Social Challenges of people living with a rare disease & carers

&

INNOVCare Project

Innovative Patient-Centred Approach for Social Care Provision

EURORDIS.ORG

Juggling care and daily life: The Balancing Act of the Rare Disease Community

First Europe-wide survey on social impact of rare diseases, involving 3,000 rare disease patients & carers

Study performed via Rare Barometer Voices and within the EU-funded INNOVCare project

Rare Barometer Voices
A EURORDIS INITIATIVE

INNOVCare

www.eurordis.org/voices

www.innovcare.eu

Illustrative photos. *This presentation does not necessarily reflect the position of the people in these photos*
Source: [Specialised social services for rare diseases]

EURORDIS
RARE DISEASES EUROPE

First Europe-wide survey on social impact of rare diseases

Juggling care and daily life:

The balancing act of the rare disease community

- Carried out via Rare Barometer Voices

- Over 3000 patients and carers participated

(62% patients; 48% carers -> 110% as some are both)

- 802 diseases, 42 countries

- Performed in 23 languages

Rare Barometer

Juggling care and daily life

The balancing act of the rare disease community

A Rare Barometer survey

Full results here

Summary of key results

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

Summary of key results

- **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**, which include for example the need to **visit different services in a short space** of time and **lack of communication between service 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**

Serious impact on patients’ everyday life

More than 70% of people living with a rare disease have difficulties with:

1. Daily activities and tasks

- Household chores
- Preparing meals
- Shopping

2. Motor/ sensorial functioning

- Visual
- Hearing
- Maintaining body position

3. Social life /relation with other people

Serious impact on patients’ everyday life

8 in 10 people living with a rare disease face **difficulties in more than one** aspect of their everyday life

Complex & often invisible

> “The difficulty lies in the **impossibility of carrying a routine** (...). The problem arises when **one day you appear completely healthy, the next day you are sick**, and two days later you appear completely normal again. Many people find it difficult to understand the disease and the process, and the absenteeism that entails”
>
> **Female, Spain**

Symptoms vary & can be invisible in many ways

Illustrative photo. *This presentation does not necessarily reflect the position of the person in this photo. Source: [EURORDIS Photo Contest]*

