

Overcoming unmet social and daily life needs of people living with a rare disease

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EURORDIS – Rare Diseases Europe



EURORDIS - Rare Diseases Europe

The voice of people living with a rare disease in Europe

✓ 724 rare disease patient **organisations**

✓ **64 countries**

✓ Covering over **4000 rare diseases**

✓ **30 million people in Europe**



ADVOCACY

INFORMATION & NETWORKING

CAPACITY BUILDING OF PATIENT ADVOCATES

HEALTH & SOCIAL POLICY , HEALTHCARE & SOCIAL SERVICES

RESEARCH, DRUGS & THERAPIES

<http://www.eurordis.org/content/become-member>



RARE
DISEASES
INTERNATIONAL
A EURORDIS INITIATIVE

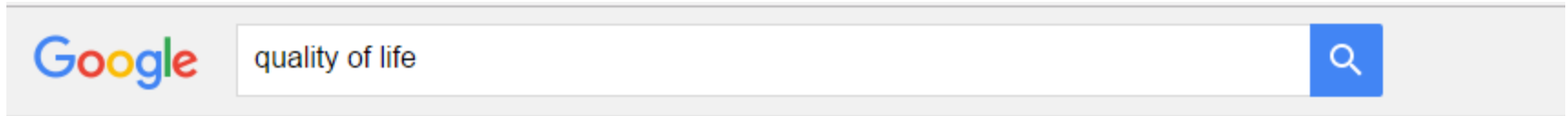


NGO COMMITTEE FOR
RARE DISEASES

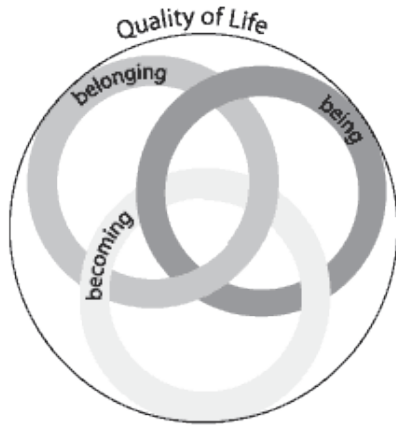


26-28 May 2016 Edinburgh
European Conference on Rare Diseases & Orphan Products

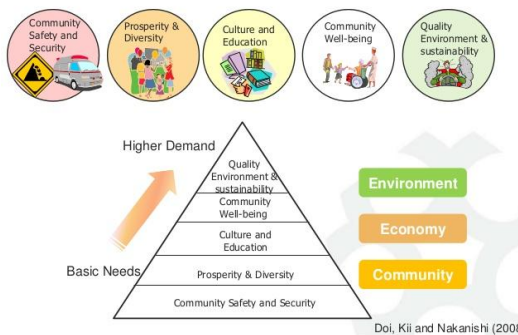
Quality of life...



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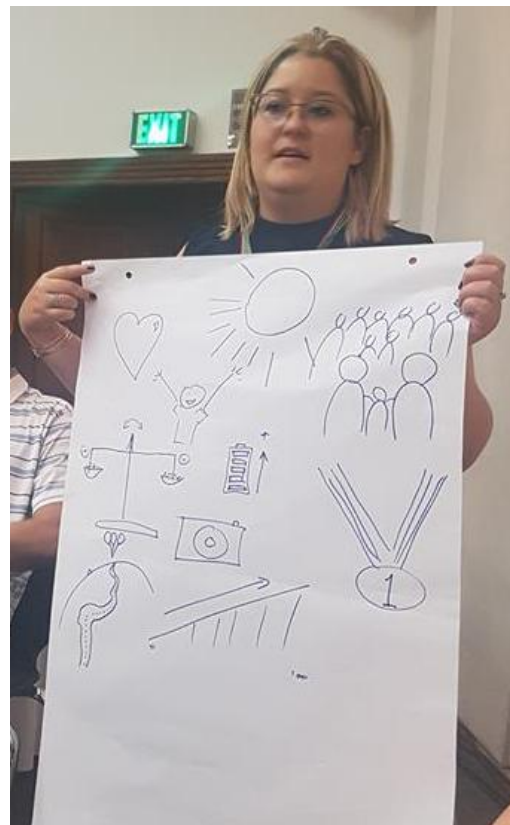
Five dimensions of Quality of Life



Quality of life...

19-22 October 2016
Cape Town, South Africa

RARE 



Rare Diseases' challenges

- Rare, highly complex, chronic, severely disabling
- Scarcity of information on diseases & consequences on daily life
- Scarcity and scattering of experts and resources
- Research is fragemented
- Lack of good practices
- **Lack of treatment** (4000+ without treatment; treatments are expensive)
- **A high % of people with a RD is affected by motor or intellectual impairments**
- They influence the person's health and daily life in a disabling way
- People living with a rare disease struggle to connect to peers and experts

Complexity is not always visible



EURORDIS Photo Contest, 2014

Impact of Rare Diseases on Daily Life

Survey conducted by EURORDIS via the [INNOVCare project](#)
& [Rare Barometer Survey Programme](#)

Time frame:

- Data collection ongoing
- Results available in January 2017

INNOVCare

Rare Barometer Voices
A EURORDIS INITIATIVE

Methodology for elaboration of questionnaire:

- Focus group within EURORDIS [Council of National Alliances](#)
- Consultation of the EURORDIS Social Policy Action Group ([SPAG](#))
- National PO directly involved in survey design
- Questions based on existing literature
- Public and private research involvement



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Respondents' profile



People with rare diseases, diagnosed/undiagnosed



Patients, families (siblings, parents, spouse...)



More than 18 years old



Only one person per household can answer



Across diseases and across European countries (48)

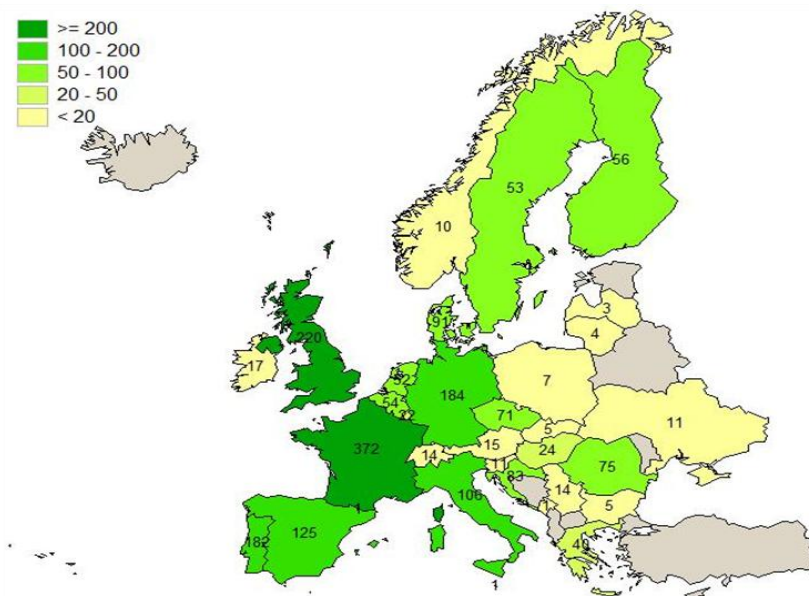
The goal is to reach a sufficient number of people in all European countries and ideally 3000 respondents to the questionnaire

