



# JUGGLING CARE AND DAILY LIFE: The Balancing Act of the Rare Disease Community

*Results of 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*



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*Illustrative photos. This presentation does not necessarily reflect the position of the people in these photos*

Source: [Specialised social services for rare diseases](#)

# 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 involved
- 802 diseases, 42 countries
- Performed in 23 languages



# Summary of key results

- Rare diseases have a serious impact on everyday life
- Significant time and care burden for patients & carers
- Impact on work-life: absence from work, stop or reduce professional activity, facing loss of income
- Patients and carers are badly informed about their rights
- Clear lack of communication between service providers
- Social services badly prepared to support people with a rare disease

[Report with analysis of key results and annex with full results](#)

# Survey methodology

# Rare Barometer Voices framework



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## Recruitment Rare Barometer Voices

- Rare Barometer Voices members
- Recruitment via social media, Google adds, patient organisations, helplines

## Ethics and security

- Approved by French data protection authority (CNIL)
- Explicit consent for being re-contacted
- Contact details replaced by automatically-generated key

## Translation

- Available in 23 most used languages in Europe
- MAPI: experts in medical translation & linguistic validation (*in-kind translation*)
- Checked by patient organisations (*volunteers*)

# Questionnaire design

- *Volunteer-based focus group (Oct 2015), 5 members of the [EURORDIS Council of National Alliances](#)*

## Questionnaire designed in collaboration with:

- **Partners of the INNOVCare project**
- **Academics and corporate partners** involved in the Rare Barometer Programme (*University of Rouen, Social Science and MAPI, Patient-Centered Research company*)
- **EURORDIS members** involved in the Rare Barometer programme (*Rare Disease Denmark & Spanish Federation for Rare Diseases - FEDER*)

# Timing and organisation: 2 stages

## 1st stage

- Impact, access to services, coordination of care & cost of disease
- 2 Aug 2016 - 28 Feb 2017

**3450 answers, including 3071 valid questionnaires**

## 2nd stage

- Employment, education, family life, social life & well-being
- 10 Nov 2016 – 28 Feb 2017

**2117 answers, including 1953 valid questionnaires**



# Survey sample

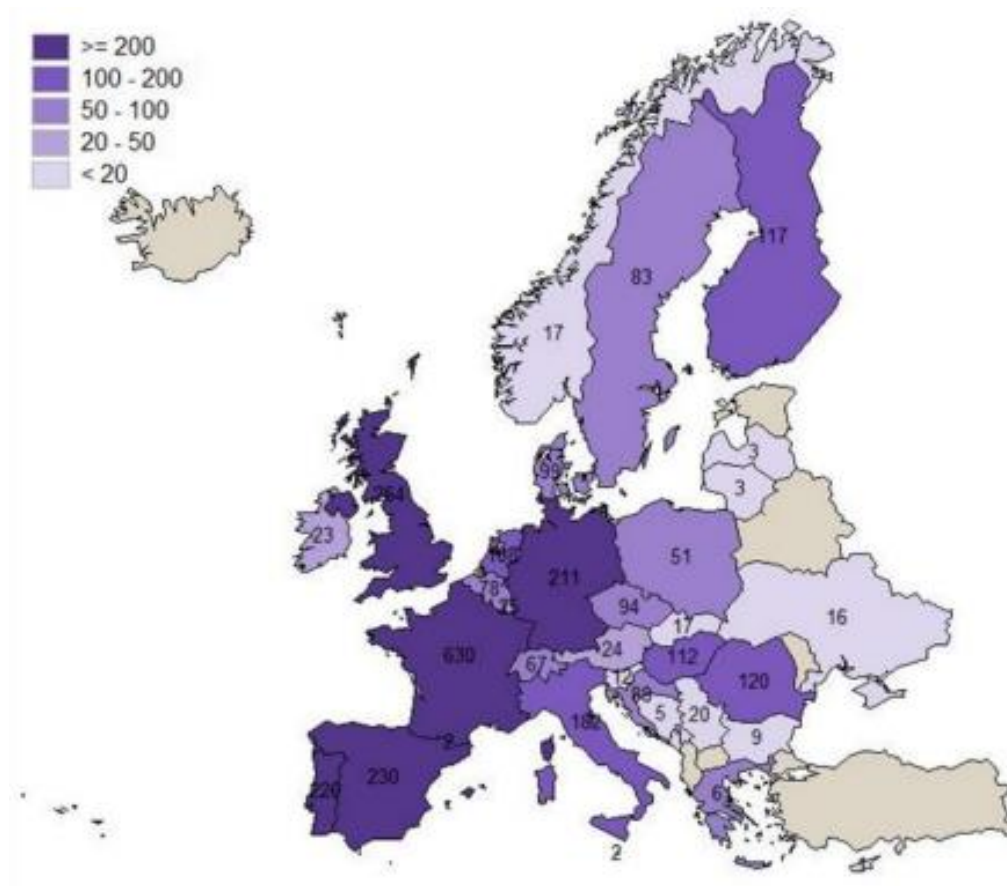
Type	Frequency
<b>Gender</b>	
Male.....	21%
Female.....	79%
Other .....	<0.5%
<b>Diagnosis Status</b>	
Diagnosed.....	92%
Undiagnosed.....	8%
<b>Respondent Status (<i>several answers possible</i>)</b>	
Patient.....	62%
Parent of a child living with a rare disease.....	37%
Grandparent of a person living with a rare disease.....	1%
Spouse of a person living with a rare disease.....	2%
Uncle/Aunt of a person living with a rare disease.....	1%
Sibling of a person living with a rare disease.....	4%
Other.....	3%