Heavy time burden for patients & carers

42% of patients & carers spend **more than 2h/day** on **illness-related tasks**

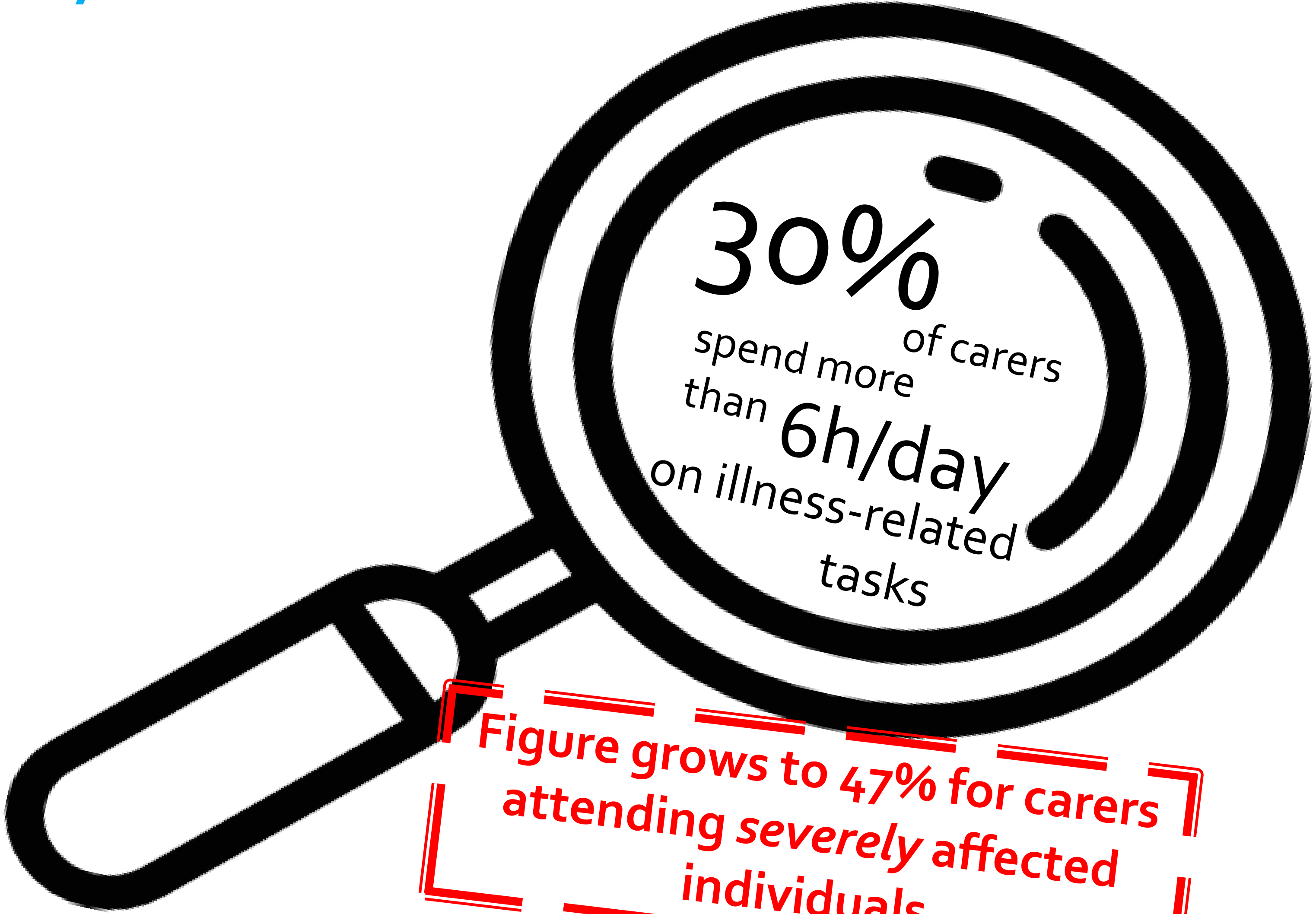
Hygiene

Administration of treatments

Helping with house cores

Helping patients to move

Heavy time burden for carers



30% of carers spend more than 6h/day on illness-related tasks

Figure grows to 47% for carers attending severely affected individuals

Organising care is time-consuming and hard to manage

7 in 10 find all this
time-consuming

Find information on the disease

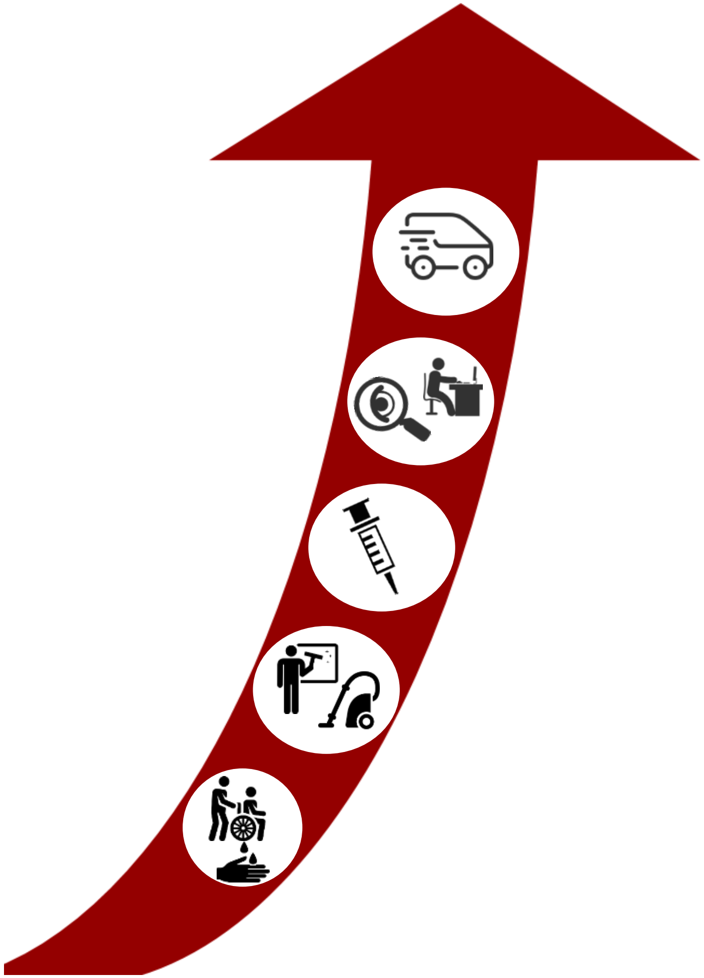
Find the right professional

arranging and attending appointments

traveling to and from appointments