Impact of Rare Diseases on Daily Life

Survey conducted by EURORDIS via the [INNOVCare project](#) & [Rare Barometer Survey Programme](#)

Preliminary Results

- 1840 valid questionnaires
- Across Europe and rare diseases
- 35 countries represented so far
- 63% patients, 36% parents, 7% other family members

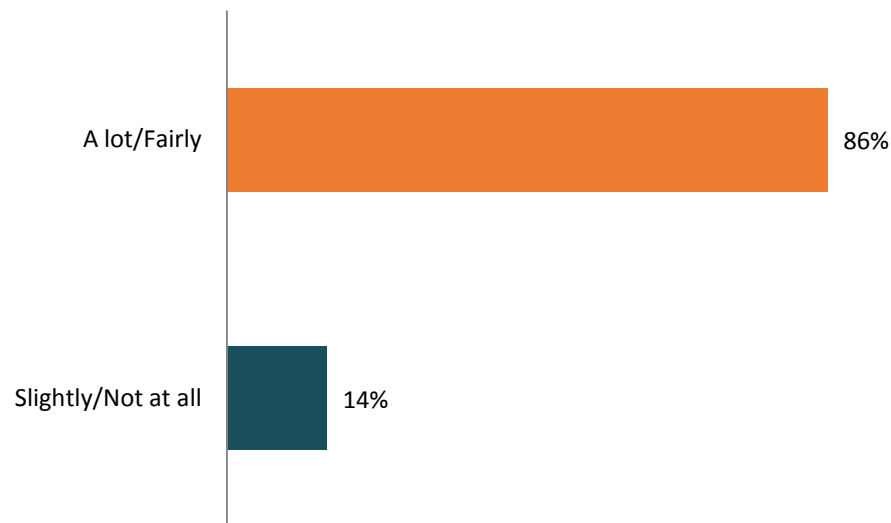


Impact of Rare Diseases on Daily Life

Survey conducted by EURORDIS via the [INNOVCare project](#) & [Rare Barometer Survey Programme](#)

Preliminary Results

How the rare diseases impacts health and everyday life of the patient



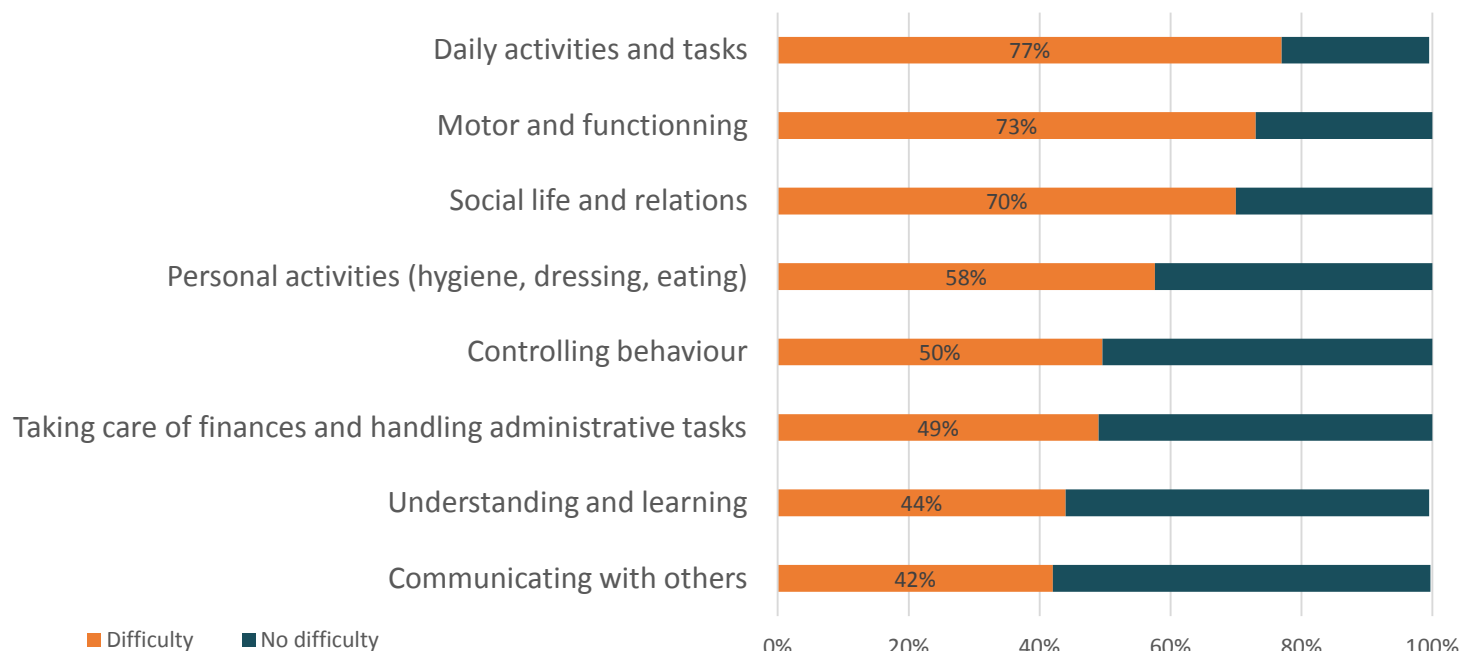
Preliminary results of ongoing study conducted by EURORDIS, via [Rare Barometer Voices](#), in 48 European Countries (35 represented so far). 1840 valid questionnaires across Europe and diseases - 63% patients, 36% parents, 7% other family members.

Impact of Rare Diseases on Daily Life

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Preliminary Results

To what extent do the patients have difficulties with:



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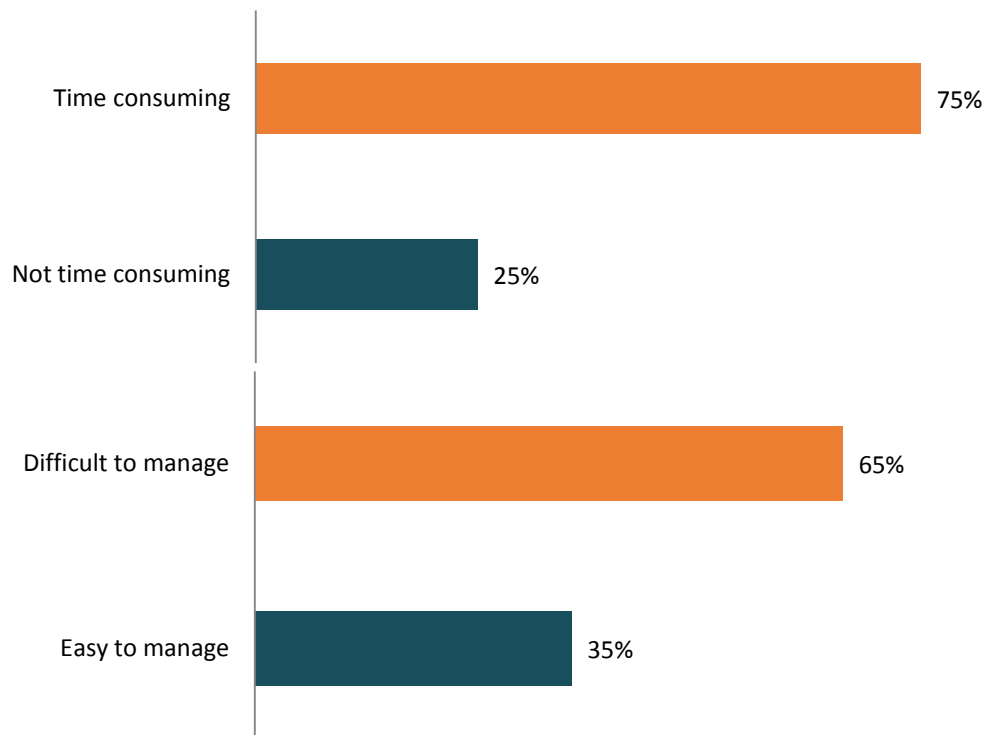
Impact of Rare Diseases on Daily Life

Survey conducted by EURORDIS via the [INNOVCare project](#) & [Rare Barometer Survey Programme](#)

Preliminary Results

Time spent organising care

Including finding information on disease, rights and administrative procedures, finding professionals, scheduling and attending appointments in health, social, local services, travel to appointments



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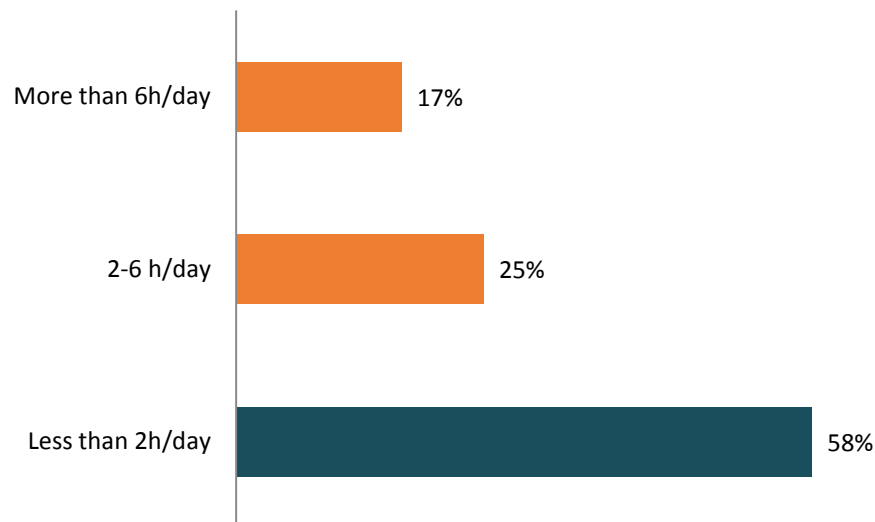
Impact of Rare Diseases on Daily Life

Survey conducted by EURORDIS via the [INNOVCare project](#) & [Rare Barometer Survey Programme](#)

Preliminary Results

Time invested on average/day for illness related tasks

Including hygiene, house chores, moving, administrative procedures



✓ **42% of patients/families invest over 2h/day**

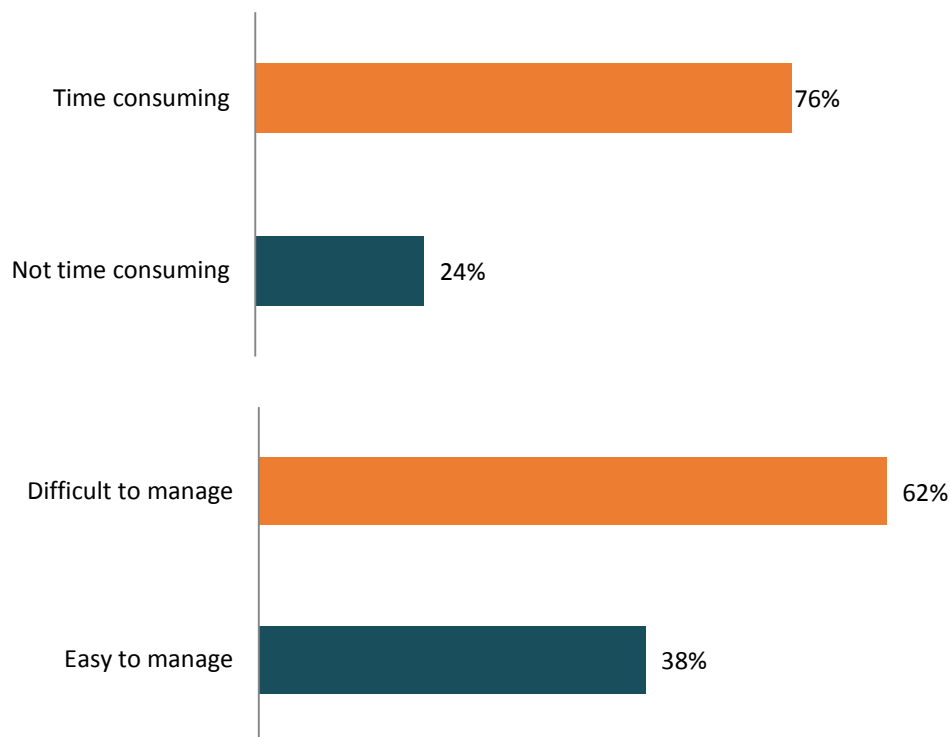
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Preliminary Results

Time spent explaining the disease to different services/experts



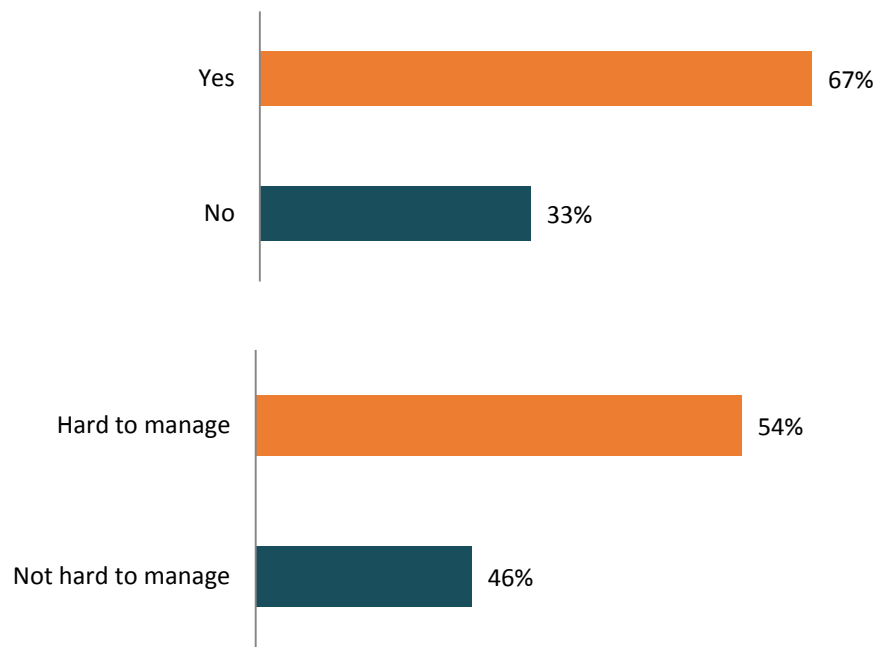
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Preliminary Results