# Survey sample

Represents the diversity of the rare disease community:

✓ 802 diseases

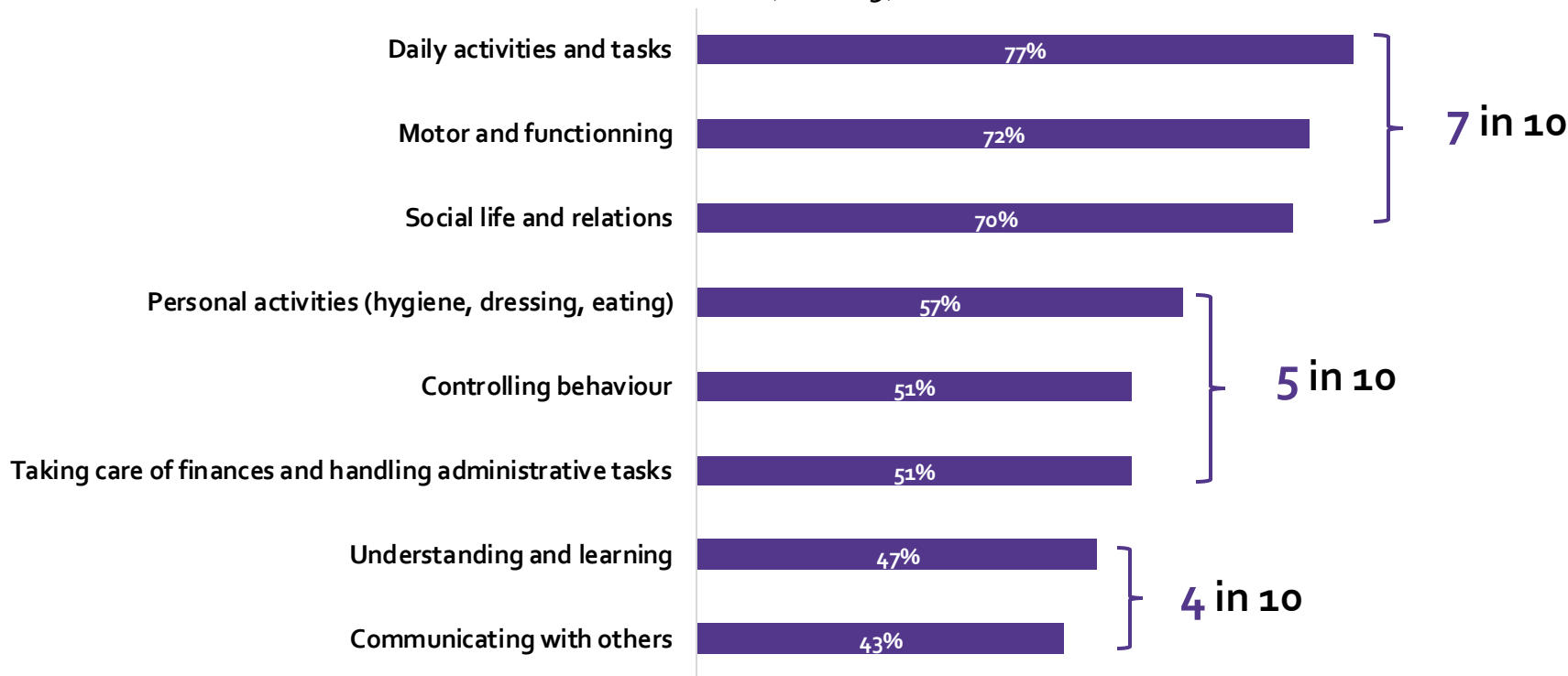
✓ 42 countries



# Survey results

# Serious