



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

Unmet daily life & care needs of people living with a rare disease:

Preliminary results of EURORDIS' ongoing survey to patients and of interviews to competent authorities in European Countries

Raquel Castro, Social Policy Senior Manager, EURORDIS
Juliette Senecat, Health and Social Projects Manager, EURORDIS

INNOVCare Workshop on Scaling Innovative Care Delivery for Rare Diseases and Complex Conditions,
Vienna, 6-7 October 2016

www.innovcare.eu



This project is co-funded by
the European Union

The information contained in this publication does not necessarily reflect the official position of the European Commission

State of the art

Study the impact of rare diseases on patients' and families' daily life

- Impact of rare diseases on daily life, care burden, financial burden
- Identification and dimension of needs

Study of care pathways in 8 European Countries

- Listing services,
- Mapping care pathway
- And collecting good practices



Comparative analysis: identify gaps between patients'/families' needs and the current care pathways (2017)

Survey on impact of rare diseases on daily life
Via EURODIS' Rare Barometer Survey Programme

EURORDIS Survey Programme – Rare Barometer



- Rare Barometer Voices: people living with a rare diseases who participate in EURORDIS surveys and studies
- Covers 48 countries
- Surveys translated in 23 languages
- Registry possible for all diseases listed on Orphanet database
- High level of data protection

Survey: methodology

Questions raised by patient organisations

Focus groups with the EURORDIS Council of National Alliances (CNA)

Feedback from the EURORDIS Social Policy Action Group ([SPAG](#))

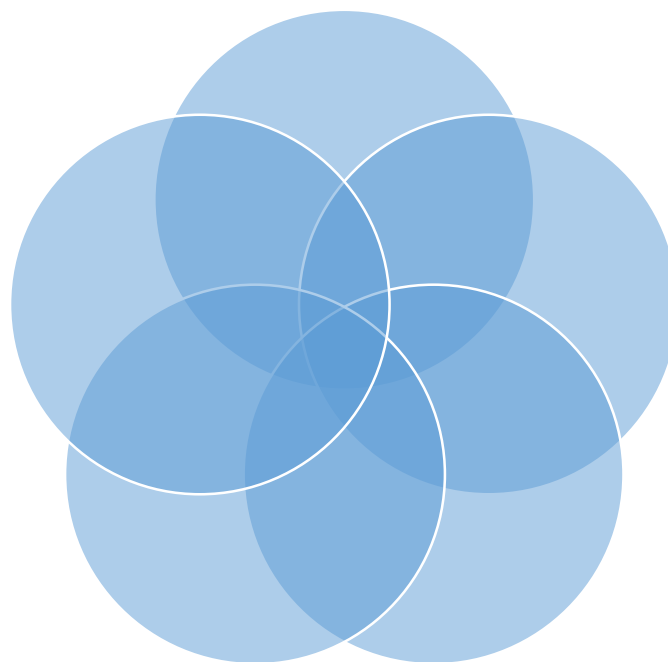
Questions based on existing literature

Only the strong survive (Rare Diseases Denmark, 2013)

ENSERIO (Feder, 2009)

Users Experience of Health Services (Frambu, 2008)

Public and private research involvement



Patient organisations involved in survey design



Rare Diseases Denmark



Allianța Națională pentru Boală Rare România

Wide dissemination & recruitment

EURORDIS members and volunteers;
EURORDIS social media and online patient communities

Feedback to participants
Results in 23 languages

Survey: timing and organisation

Data collection:

- **Stage 1:** Ongoing - questions care needs, access, costs and coordination.
- **Stage 2:** Starting in October - questions on employment, school and level of stress
- Ongoing until end of November

Results:

- January 2017: INNOVCare survey report available
- February 2017: Results available for patient organisations and participants

