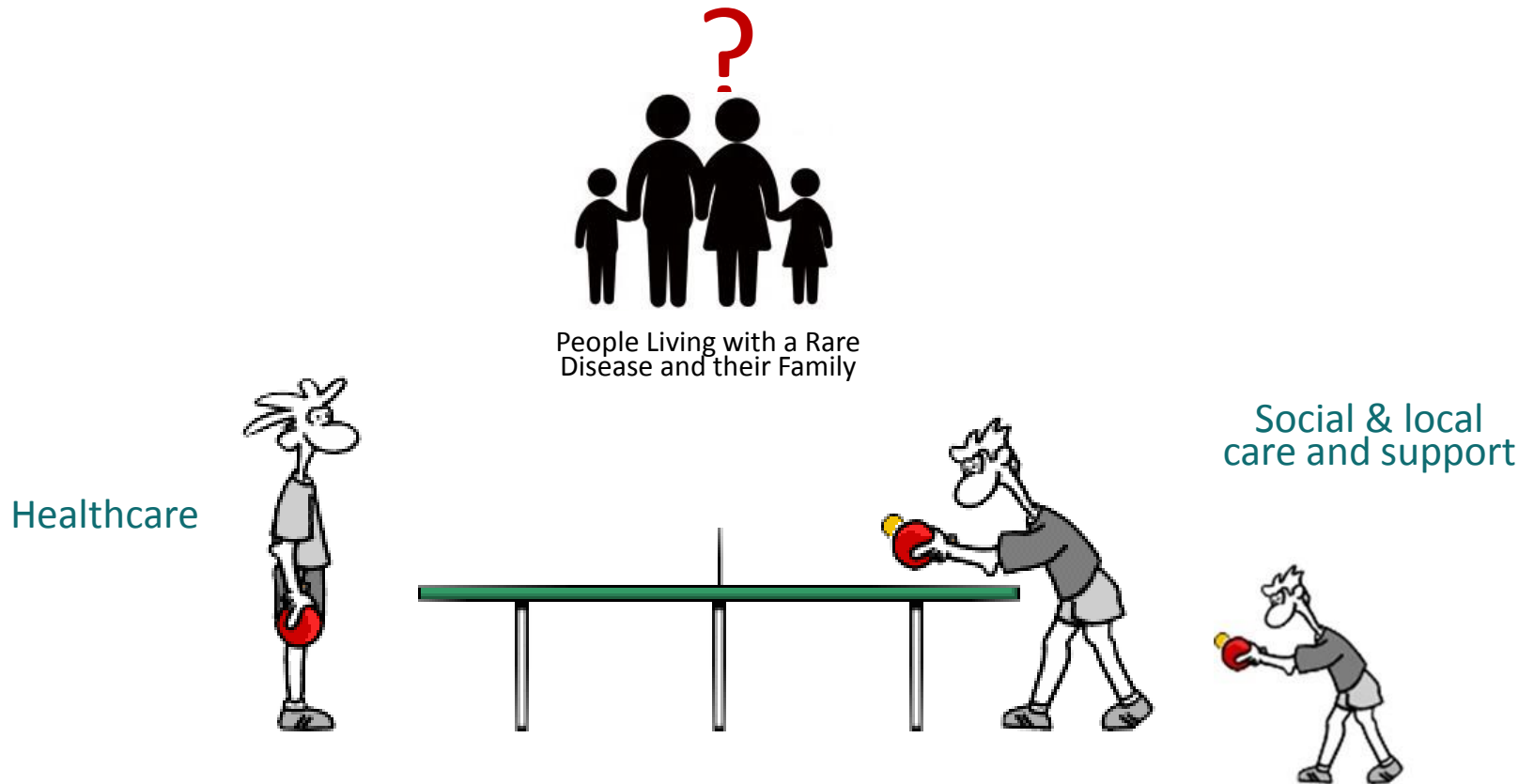
Preliminary results of 42 interviews 42 interviews conducted by EURORDIS to competent authorities and relevant health/social stakeholders in Austria, France, Hungary, Luxembourg, Romania, Spain, Sweden, United Kingdom (*countries selected include different geographic and population sizes, welfare states, public administration, GDP per capita*).

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



The dilemma



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

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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 – led by public bodies in Spain (3), Italy (2), Netherlands (1) and Latvia (1)
- 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