6 in 10 find all this
hard to manage

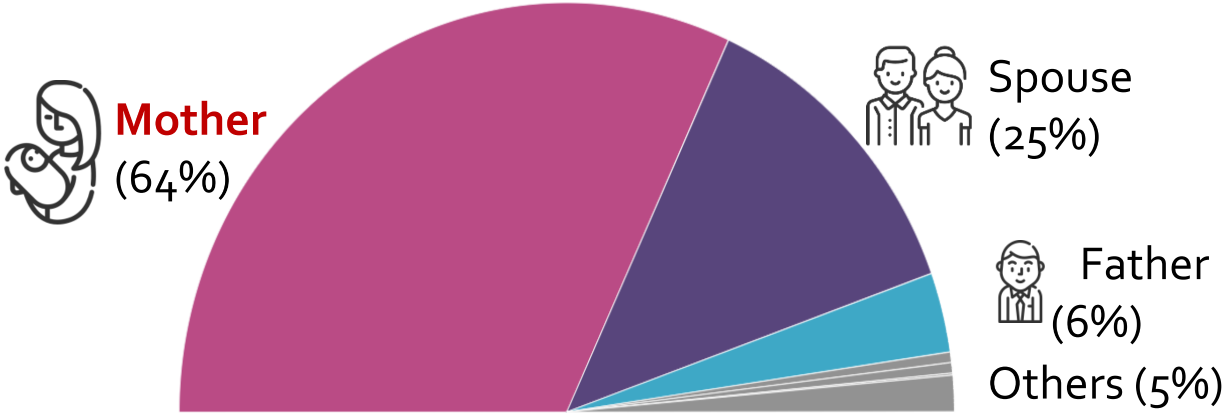
Accumulation of tasks= increased burden



Gender

A burden that heavily falls on women

The role of the primary carer for people living with a rare disease is primarily assumed by women



Who organises and coordinates care in your household?

“The disabled person has to **deal with several different services** to receive help and benefits

There are therefore often **waiting times** of around 6 months whilst dealing with each service or **waiting for service A to send your paperwork to service B**.

During this time, you have not had time to employ someone and **you are still not working**”