impact on patients' everyday life

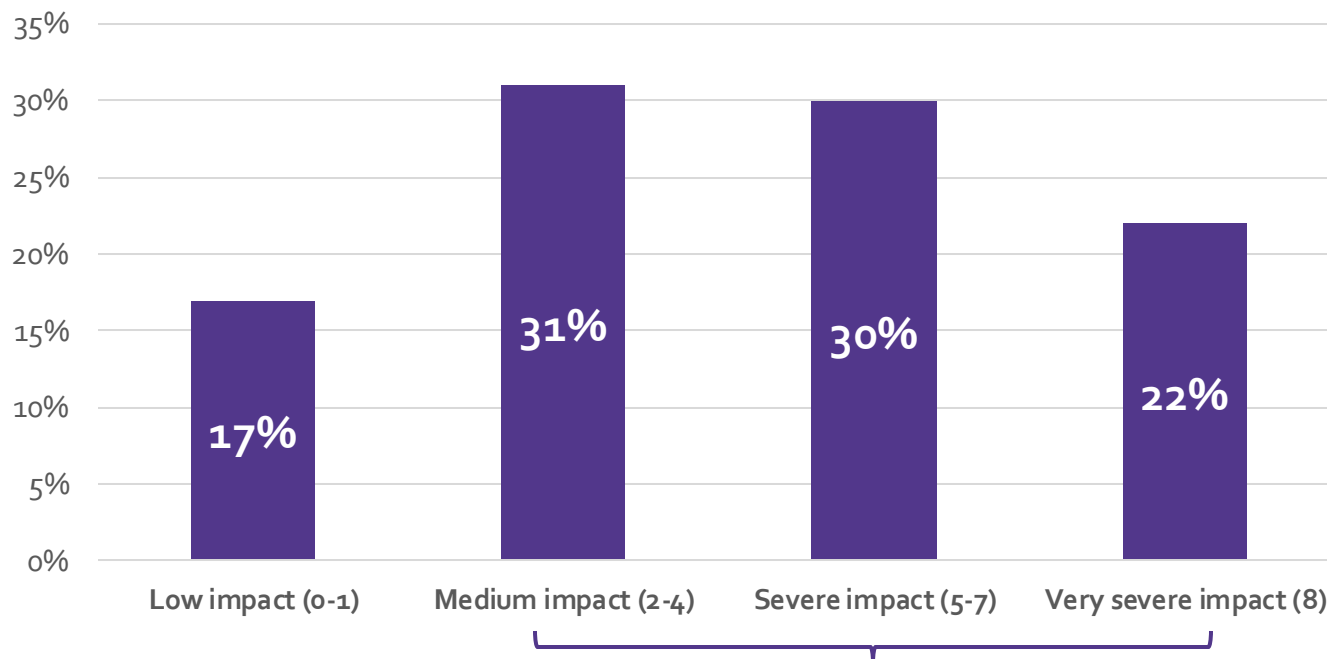
*To what extent does the person living with a rare disease have **difficulties** with...*  
(n=2689)