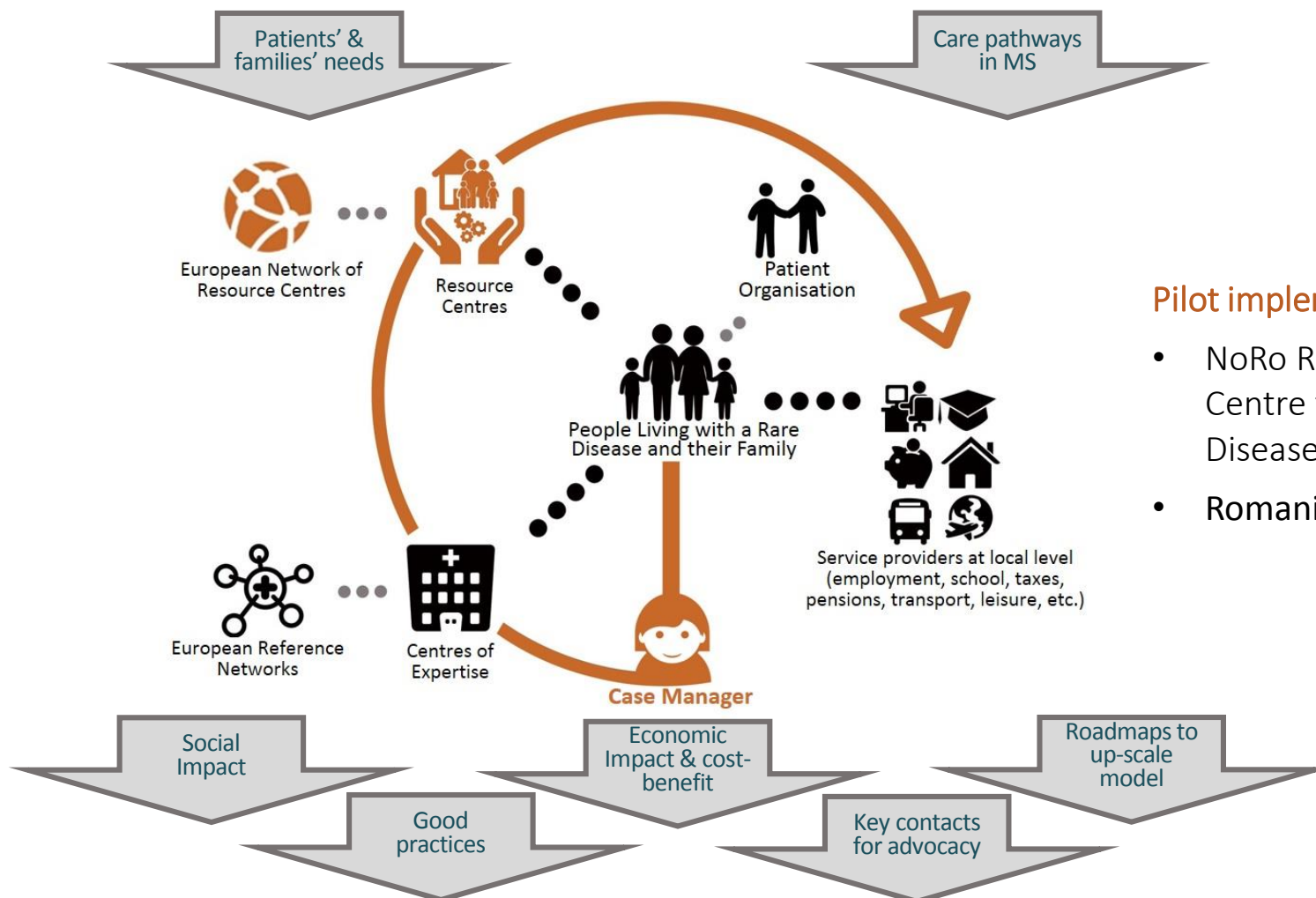
Consortium:

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

Total budget:

- 1 994 414.72€

Project Concept



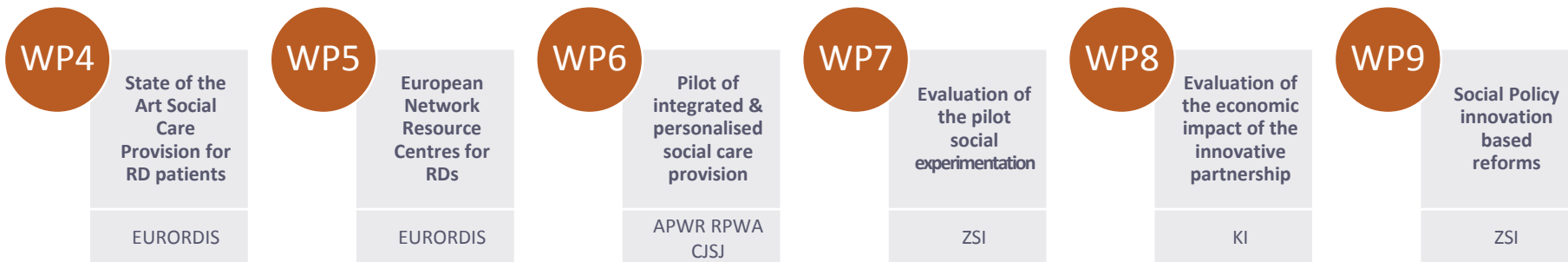
Pilot implementation

- NoRo Resource Centre for Rare Diseases
- Romania, 2017

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

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 - Anette Scoppetta

KI Karolinska Institutet – Sweden - Peter Lindgren

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	Consortium; patient reps;	15	WP9	ZSI
			Advisory Group	MS health/social	20	WP5	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

INNOVCare pilot - summary

Regional case managers to be hired by NoRo:

- 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;