Female carer, France

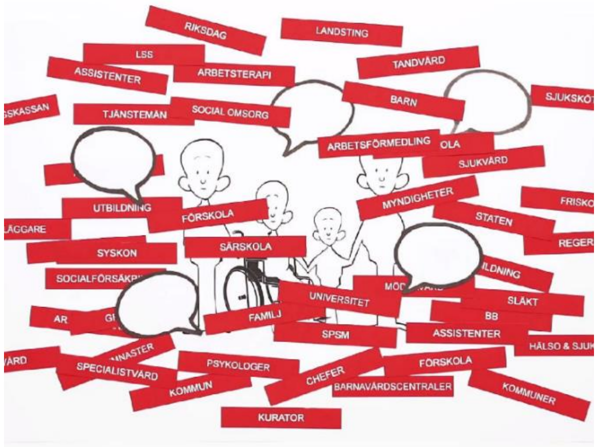
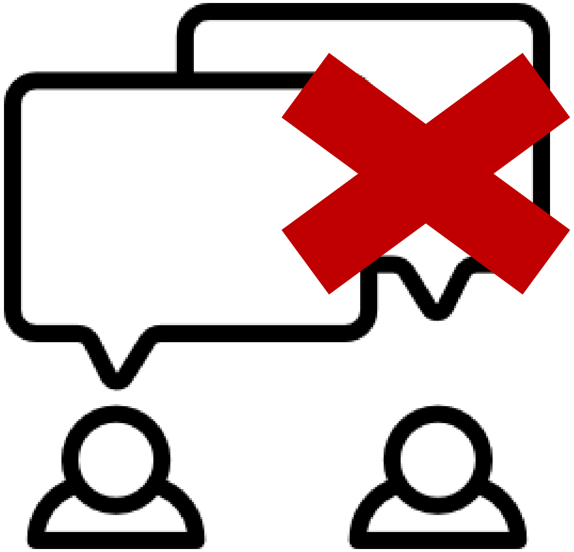


Image used for illustration purposes. Source:
Nationella Funktionen Sällsynta Diagnoser, Sweden

Lack of coordination between care providers

67% of the patients and carers say that health, social and support professionals **communicate badly**



About:

- *Patient*
- *Disease & consequences*
- *Treatment*

“ The **appointments should be multidisciplinary** allowing for the various specialists to see the patient on the **same day and the same place**

Besides **facilitating communication** and the definition of **adequate treatment** it would also **avoid that the patient has to travel** to different appointments and places, **being absent from work** (**loosing income** and facing **discrimination** at the workplace) and **spending** a lot in travel”

Female, Portugal

Significant impact on professional life

Time & care burden

+

Fatigue

+

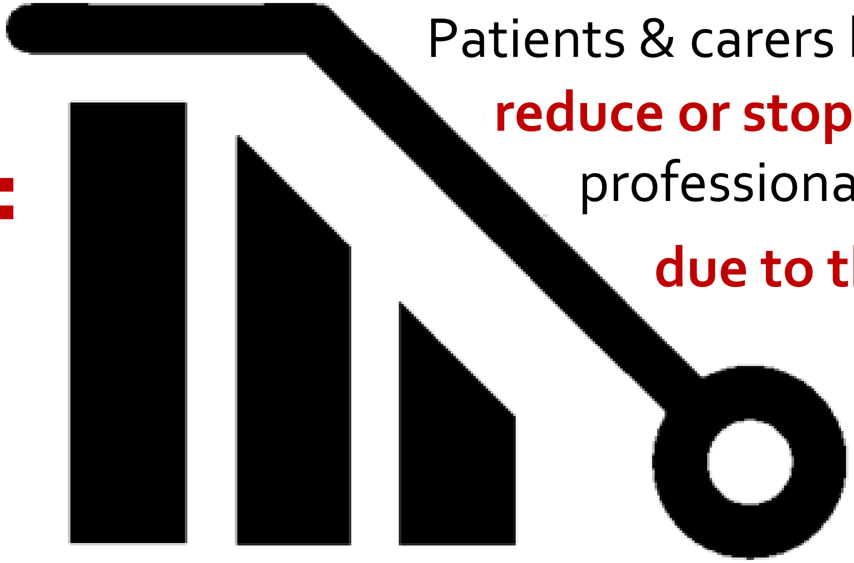
Memory issues

+

Difficulty to commute

=

7 in 10



Patients & carers had to **reduce or stop** professional activity **due to the disease**

Lack of flexibility and adaptation of tasks

Need to stop working during most challenging times:

- **58% absent from work over 15 days/year**
- **41% asked for special leave from work but could not obtain it**

“The worse time, was the time we were **looking for a diagnosis, which took roughly 6 years**.