Survey: profile of respondents



People with rare diseases, diagnosed/undiagnosed



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



More than 18 years old



Only one person per household can answer

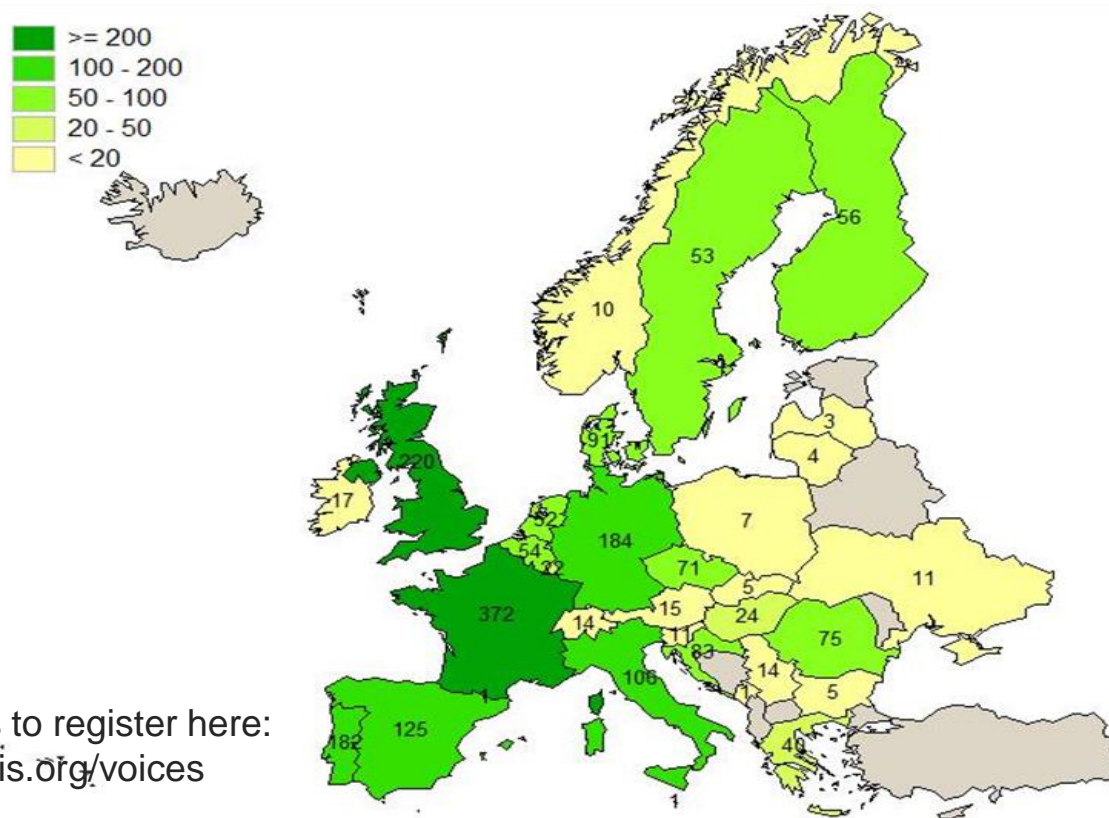


Across diseases and across European countries (48)

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

Survey: preliminary results

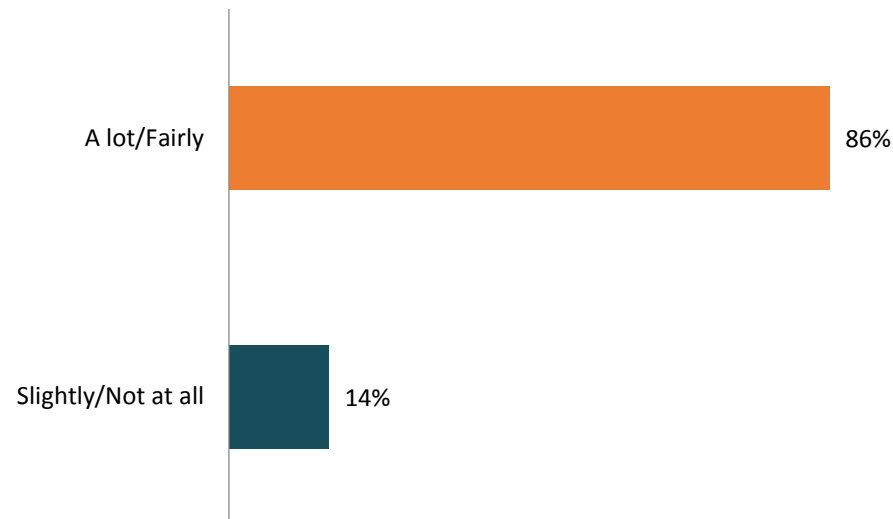
- 1840 valid questionnaires across Europe and rare diseases
- 63% patients, 36% parents, 7% other family members
- 35 European countries represented so far



Ask your contacts to register here:
<http://www.eurordis.org/voices>

Survey: preliminary results

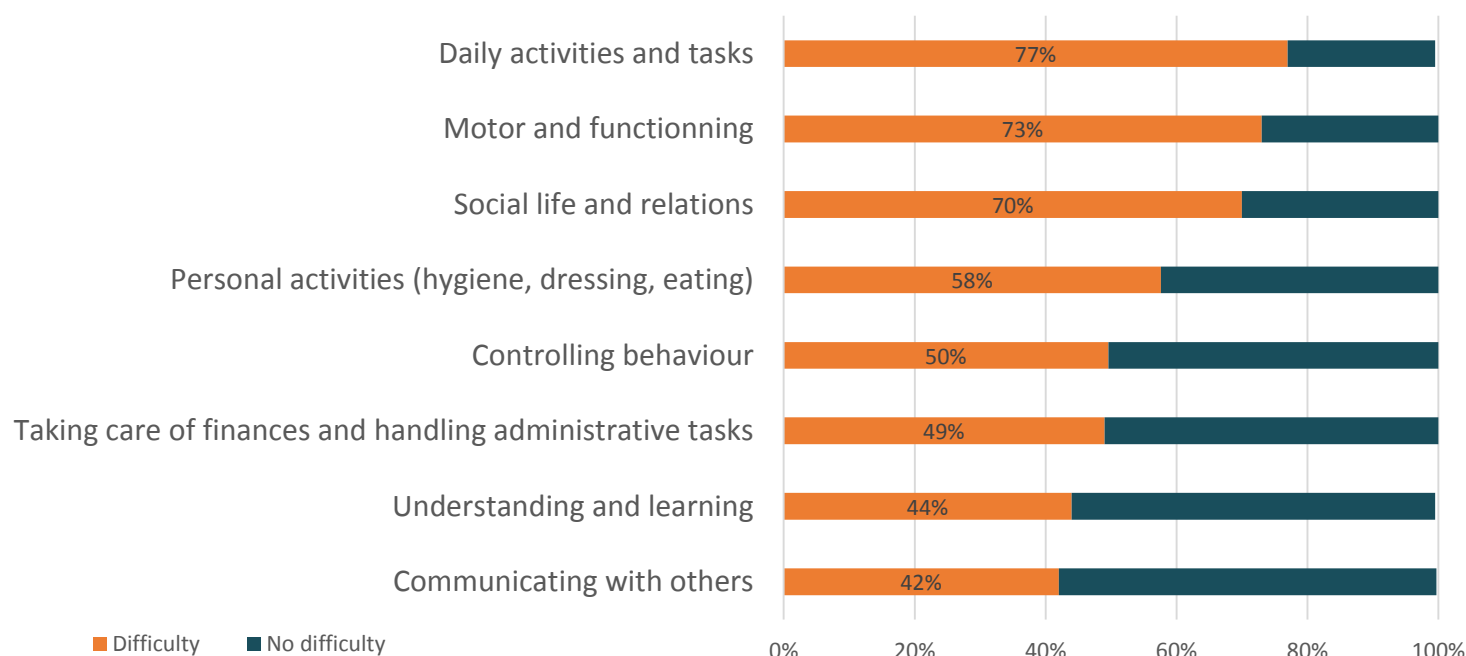
How the rare diseases impacts health and everyday life of the patient