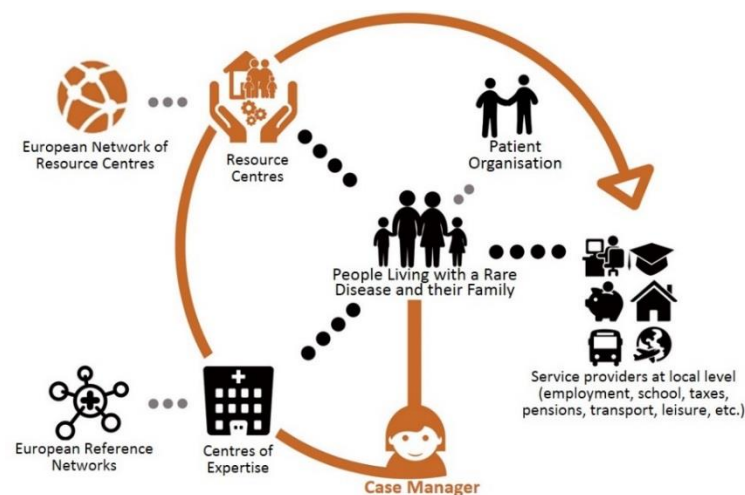
- Geographical scope: region of Salaj, Romania;

- Number of case managers employed: 2;

- Profile of case managers: social worker and lawyer;

- Nr. of simultaneous “cases” per case manager: 30;

- Service provision should be focused on a few key areas in order to have more meaningful results.

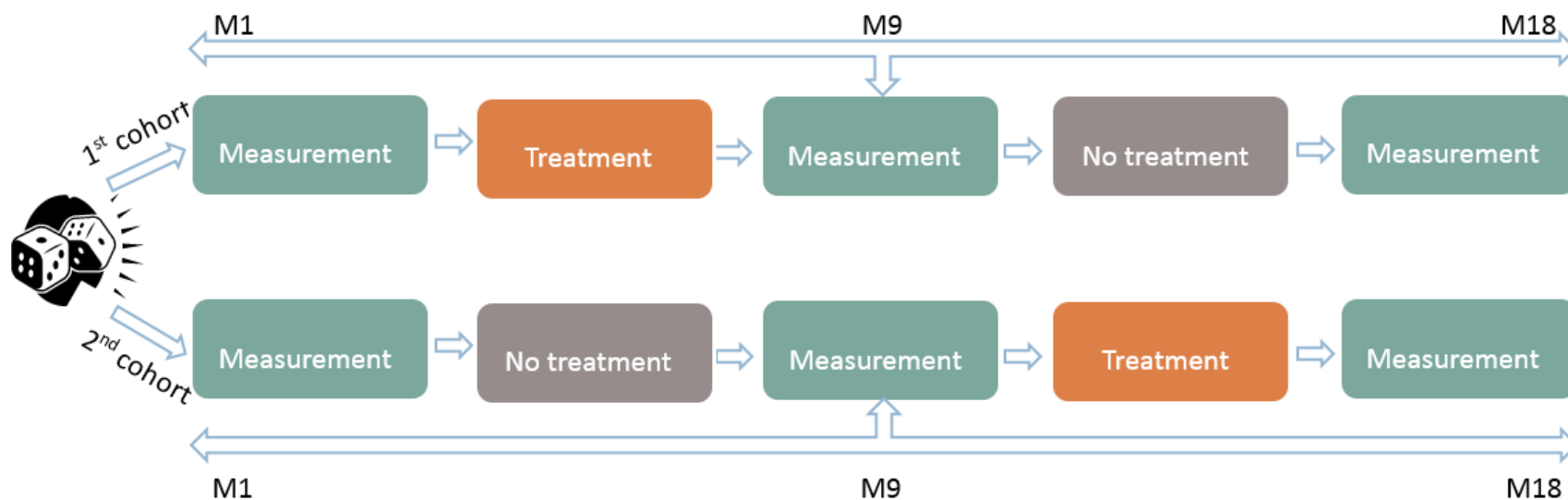


INNOVCare pilot – possible role of the case manager

- **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**



Proposed method to evaluate impact of case management at NoRo (INNOVCare pilot)



A two-condition repeated-measures design

Up-scaling the pilot to other European countries

- INNOVCare will be working with policy makers and stakeholders to develop road maps to up-scale the INNOVCare pilot to other European countries
- Virtual focus groups with practitioners of pilot projects to validate findings
- Upcoming meeting in Vienna with policy makers:
<http://www.innovcare.eu/index.php/event/workshop-on-social-policy-innovation-and-sustainability/>
- INNOVCare Advisory Group: 20 representatives of competent authorities from 16 countries across Europe. Composition:
<http://www.innovcare.eu/index.php/innovcares-advisory-group/>

Find out more at innovcare.eu

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](#)



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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*This workshop is organised within the
INNOVCare project*

www.innovcare.eu



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Germany



Stiftung für Kinder mit
Seltene Erkrankungen
*Foundation for Children
with Rare Diseases*



www.creenfermedadesraras.es



www.apwromania.ro



www.cjsj.ro



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