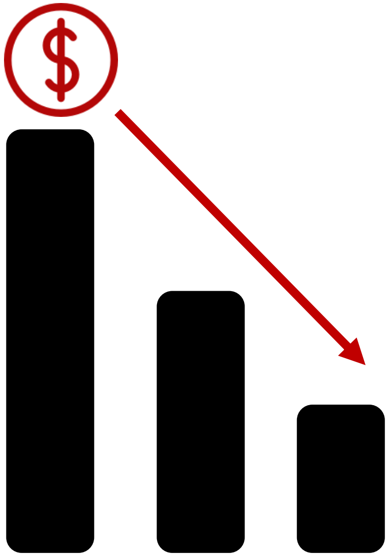
By **asking a year "non paid break“** (…) I received a **refusal from the employer**. So I decided to **give up my job** and stayed **unemployed for 4 years**.

(…) **After the diagnosis** (...), **I decided to pick up work again**. One year: **part-time** and thus **earning half** as much as before.”

Female, Luxembourg

Economic Burden

Decrease of income



The rare disease led to
an **income decrease**
for 69% of patients and carers

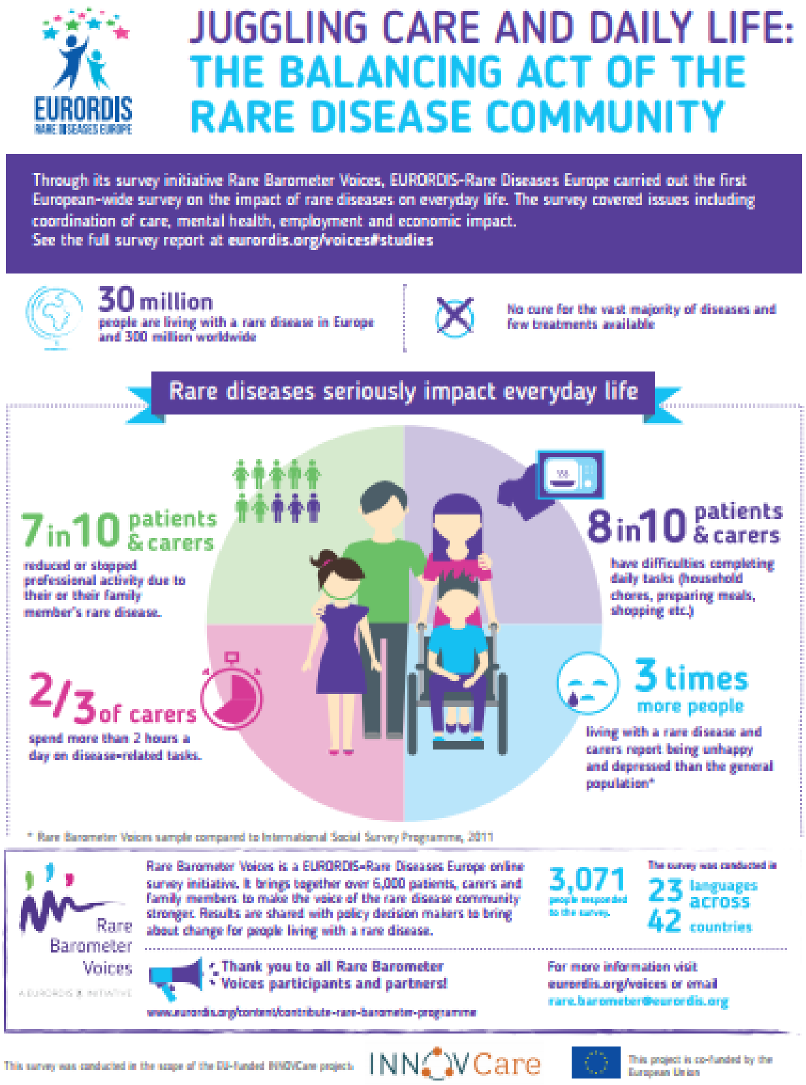
Deteriorated mental health

Rare disease patients & carers		General population*
37% *declared having often/very often felt depressed/unhappy*	**>3x**	***11%***
34% *declared having often/very often felt they could not overcome their problems*	**>4x**	***8%***