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.

Survey: preliminary results

To what extent do the patients have difficulties with:

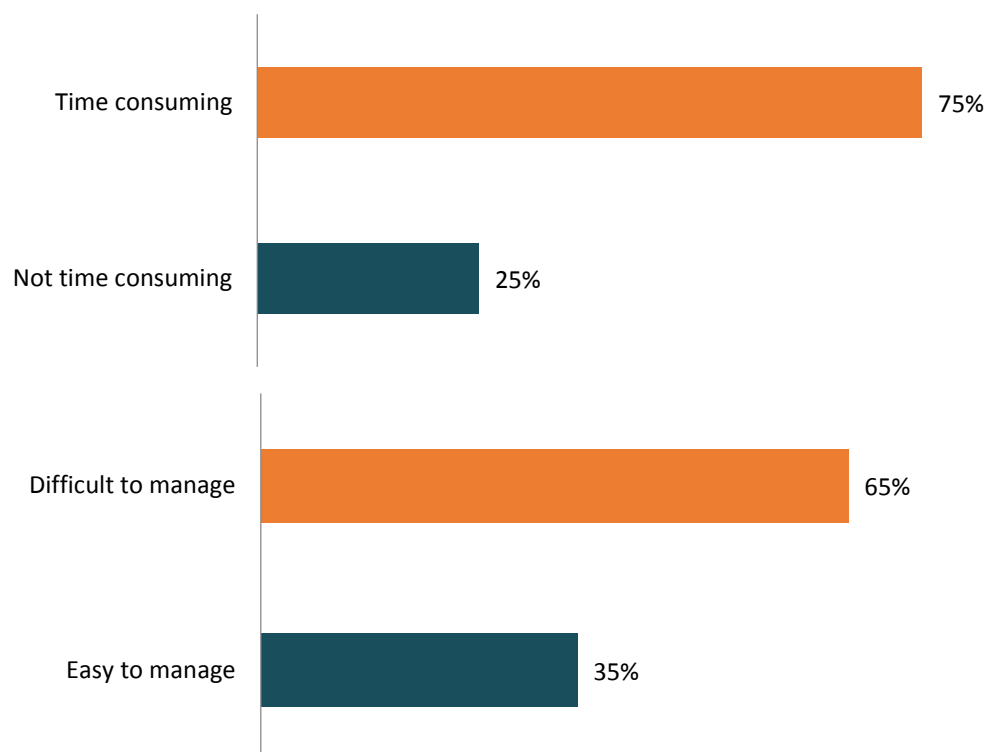


Preliminary results of ongoing study conducted by EURORDIS, via [Rare Barometer Voices](#), in 48 European Countries (35 represented so far). 1840 valid questionnaires across Europe and diseases - 63% patients, 36% parents, 7% other family members.

Survey: 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

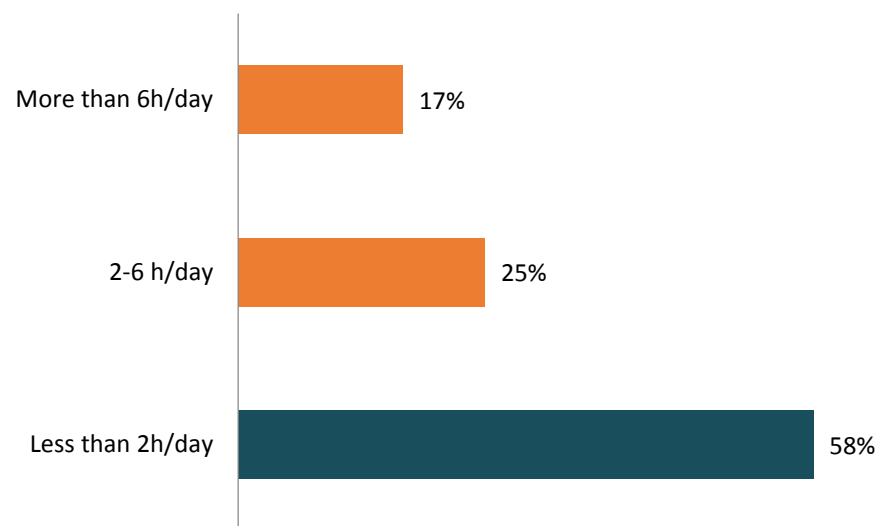


Preliminary results of ongoing study conducted by EURORDIS, via [Rare Barometer Voices](#), in 48 European Countries (35 represented so far). 1840 valid questionnaires across Europe and diseases - 63% patients, 36% parents, 7% other family members.