Visiting different health, social and local support services and specialists in a short period of time



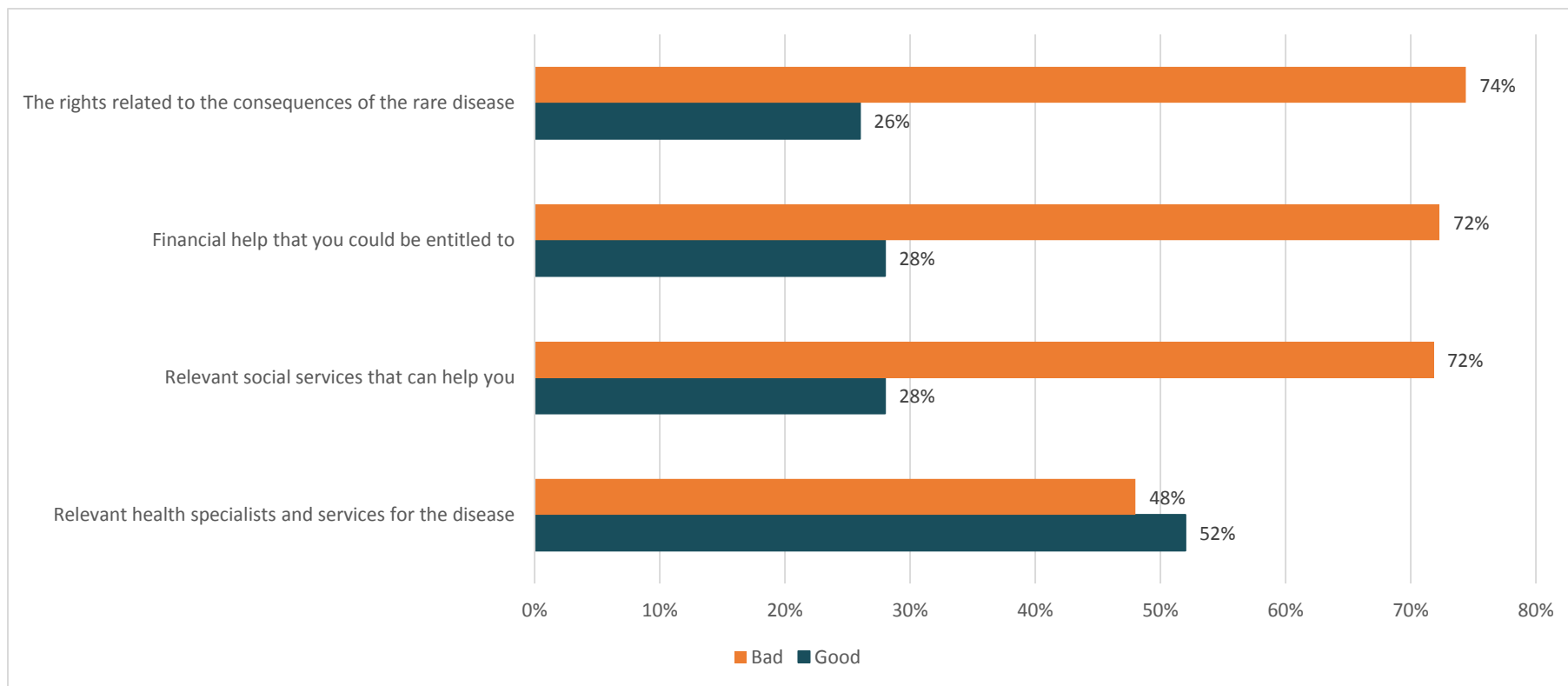
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Preliminary Results

Level of information of patients



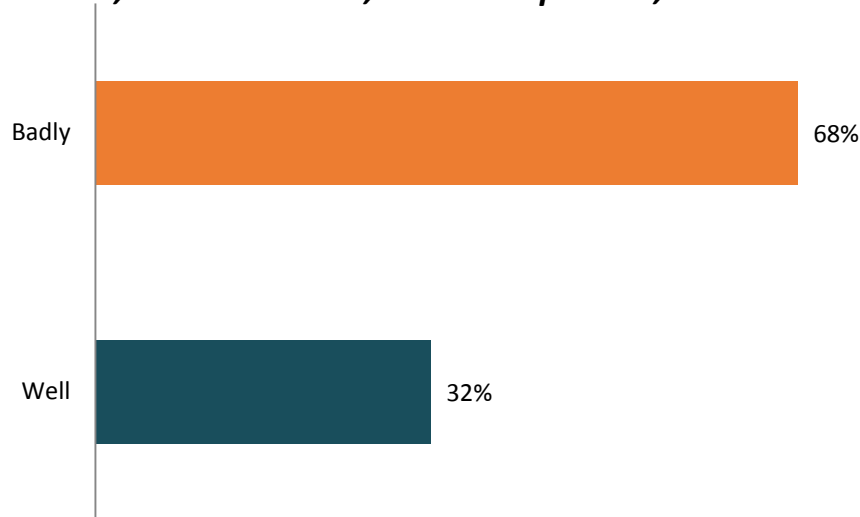
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Preliminary Results

**How patients feel that different service providers
communicate/exchange**
about the rare disease, the treatments, the consequences, and other relevant information