** International Social Survey Programme. Health module, International Social Survey Programme, 2011*

“ (…) **I don't look ill but am very ill** with a condition which no one understands or has heard of, **so get no sympathy**. There's no cure or any hope of improvement,
it's depressing and I feel alone. (…)”

Female, United Kingdom



JUGGLING CARE AND DAILY LIFE: THE BALANCING ACT OF THE RARE DISEASE COMMUNITY

Through its survey initiative Rare Barometer Voices, EURORDIS-Rare Diseases Europe carried out the first European-wide survey on the impact of rare diseases on everyday life. The survey covered issues including coordination of care, mental health, employment and economic impact.
See the full survey report at eurordis.org/voices#studies

30 million people are living with a rare disease in Europe and 300 million worldwide

No cure for the vast majority of diseases and few treatments available

Rare diseases seriously impact everyday life

7 in 10 patients & carers reduced or stopped professional activity due to their or their family member's rare disease.

8 in 10 patients & carers have difficulties completing daily tasks (household chores, preparing meals, shopping etc.)

2/3 of carers spend more than 2 hours a day on disease-related tasks.

3 times more people living with a rare disease and carers report being unhappy and depressed than the general population*

* Rare Barometer Voices sample compared to International Social Survey Programme, 2011

Rare Barometer Voices
A EURORDIS ✱ INITIATIVE

Rare Barometer Voices is a EURORDIS-Rare Diseases Europe online survey initiative. It brings together over 6,000 patients, carers and family members to make the voice of the rare disease community stronger. Results are shared with policy decision makers to bring about change for people living with a rare disease.

3,071 people responded to the survey.

The survey was conducted in **23** languages across **42** countries

Thank you to all Rare Barometer Voices participants and partners!

www.eurordis.org/content/contribute-rare-barometer-programme

For more information visit eurordis.org/voices or email rare.barometer@eurordis.org

This survey was conducted in the scope of the EU-funded INNOVCare project.

INNOVCare

This project is co-funded by the European Union

[Download the infographics here]

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

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

10 recommendations

Unanimously adopted by representatives of all EU Member States (April 2016)

Commission Expert Group Recommendations to Support Integration of RD into Social Policy

1. The **incorporation of RD specificities into mainstream social services and policies** is a **necessary** element to be considered in future **National Plans** and Strategies (NP/NS) for RD and should be incorporated when existing NP/NS are evaluated and revised

Commission Expert Group Recommendations to Support Integration of RD into Social Policy

2. Centres of Expertise have a key role in facilitating integrated care provision in line with the EUCERD recommendations on Quality Criteria for Centres of Expertise on Rare Diseases:

- Centres of Expertise (CEs) bring together, or coordinate, within the specialised healthcare sector multidisciplinary competences/skills, including paramedical skills and social services;

- CEs provide education and training to (…) non-healthcare professionals (such as school teachers, personal/homecare facilitators);

- CEs contribute to and provide accessible information adapted to the specific needs of patients and their families, of health and social professionals.

Commission Expert Group Recommendations to Support Integration of RD into Social Policy

3. European Reference Networks for RD have a key role in facilitating integrated care provision in line with the EUCERD recommendations on European Reference Networks for Rare Diseases (10)23 and the Directive on patients' rights in cross-border healthcare:

- Rare Disease European Reference Networks (RD ERNs) need to collaborate with each other, as well as with patient groups, health and social care providers;
- RD ERNs follow a multi-disciplinary approach;
- RD ERNs could function as a platform to share experiences and promote cooperation between MS, to develop precise descriptions of the services required and elaborate common guidelines.