Survey: preliminary results

Time invested on average/day for illness related tasks

Including hygiene, house chores, moving, administrative procedures

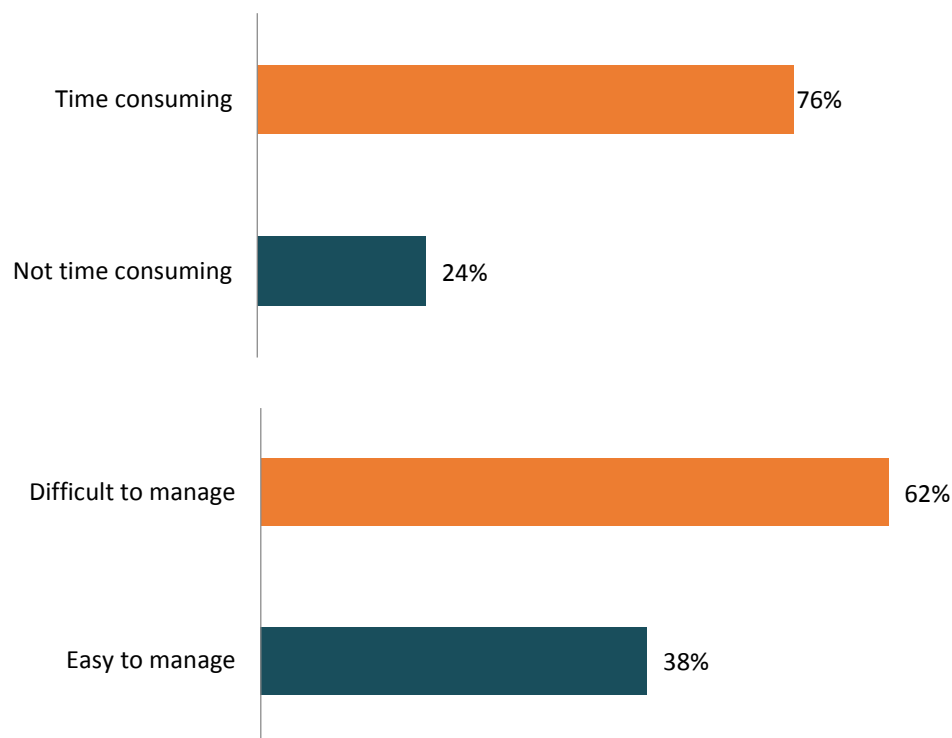


✓ **42% of patients/families invest over 2h/day**

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.

Survey: preliminary results

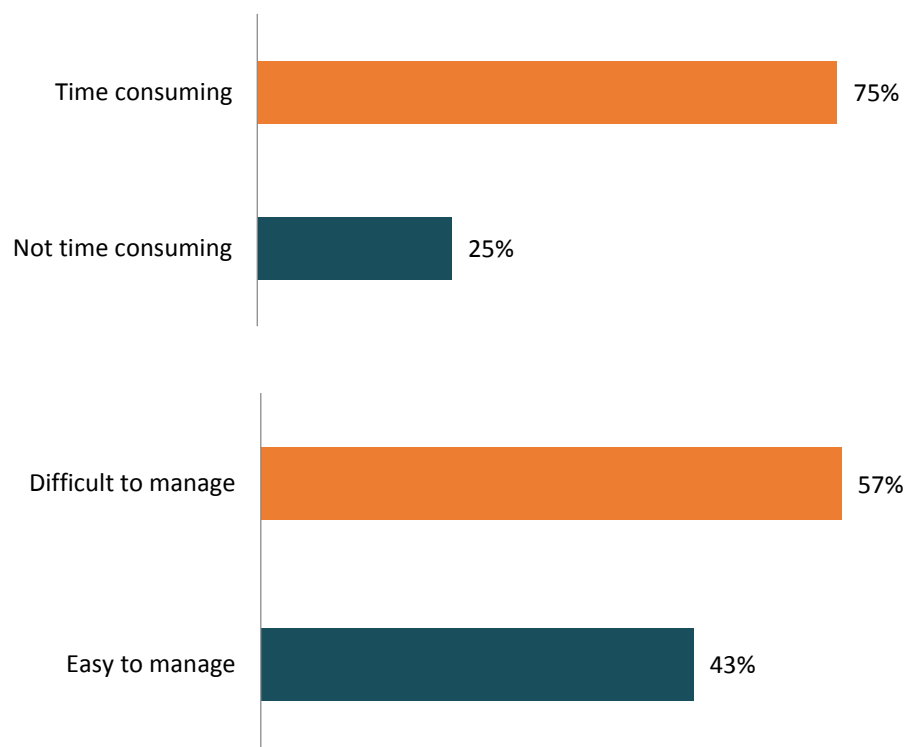
Time spent explaining the disease to different services/experts



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.