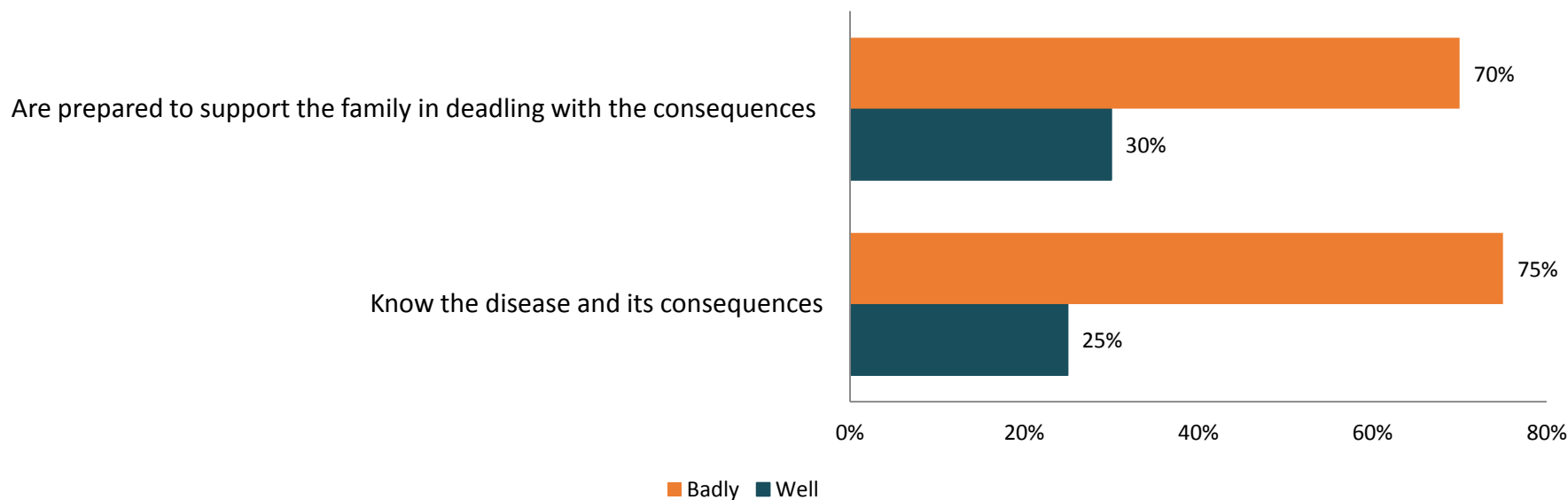
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Preliminary Results

Patients think that professionals who support them in social, local and support services...

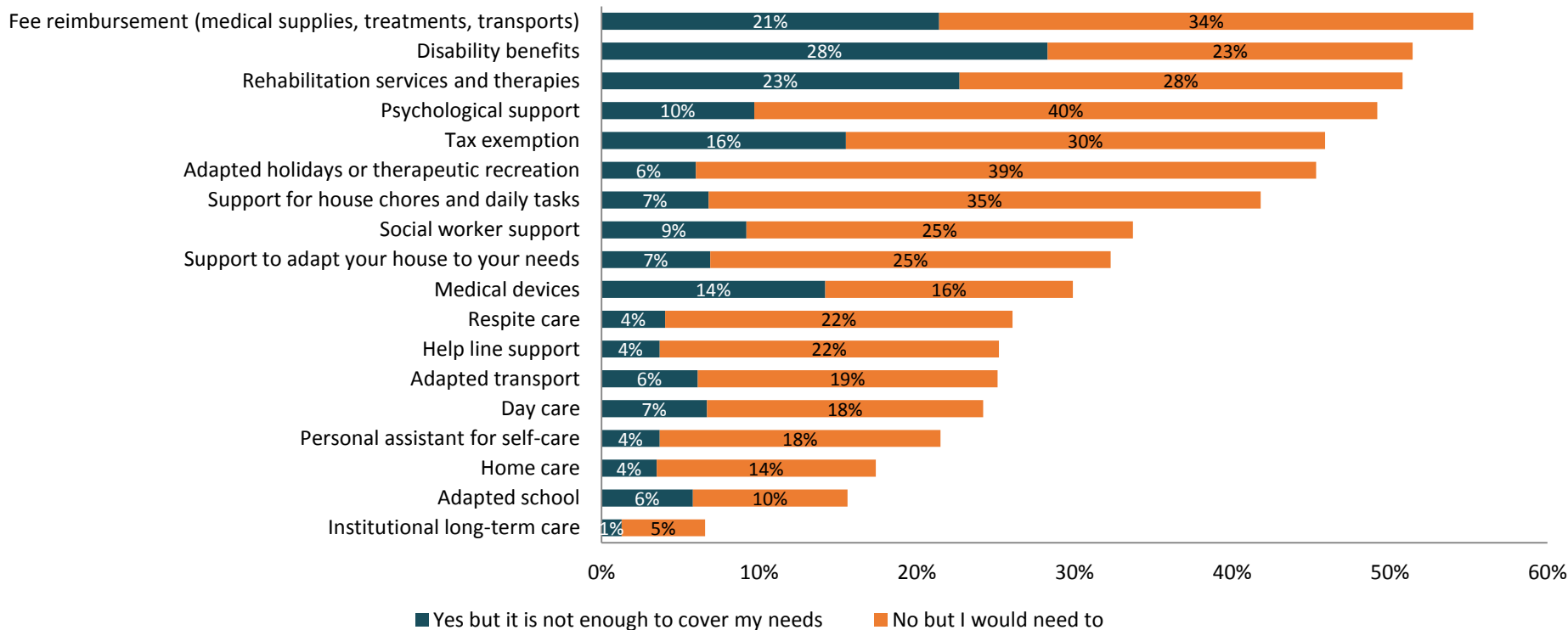


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Preliminary Results



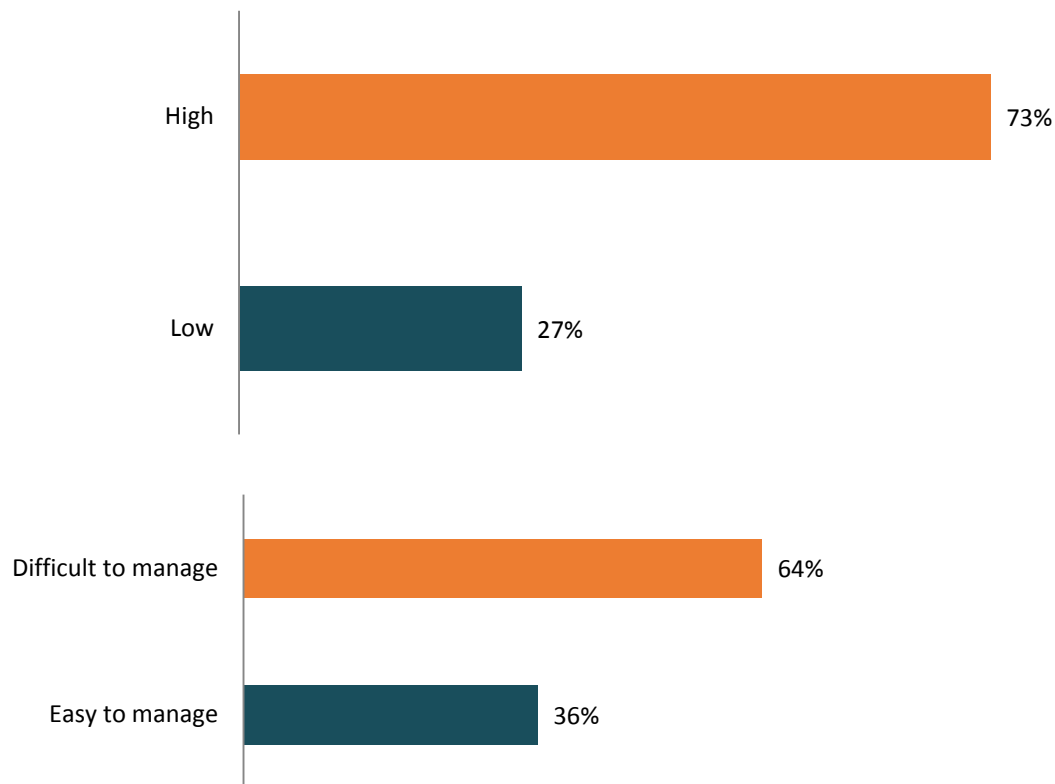
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Preliminary Results

Costs associated to the rare disease



Preliminary results of ongoing study conducted by EURORDIS, via [Rare Barometer Voices](#), in 48 European Countries (35 represented so far). 1840 valid questionnaires across Europe and diseases - 63% patients, 36% parents, 7% other family members.