Commission Expert Group Recommendations to Support Integration of RD into Social Policy

4. **Member States (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

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



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 Overview

Call for proposals from EC DGEMP (2014) - "Social policy innovation"

- Focus on one stop shop services & case handlers

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

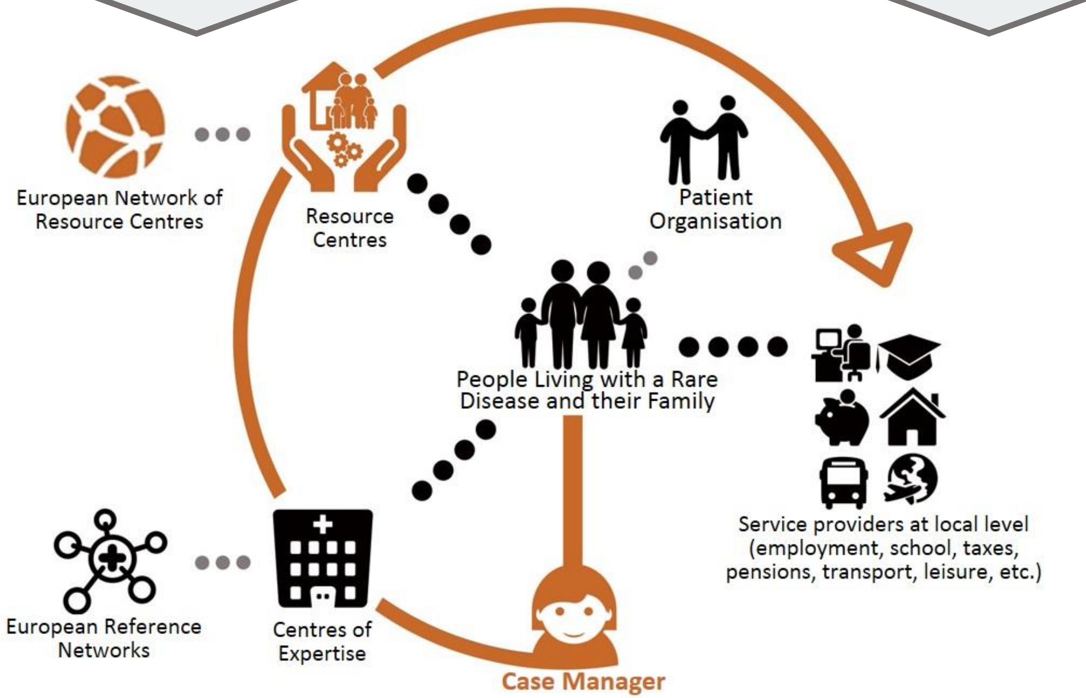
Co-Applicants

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

Project Concept

Patients' & families' needs

Care pathways in MS



Social Impact

Economic Impact & cost-benefit

Roadmaps to up-scale model

Good practices

Key contacts for advocacy

Pilot implementation

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

Project Objectives

- **Assessment of social needs of people living with a RD in Europe**
- **Proposal of an innovative care pathway – case management:**
  - Implementation of a pilot in Romania
  - Evaluation of the socio-economic impact of the care model
  - Analysis of opportunities to upscale the model to other MS/diseases
- **Creation of the European Network of Resource Centres** & exchange of good practices between social services for rare diseases via workshops
- **Strengthening partnerships between stakeholders**: creation of an Advisory Group with competent authorities & involvement of stakeholders in project workshops

✓**Link to Commission Expert Group on Rare Diseases**

✓**Link to RD-Action project (2015-2018), policy work package**

INNOVCare pilot – NoRo Resource Centre

- Zalau, County of Salaj, Romania
- **One-stop-shop style of service**
- Recognised as social and healthcare provider *(Centre of Expertise for rare diseases)*
- **Providing services to patients** at local, county and national level
- Run by a patient organisation

INNOVCare pilot - Summary

Regional case managers hired by NoRo resource centre Romania:

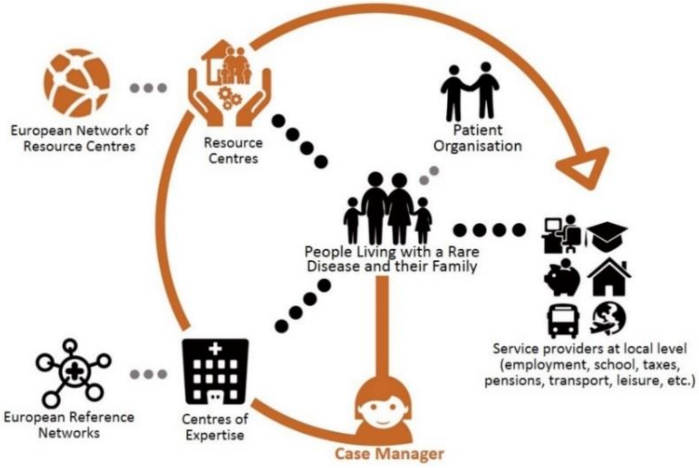
- ✓ **To bridge the gaps in coordination between health, social and local services**
- ✓ **To reduce care burden for patients and families**

Time frame:

- 18 months, 03/2017 - 08/2018
- 9 months for each patient/family

Target population:

- Patients and families: rare diseases & complex conditions
- 118 cases



Geographical scope: region of Salaj, Romania

Resources and service provision:

- Number of case managers employed: 4
- Nr. of simultaneous "cases" per case manager: 30
- **Profile of case managers**: 2 social workers, 1 lawyer and 1 special education teacher
- Service focused on key areas to have 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 – Outline of training for case managers

1. Introduction
- Project presentation
- Vision, definition of case management
- Skills, qualification and abilities for case managers
- Case studies – other national experiences

2. Rare diseases - general information
- Testimonials from patient and families
- Access to diagnosis/diagnosis tools
- Assessment of the degree of disability
- Access to education
- Employment
- Social inclusion

3. Case management and communication
- Communication
- Efficient communication: personal and virtual communication
- Developing communication skills
- Conflict solving & Networking

4. Resilience
- General information on family resilience
- Empowering patients and families
- Announcement of diagnosis and impact on family
- Personal development and self-esteem

5. Development and coordination
- Description, definition and possibilities
- Legislation - rights and obligations, health and social welfare and insurance system
- Finding the right information and accessible
- Available Services
- Organising trainings for professionals

6. Work methodology
- Methodology of case management for people with rare diseases and their families
- Ethics and data protection
- Tools used in case management for rare diseases
- Supervision of case managers

7. Fundraising

Skills for Case Manager:
- Positive approach
- Effective communication and negotiation skills
- Ability to perform ongoing evaluation
- Critical thinking and analysis
- Ability to plan and organise
- Ability to promote client autonomy and self-determination

RareResourceNet

> ***Advancing holistic high quality care and services for people living with rare diseases across Europe***

> ***Resource centres: a one stop shop style service designed for people living with a rare disease and their carers***

- **Complementary to health care and social services**
- **Holistic care and support**

https://innovcare.eu/social-services/rareresourcenet/

The gathering of services in this network is possible following the mapping of specialised social services for rare diseases performed within the European Joint Action for Rare Diseases (EURCERD Joint-Action, 2012-2015). RareResourceNet subscribes the European Commission Expert Group Recommendations to Support the Integration of Rare Diseases into Social Services and Policies (2016) & 2030 Agenda for Sustainable Development adopted by the United Nations (2015)

Project Events

Date	Place	Event
8-9 Sept 2016	Gothenburg	Workshop on Improving Integrated Care for People Living with Rare Diseases and Complex Conditions
6-7 Oct 2016	Vienna	Workshop on Scaling Innovative Care Delivery for Rare Diseases & Complex Conditions
1-2 June	Cluj-Napoca	Workshop on Advancing Holistic & Innovative Care for Rare Diseases & Complex Conditions
12-13 April 2018	**Oslo**	**Workshop on Creating a Sustainable Environment for Holistic & Innovative Care for Rare Diseases & Complex Conditions**
Sept 2018	**Brussels**	**Final conference**

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

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