Survey: preliminary results

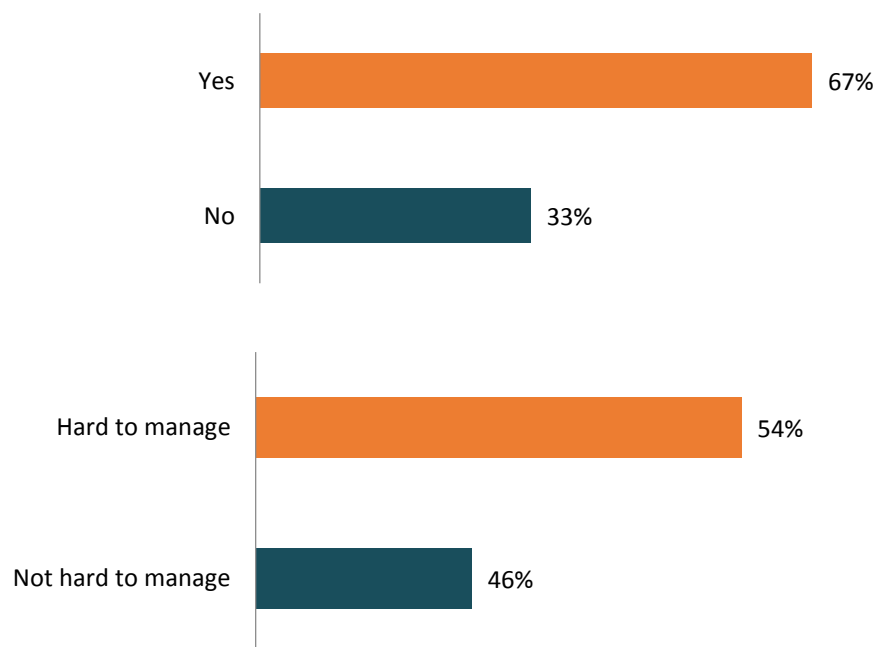
Time spent in health related administrative procedures representes



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.

Survey: preliminary results

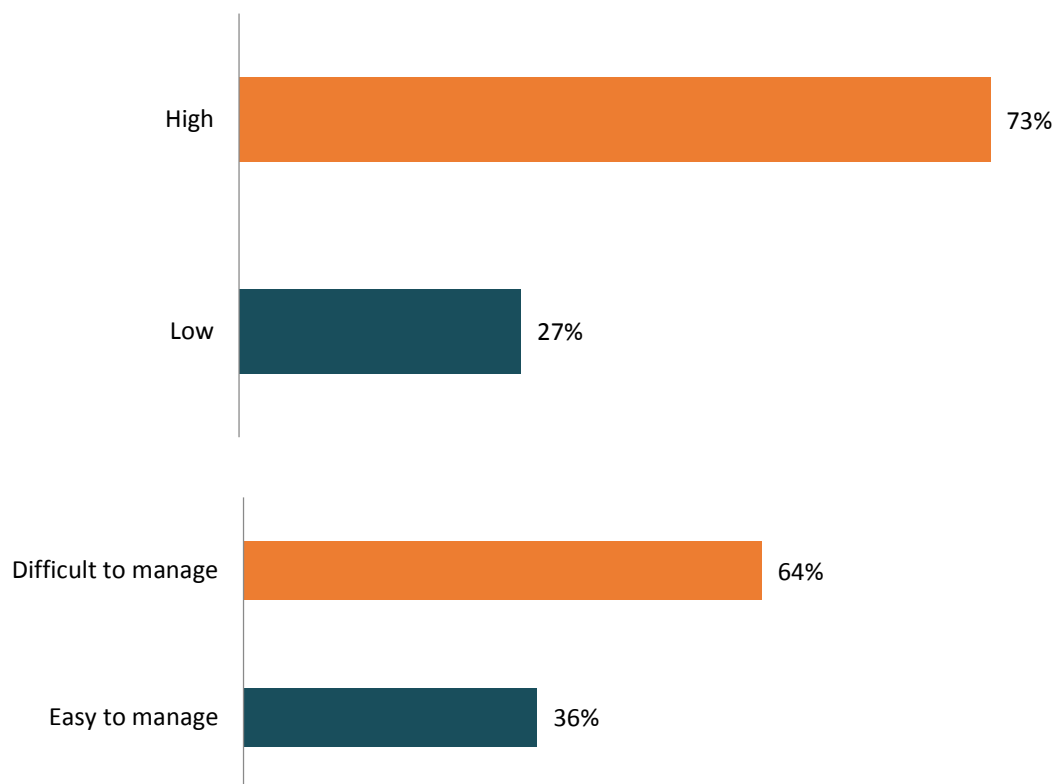
Visiting different health, social and local support services and specialists in a short period of time



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.