*Some modalities have been grouped; Difficulty=Completely unable + A lot of difficulty + Some difficulty*

# Serious impact on patients' everyday life

*To what extent does the person living with a rare disease have difficulties with...-> Number of difficulties expressed*  
(n=2689)



**8 in 10**

# 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*

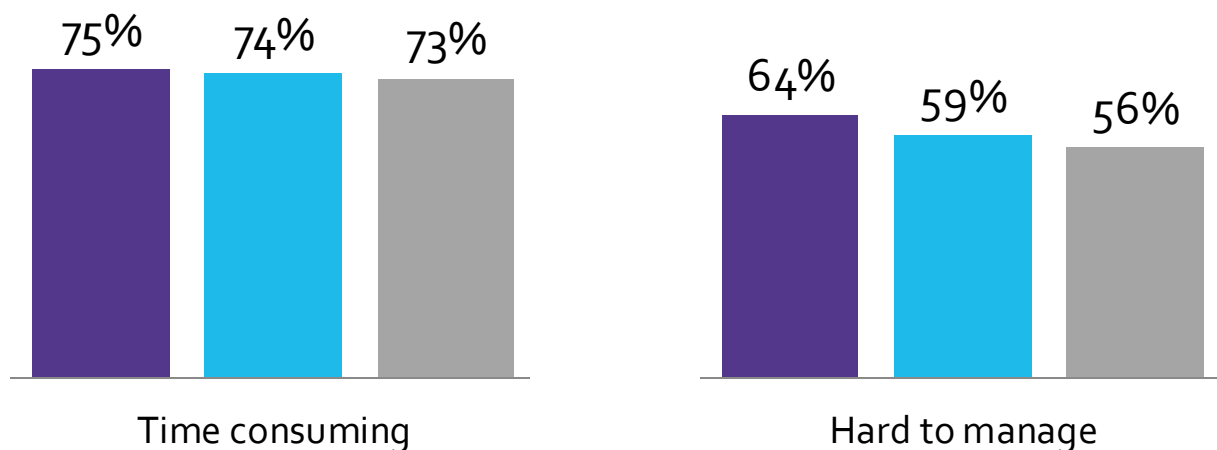
*Source: [EURORDIS Photo Contest](#)*

# Heavy time burden for patients & carers

*Spending more than 2h/day on health related tasks:*

- **3 in 10 patients** (29%)
- **6 in 10 carers** (62%)
  - 30% of carers spend over 6h/day

**Time spent organising care:**



- Finding information on the disease, rights, appointments & travelling for appointments
- Explaining the disease
- Health related administrative procedures

“ Everyone becomes self-involved in their own tasks and  
**forgets about the bigger picture**

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

There are therefore often **waiting times** (...) 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, Spain



# Social services professionals poorly prepared

**75%** of respondents consider that their **level of knowledge** on their disease and its consequences **is deficient**

**71%** consider they are **not sufficiently prepared** to support them

**Over 7 in 10**

# Lack of communication between service providers

**67%** of the respondents say that they communicate the disease-related information badly

**Almost 7 in 10**

**“We face an absence of communication and coordination between the health teams and, on a broader scale”**

**Female, Portugal**

**“Interprofessional communication works only through the good intentions and efforts of particular professional individuals, but not as a course of action”**

**Male, Czech Republic**

“ It took **two years to obtain social care support...departments don't talk to one another** so records weren't passed on (...) I was discharged without help...

This isn't the first time...