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

Care Pathways in European Countries

Study conducted by EURORDIS via the [INNOVCare project](#)

- ✓ 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 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).

Quality of life...?

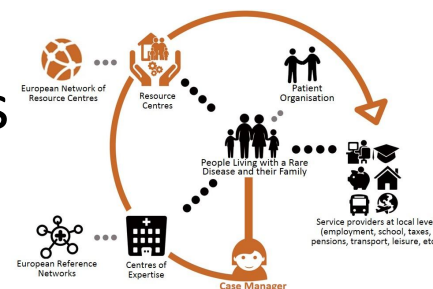


Overcoming the unmet social and daily life needs of people living with a rare disease

Holistic and integrated care provision to people living with a rare disease

Recent activities at European level

1. Understanding the needs of people living with a rare disease and raising awareness
2. Promoting the integration of rare diseases into social services and policies: specialised services & mainstream services
3. Promoting integrated care for rare diseases



Understanding the needs & raising awareness

- Studies and surveys to patients and families
- Testimonials
- Using real stories to show complexity is not always visible



Useful resources:

- Background Document: [Rare Diseases: Addressing the Need for Specialised Social Services and Integration into Social Policies](#) (Nov. 2012)
- Ongoing INNOVCare study – to be published [here](#) (Jan 2017)

«When you have a rare disease it feels like you are so alone and no one cares»

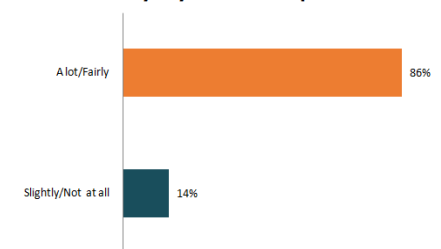
Janet, mid 50's, living with Alkaptonuria, USA



«My wife, Svitlana, Yuliya's mother is a wonderful woman! Her work deserves other publication – "how mothers fight with a Rare Disease at home". There is no professional help at home – for our category, a staff is not stipulated, there are no volunteers»

Vitaly Matyushenko, father of Yuliya, 5 years old, living with Spinal Muscular Atrophy, Ukraine

How the rare diseases impacts health and everyday life of the patient



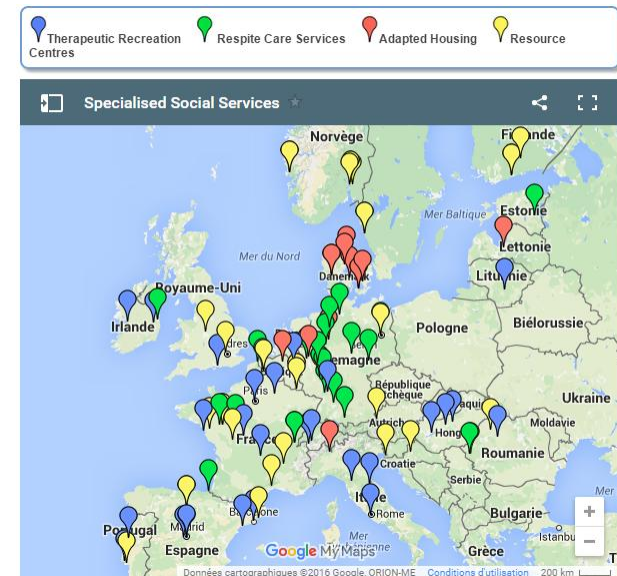
Promoting integration into specialised social services

- Mapping and showcasing existing services
- Factsheets presenting type of services and importance
- Good practices for specialised social services
- Promoting the integration of social issues in national policies for RD - inclusion of issue in content outline for national conferences



Useful resources:

- [Map of Specialised Social Services in Europe](#)
- ['Guiding Principles for Specialised Social Services'](#) (2013)



Promoting integration into specialised social services

Useful resources:



Therapeutic Recreation Programmes

- Definition: [fact sheet](#)
- Inspiration:
 - [Case Studies](#)
 - [List of services in Europe](#)
- Impact: [Testimonials](#)

Respite Care Programmes

- Definition: [fact sheet](#)
- Inspiration:
 - [Case Studies](#)
 - [List of services in Europe](#)
- Impact: [Testimonials](#)

Adapted Housing

- Definition: [fact sheet](#)
- Inspiration:
 - [Case Studies](#)
 - [List of services in Europe](#)
- Impact: [Testimonials](#)

Resource Centres

- Definition: [fact sheet](#)
- Inspiration:
 - [Case Studies](#)
 - [List of services in Europe](#)
- Impact: [Testimonials](#)

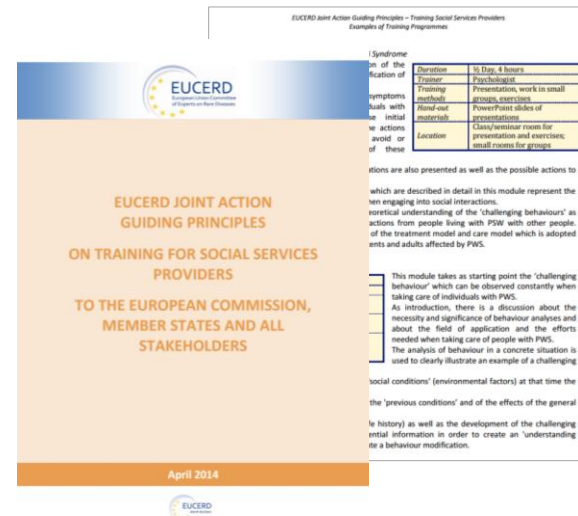


Promoting integration into mainstream services

- Guiding principles for training of social services providers
- EURORDIS partners with European Federation of Social Workers Europe
- **European recommendations to support the integration of rare diseases into social services and policies**
- Promoting the inclusion of social and integrated care into national strategies for RD -> support to the organisation of national conferences

Useful resources:

- ['Guiding Principles on Training for Social Services Providers'](#) (2014)
- [Examples of training programmes for social providers](#) (2014)



Promoting integration into mainstream services



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

What is the European Commission Expert Group on Rare Diseases?