Survey: preliminary results

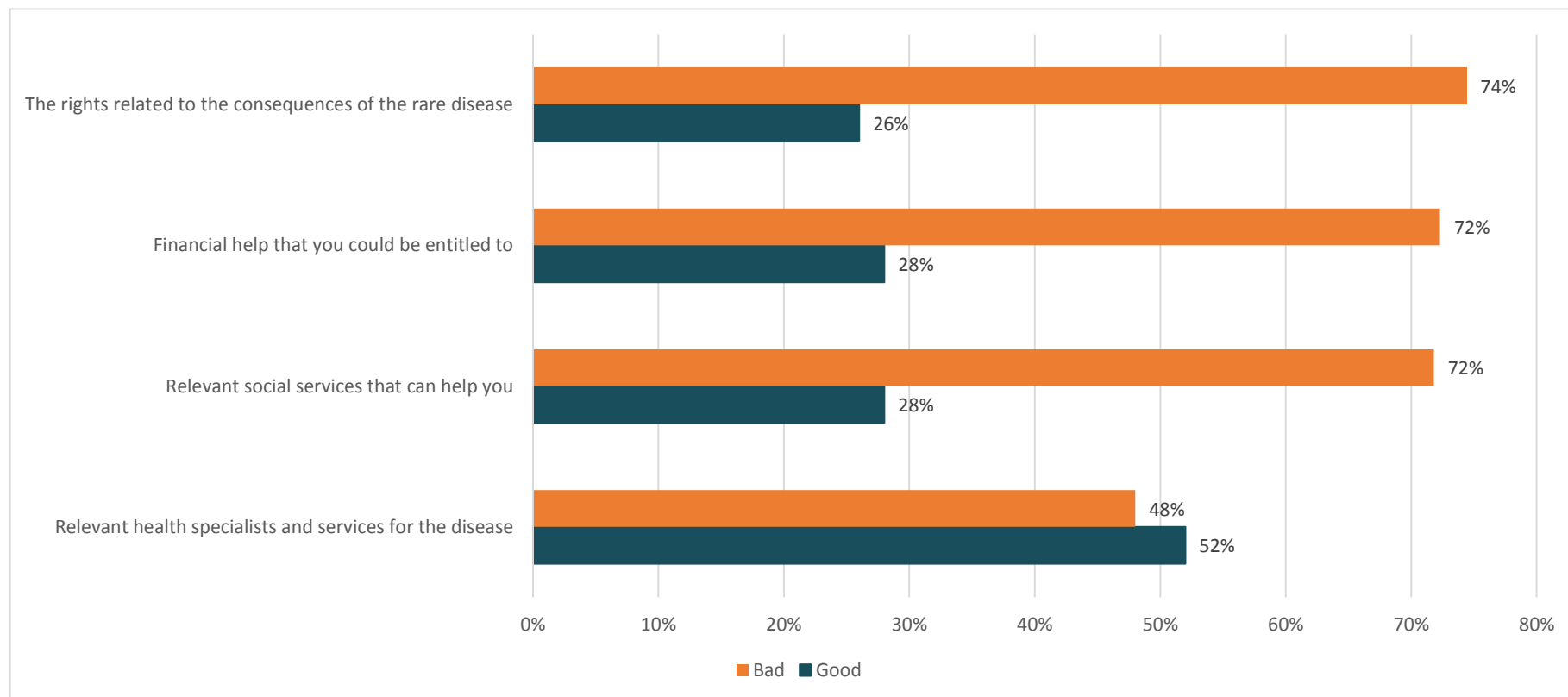
Costs associated to the rare disease



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.

Survey: preliminary results

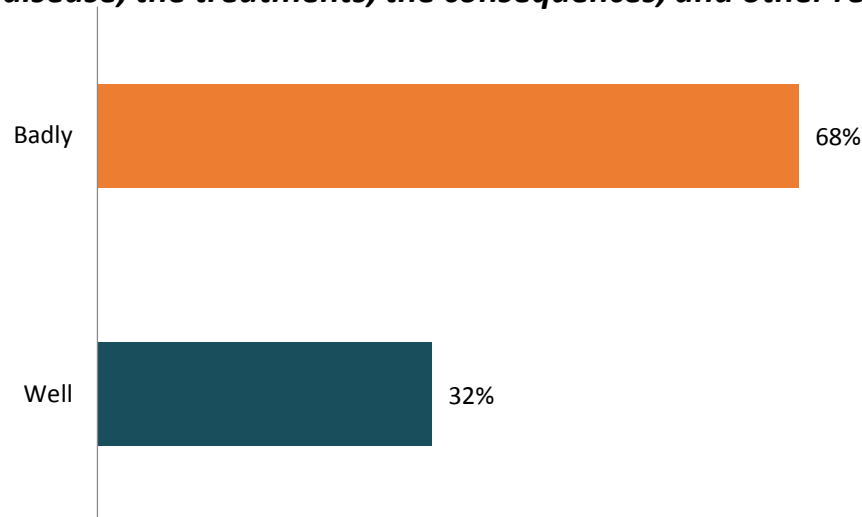
Level of information of patients



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.