**It's a constant battle”**

**Female, United Kingdom**



*Illustrative photo. This presentation does not necessarily reflect the position of the person in this photo*

*Source: [EURORDIS Photo Contest](#)*

# Patients & carers badly informed about their rights

**74%** have poor knowledge **about their disease-related rights**

**73%** on the **financial help** they may be entitled to

**71%** on the relevant **social services** that can support them

**Over 7 in 10**

“ 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 work-life & income

**70%** of patients & carers had to **stop/reduce professional activity due to the disease**

**58%** absent from work over **15 days/year**

**41%** needed leave from work but could not obtain it

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

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

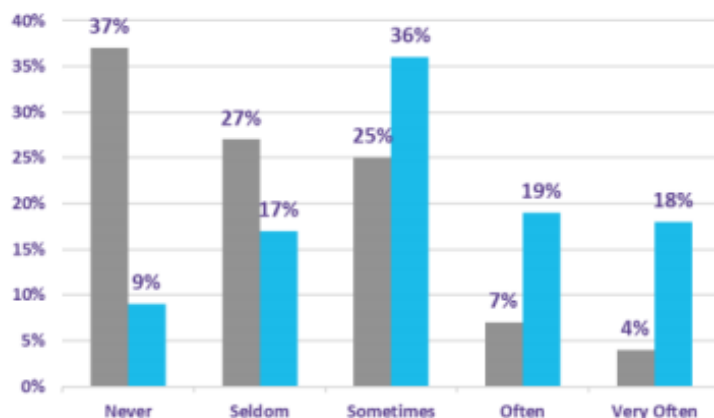
By asking a year **"non paid break"** (...) I received a **refusal from the employer.** So I decided to **give up my job** and stayed **unemployed for 4 years.**

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

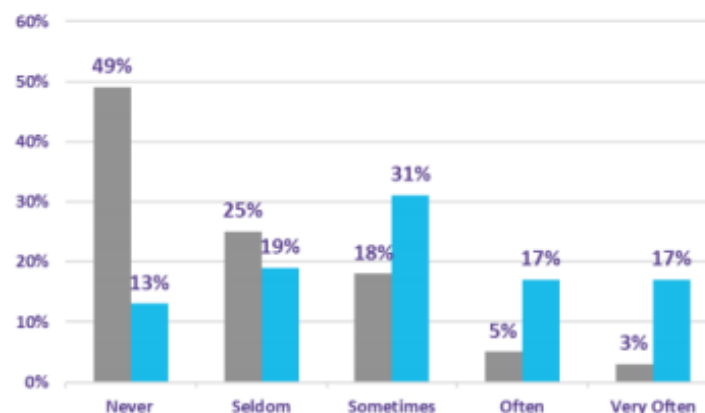
*Female, Luxembourg*

# Deteriorated mental health compared to general population

*In the past 4 weeks, how often have you felt unhappy and/or depressed?*



*In the past 4 weeks, how often have you felt you could not overcome your problems?*



■ ISSP 2011 \*

■ INNOVCare 2016

Rare disease patients and carers:

- 3 times more likely to often feel unhappy and/or depressed
- 4 times more likely to often feel they could not overcome their problems

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



# Where to find the results?

- PowerPoint presentation of key results: [http://innovcare.eu/wp-content/uploads/2017/07/European-Survey-Results\\_Juggling-Care-and-Daily-Life\\_Rare-Diseases.pdf](http://innovcare.eu/wp-content/uploads/2017/07/European-Survey-Results_Juggling-Care-and-Daily-Life_Rare-Diseases.pdf)
- Report with analysis of key results & annex with full results (in English): [http://download.eurordis.org.s3.amazonaws.com/rbv/2017\\_05\\_09\\_Social%20survey%20leaflet%20final.pdf](http://download.eurordis.org.s3.amazonaws.com/rbv/2017_05_09_Social%20survey%20leaflet%20final.pdf)
- Reports in different languages: <http://www.eurordis.org/voices/> (*choose your language via menu at the header of the page -> scroll down to "previous studies" section*)
- EURORDIS press release: [http://download.eurordis.org.s3.amazonaws.com/rbv/PR\\_INNOVCare\\_Final.pdf](http://download.eurordis.org.s3.amazonaws.com/rbv/PR_INNOVCare_Final.pdf)



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