



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

# Juggling care and daily life

The balancing act of the rare disease community.

Raquel Castro, EURORDIS



*Survey performed via  
Rare Barometer Voices,  
a EURORDIS Initiative*

INNOVCare Workshop on Advancing holistic and innovative care for rare diseases and complex conditions, 1<sup>st</sup> June 2017

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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](#)

# Survey methodology

# Rare Barometer Voices framework



A EURORDIS INITIATIVE

## Recruitment Rare Barometer Voices

- Rare Barometer Voices members participated
- External link disseminated by partners on social media, Google adds, email from patients organisations, helplines

## Ethics and security

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

## Translation

- Survey available in 23 most used languages in Europe
- MAPI: experts in medical translation & linguistic validation (*translation provided in-kind*)
- 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

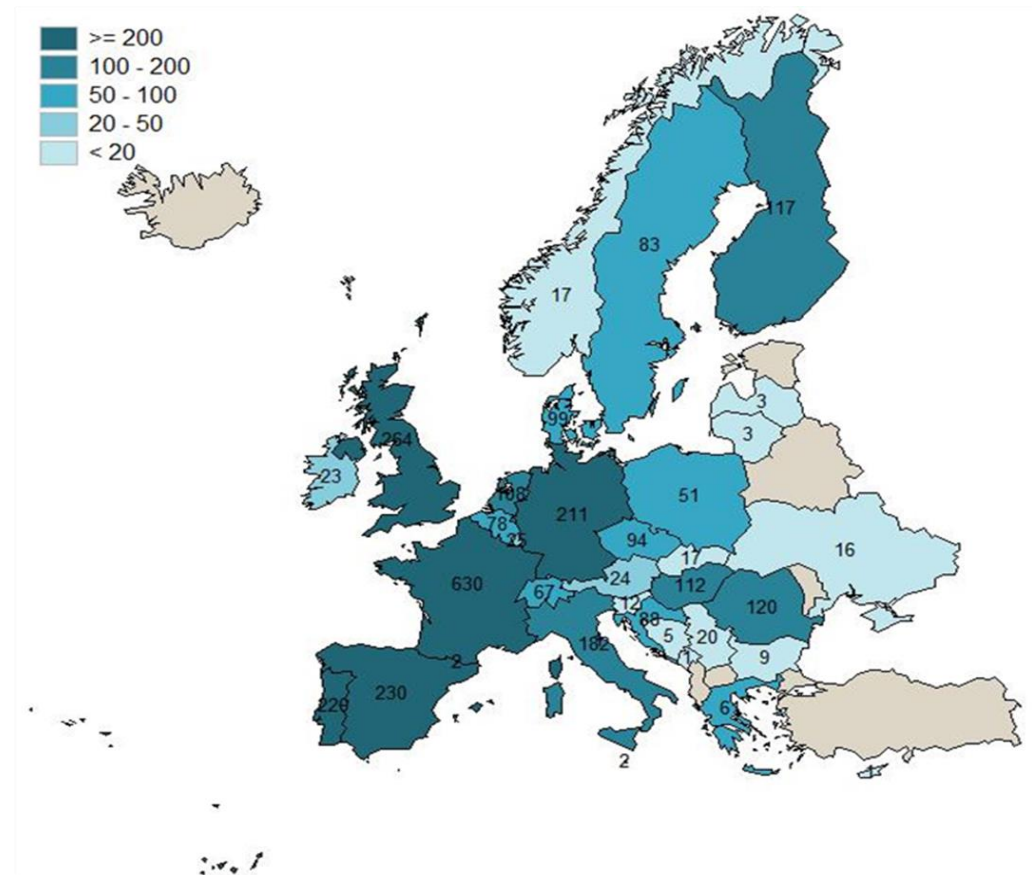
**2117 answers, including 1953 valid questionnaires**