Survey: preliminary results

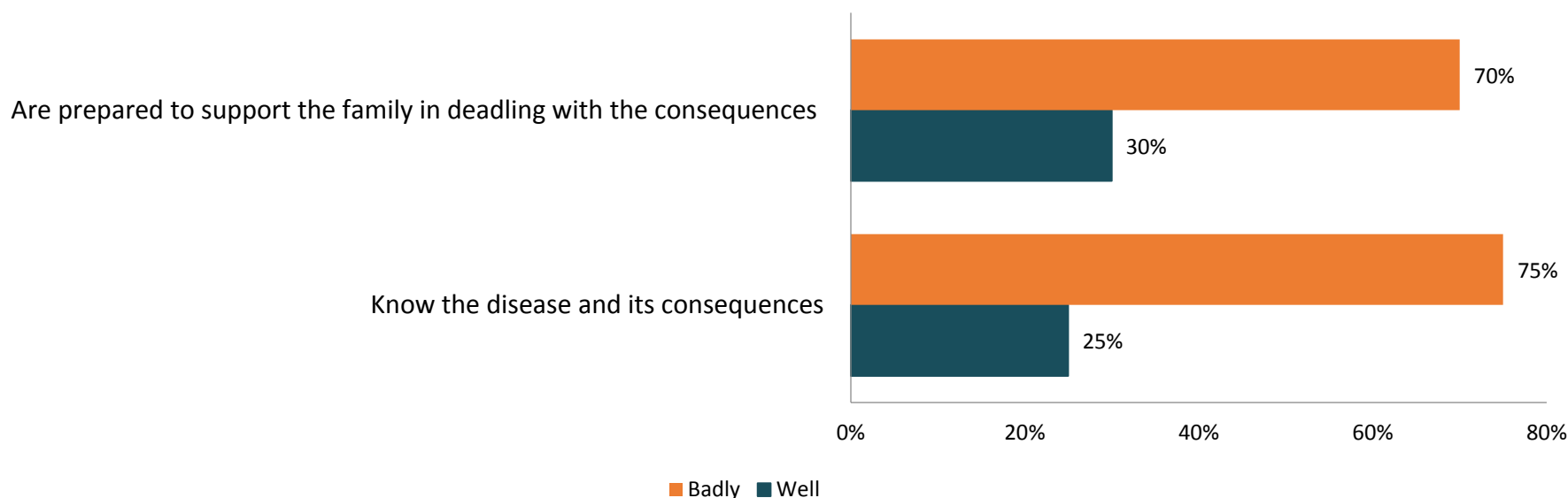
**How patients feel that different service providers
communicate/exchange**
about the rare disease, the treatments, the consequences, and other relevant information



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.

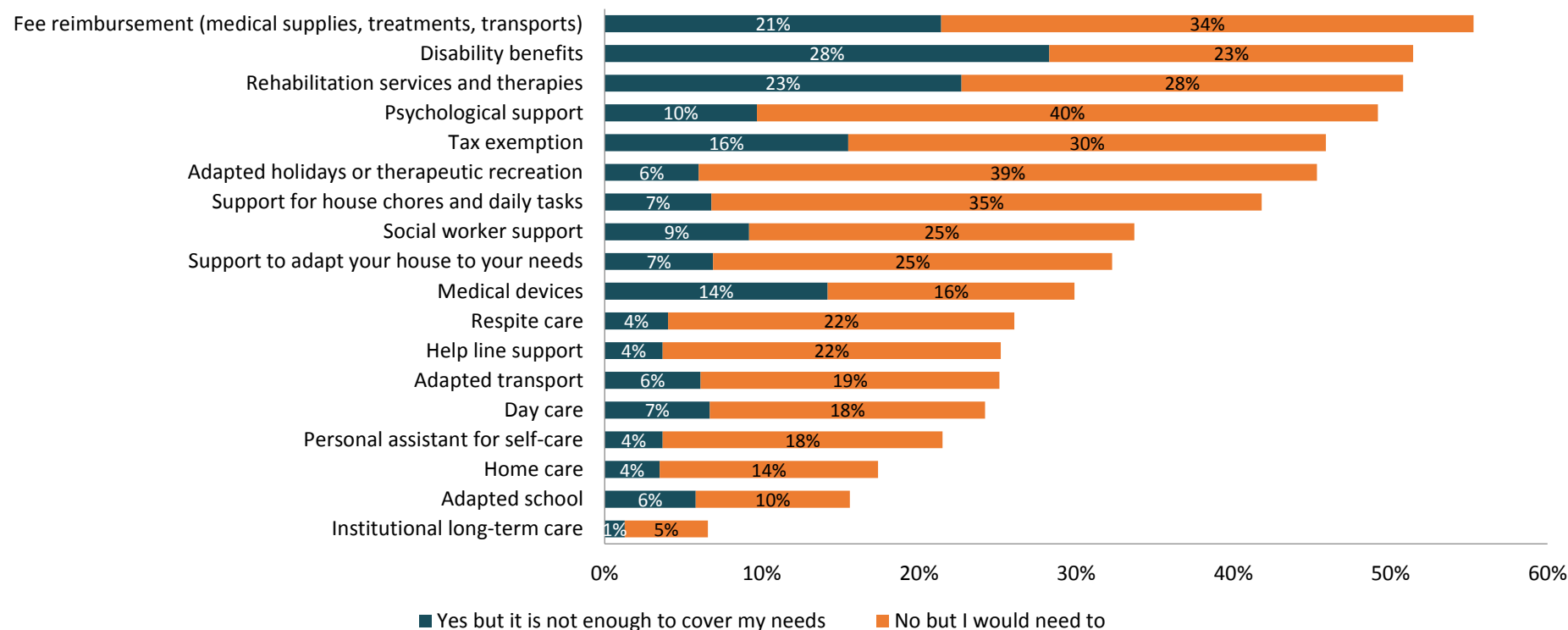
Survey: preliminary results

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



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.