- Mission: coordinate actions & initiatives to develop health activities and actions to support policy on RD
- Members: Representatives of EU MS, patients, pharmaceutical industry, insurance, experts in the field and involved in European funded RD projects
- More information here: http://ec.europa.eu/health/rare_diseases/expert_group/index_en.htm

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

Moving forward from recommendations to implementation of holistic care for rare diseases

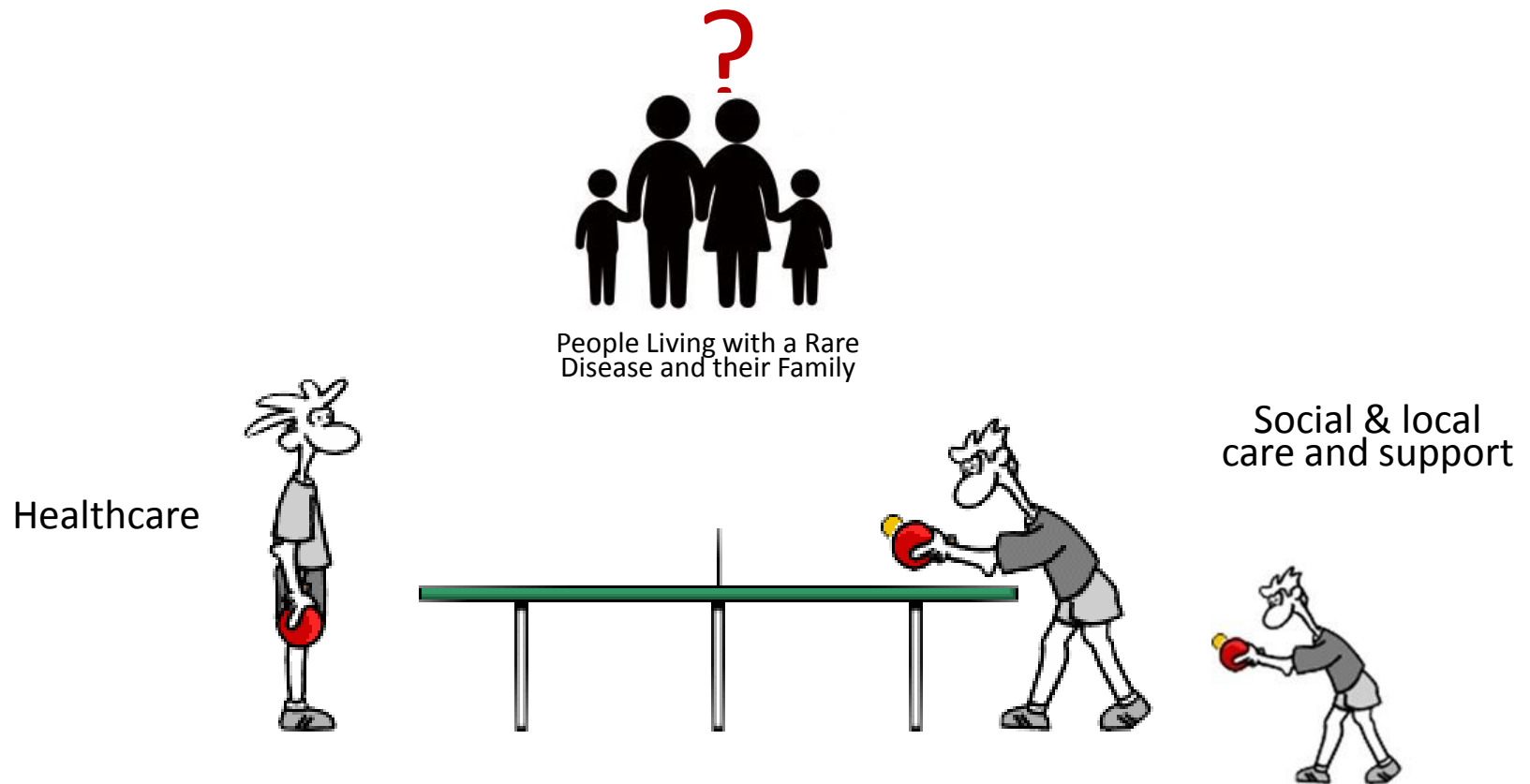
INNOV Care

2015-2018

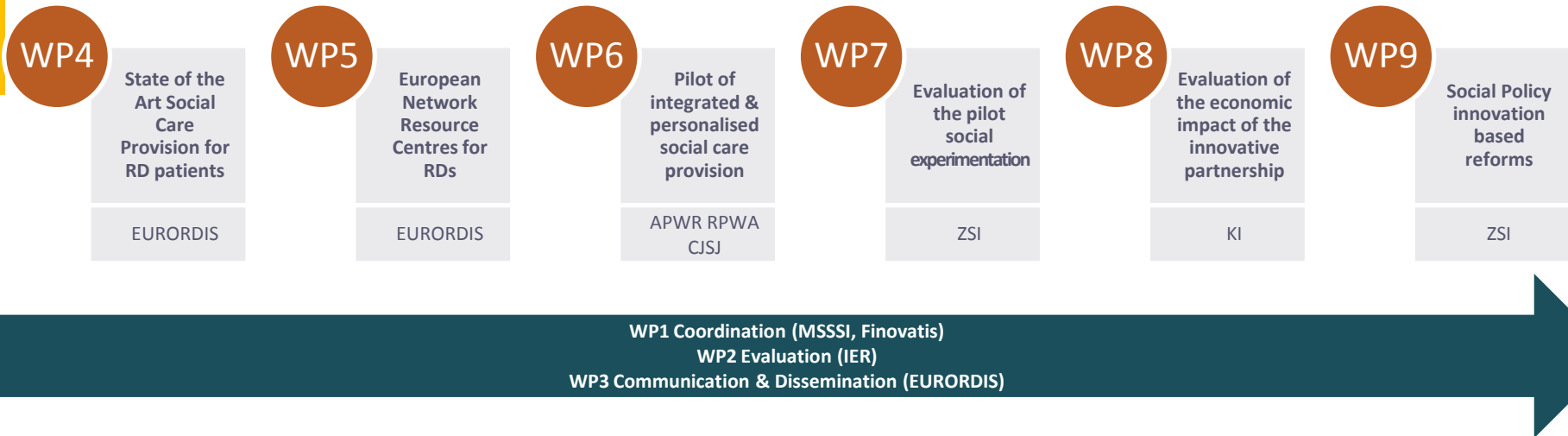
Bridging the gaps between **health**, **social** and **local services** to improve care of people living with rare and complex conditions