# 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%

**Represents the diversity of the rare disease community:**

✓ 42 countries

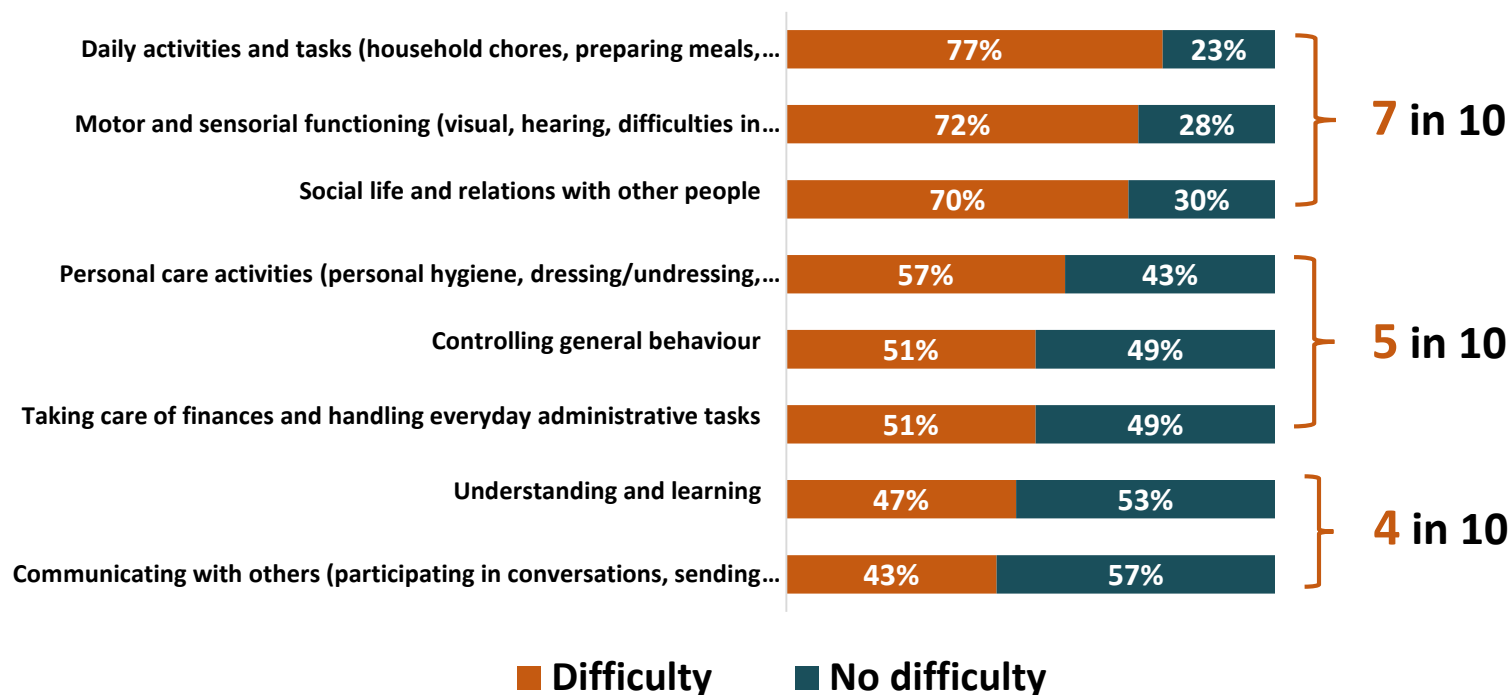




# Survey results

# Serious impact on patients' everyday life

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



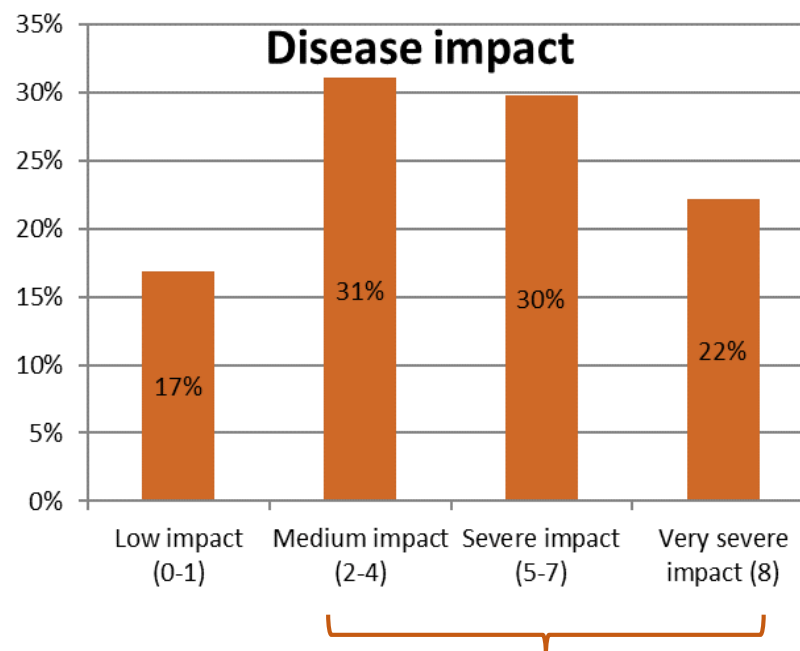
*Some modalities have been grouped; Difficulty=Completely unable + A lot of difficulty + Some difficulty*