Survey: preliminary results



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.

Study of care pathways in European Countries

Care pathways in European Countries

Methodology - Interviews to competent authorities in 8 EU countries

- ✓ **Methodology:** Review of relevant **publications** and **interviews with national authorities**.
- ✓ **Collection of background information:**
 - **Collection of information via the review of publications** on care pathways and care systems in EU Member States, useful studies, reports by relevant national and European organisations, etc.
 - **Contacts with key informants** such as patient organisations (including National Alliances for rare diseases), INNOVCare project partners, other European projects and key stakeholders.
- ✓ **42 interviews** (visits to Member States and remote interviews) conducted by EURORDIS among 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*).
- **List of issues discussed during interviews:**
 - **Listing services available** for people living with a rare disease;
 - **Mapping the care pathway:** connections between services and complexity of care pathway;
 - **Describing** integration of health/social services, employment policies.
 - **Identifying good practices** for the integration of people living with a rare disease into social services/policies.

Care pathways in European Countries –

Preliminary results of interviews to competent authorities in 8 EU countries

✓ Separation between social and health sector is common

- Welfare systems studied are characterised by a high level of **fragmentation between health care and social care** and **between different levels of care (national, regional, local)**.

✓ Lack of connection/coordination between different services

- National authorities have identified insufficiencies in terms of **coordination between professionals and in terms of communication between services**.
- Connections between services often **lack a clear framework** and **depend on the level of awareness of professionals** in charge of health care and social support.

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).

Care pathways in European Countries –

Preliminary results of interviews to competent authorities in 8 EU countries

✓ **Patients, patient organisations often have to coordinate care**

- Fragmentation leads to an **increased burden on patient and families** who are frequently the coordinators of their own care.

✓ **Fragmented care pathways**

- Health systems **lack a clearly defined, integrated care pathway** for rare diseases.
- Moreover, in existing care pathways, **transitions are in many cases a challenge** (e.g. transitions between inpatient/outpatient care; from child to adult care...).

✓ **Different funding systems affect services' capacity to work together**

- **Fragmentation of budgets** between health and social care is a **barrier** to integration of 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).

Good practices: Case management, coordination of care

Preliminary results of interviews to competent authorities in 8 EU countries

✓ Permanent coordination contact and individual coordinating plan (Sweden):

People with certain functional impairments are **entitled by law** to :

- a permanent coordination contact that **connects** health care contacts and other stakeholders
- an individual coordinating plan providing an **overview of needs and coordination of stakeholders, treatment and services**.

✓ Regional Teams for Disability (France):

- These regional teams ensure the **follow-up of care pathways** of people in a situation of **rare disability**, based on the resources of the territory.
- They are **mobile, multidisciplinary** and work in **subsidiarity**.

✓ Parent project (Romania):

- The NGO Parent Project Romania is at the origin of an experimental projects based on the **coordination of assistance to families of children affected by muscular dystrophies**, with the support of **case managers**.
- Objective: **improving integration into the community** for people living with muscular dystrophies

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).

Good practices: Organisation of care pathways

Preliminary results of interviews to competent authorities in 8 EU countries

✓ Permanent Health Networks for Rare Diseases (France):

- 23 Health Networks for Rare Diseases created by the Ministry of Health, in charge of **coordinating actions and reinforcing connections** between different stakeholders involved in **provision of care** (health, social care, research, patient organisations, etc.).
- They are also in charge of **facilitation of entry and orientation in the care pathway**.

✓ Node of personalised care for rare diseases - NAPER (Spain, Extremadura region):

- Connection point that **locates existing resources in the region of Extremadura**, involved in caring for those affected by a rare disease
- **The NAPER directs people in a coordinated manner**, to the public health system and to other support services (social care, education, work, etc.).

✓ Bridging the Gap Project (United Kingdom):

- Implemented by an NGO, Muscular Dystrophy UK, with funding from the Department of Health, this projects aims at ensuring a **neuromuscular care pathway** in England and more broadly, in the UK.
- Another objective is to make sure that people living with rare diseases play **a leading role in the development and commissioning of services** they use.

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).

Good practices: provision of multidisciplinary care

Preliminary results of interviews to competent authorities in 8 EU countries

✓ EB House (Austria):

- The EB House provides **multidisciplinary care** to patients living with Epidermolysis Bullosa in Austria
- The approach of the centre is combining health care services with rehabilitation, psychological and social counselling, also serving as a platform for exchange of knowledge.

✓ Early Intervention Centre (Hungary):

- This centre provides a **package of services to children with delayed or impaired development**, delivered by a multidisciplinary team
- The centre provides a **global approach to care**, focusing on the development of the child as well as the needs and circumstances of the family.

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).

Good practices: Provision of information

Preliminary results of interviews to competent authorities in 8 EU countries

✓ National centre for information on disability – Info Handicap (Luxembourg):

- This centre has an agreement with the Ministry of Family and Integration and **provides information and guidance to disabled people and their relatives and carers**
- This involves editing disability guides on the rights of people with disabilities and services they can access, providing legal information and trainings, among other activities.

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).



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

Thank you

Raquel Castro | raquel.castro@eurordis.org

Juliette Senecat | juliette.senecat@eurordis.org

www.innovcare.eu



 This project is co-funded by the European Union

The information contained in this publication does not necessarily reflect the official position of the European Commission