The dilemma



Project Structure



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

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

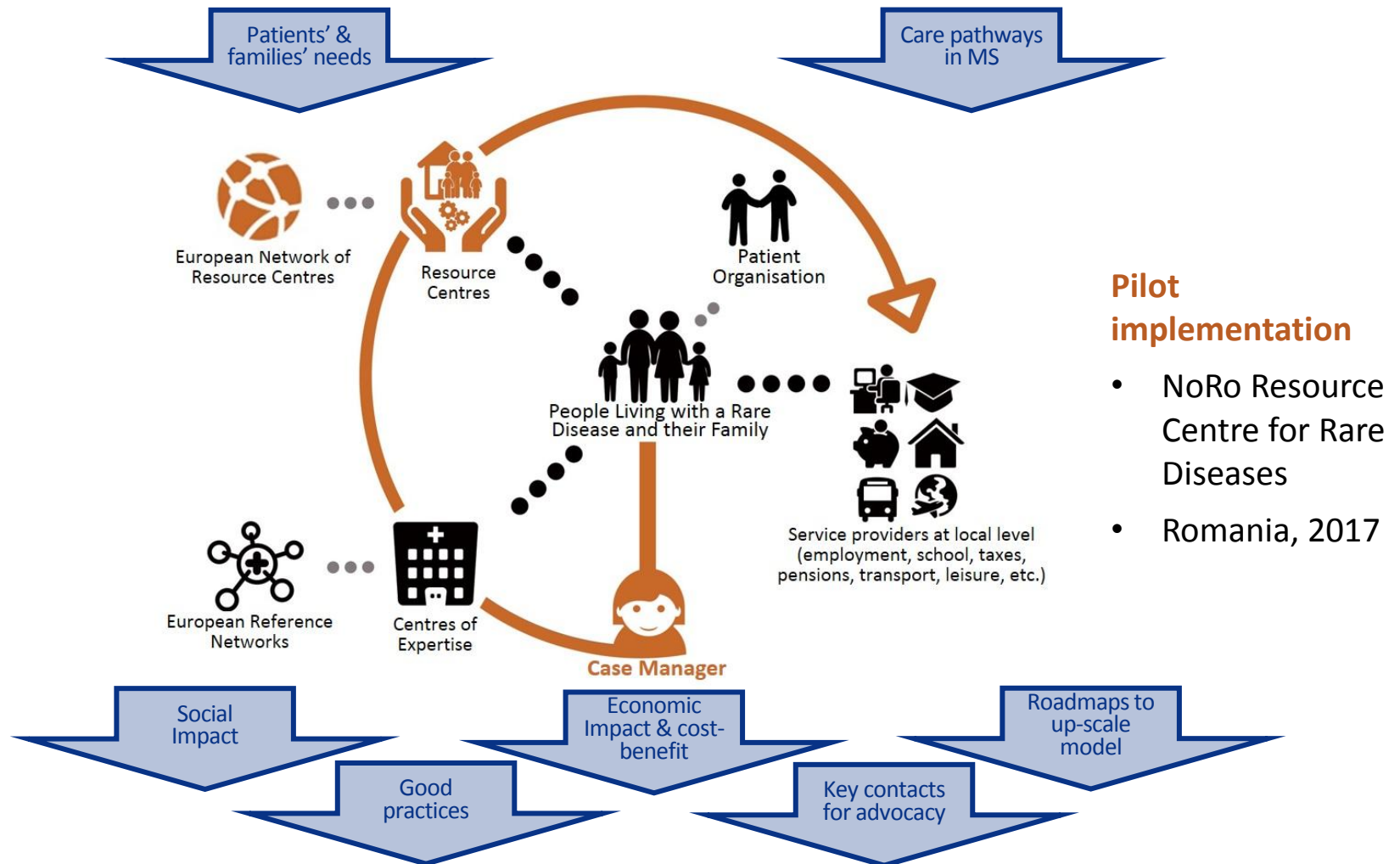
APWR RPWA Asociatia Prader Willi din Romania (NoRo) – Romania – Dorica Dan

CJSJ Regional County Sălaj – Romania - Monica Avram

ZSI Zentrum für Soziale Innovation – Austria - Anette Scoppetta

KI Karolinska Institutet – Sweden - Peter Lindgren

Project concept



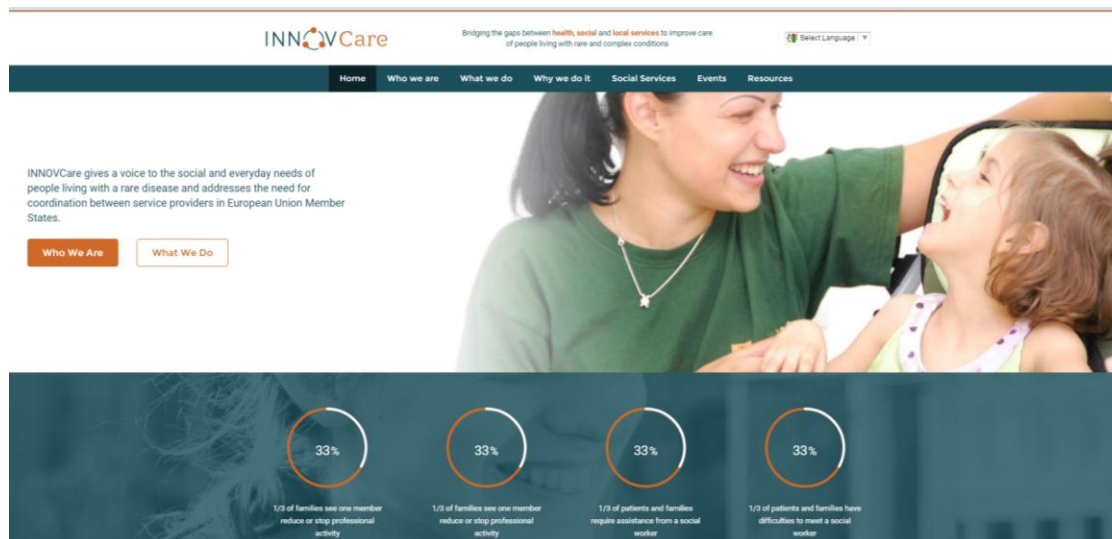
Some key features of the project

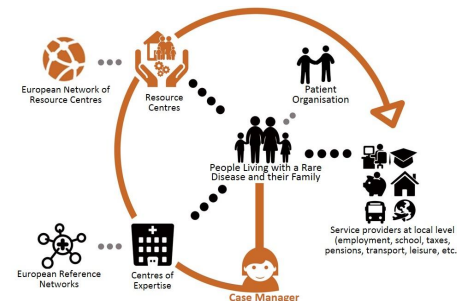
- Assessment social unmet needs of people with a RD and their family
- Analysis of existing social care models in MS
- Exchange of expertise/good practices
- Creation of a European Network of Resource Centres for Rare Diseases: learning from each other & influencing policy
- Proposal of a care model using case managers:
 - Collection of information on role of case manager
 - Pilot implementation & assessment of social and economic impact
 - Analysis of opportunities to transfer the model to other countries
- Project [Advisory Group](#): 20 representatives from competent authorities in 16 European countries -> engaging into workshops & discussions to advance integrated care for RD

Useful resources

- Workshop Improving Integrated Care for People Living with Rare Diseases and Complex Conditions – [Presentations & breakout sessions' outcomes](#)
- Workshop Scaling Innovative Care Delivery for Rare Diseases and Complex Conditions – [Presentations](#)
- [Fact sheet on Resource Centres for rare diseases](#)

Find out more at innovcare.eu





EU-funded projects that have supported these actions



Co-funded by
the Health Programme
of the European Union



This project is co-funded by
the European Union

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



Thank you

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