# 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

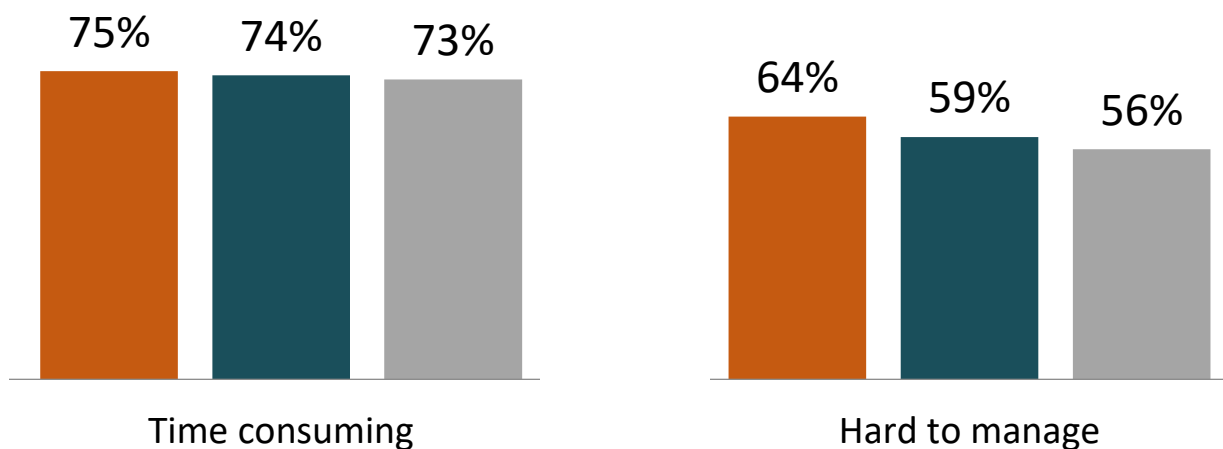
## Spending more than 2h/ day on health related tasks:

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



At least 64% of the carers are women

## 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, between therapists”

**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**

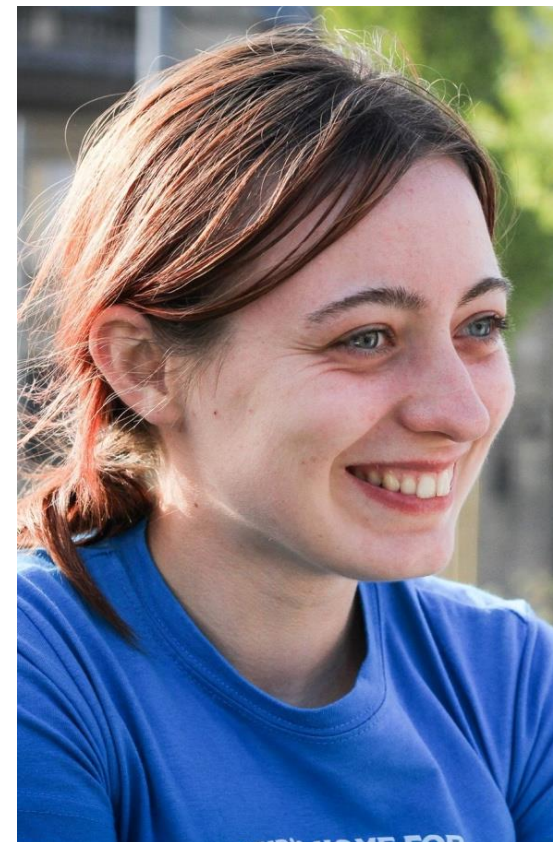


“ It took **two years to obtain social care support...departments don't talk to one another** so records weren't passed on (...) I was discharged without help...

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** and 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**

# Need to be absent from work

**58%** of patients & carers were **absent over 15 days/year**

**28%** of patients were **absent more than 90 days**

**41%** of patients & carers **needed special leave from work but could not obtain it**

**35%** of work part-time against **17%** in the general population\*

\* OECD. Labour Force Statistics, [OECD Labour Force Statistics](#), 2016

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

**By asking a year "non paid break"** (to pursue my diagnosis journey and to take care of my children, one of them also having similar symptoms) I received a **refusal from the employer**. So I **decided to give up my job** and stayed **unemployed for 4 years.**

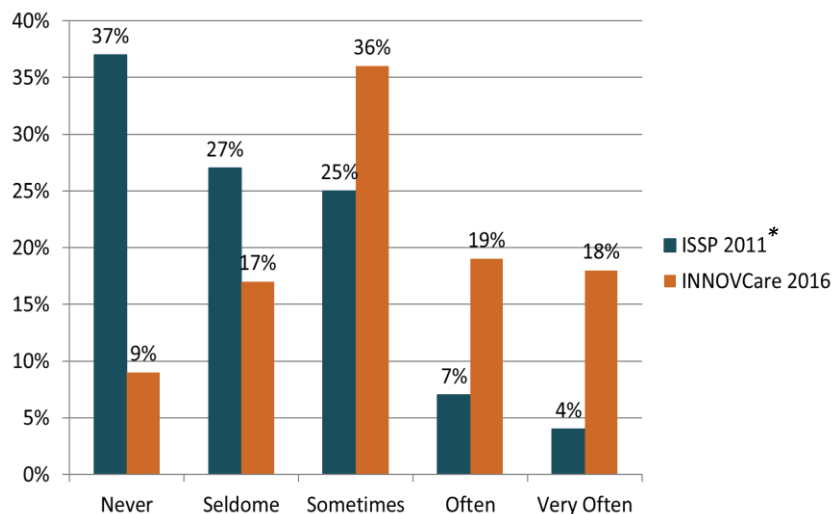
Strangely, feeling stronger **after the diagnosis (...)**, I **decided to pick up work again**. One year: **part-time** and thus **earning half** as much as before.

**Later on and until now: working less then a part time and earning even less;** but the job is my dream job and I still have a husband who is the main "breadwinner". That's how we manage to make ends meet”

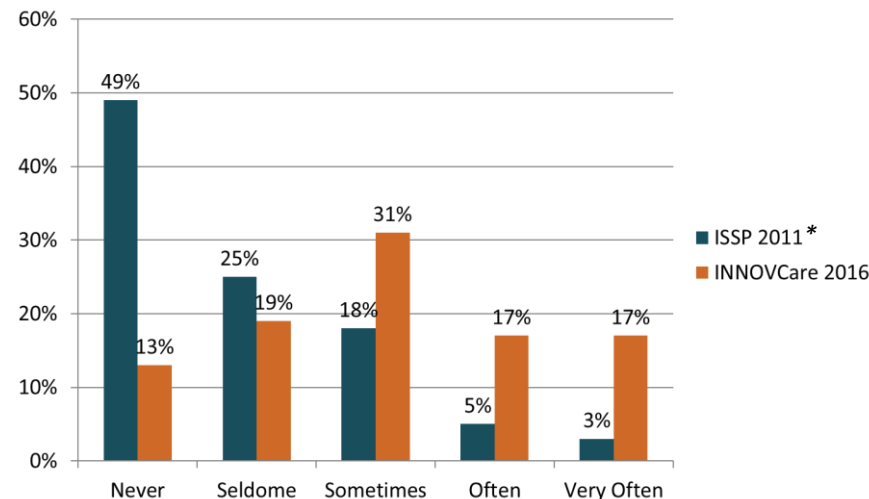
**Female, Luxembourg**

# Deteriorated mental health

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 ?



Rare disease patients and carers:

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

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



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# Thank you

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