INNOVCare

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

What are the challenges & how did INNOVCare approach them

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Conference: Advancing person-centred and integrated care for rare diseases and complex conditions across Europe– Brussels, 5th September 2018

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This project is co-funded by the European Union

What is a rare disease?

OVER
6000
distinct rare diseases

Rare, **complex**, **chronic**, **disabling**, progressive, degenerative, often life-threatening

Each one affects fewer than
1 IN 2000 PEOPLE

NO CURE
for the vast majority of diseases and few treatments available

All together, an estimated
30 MILLION PEOPLE
are living with a rare disease in Europe

They are **geographically scattered** and often **isolated**

Expertise, **knowledge**, **information** on diseases and their consequences are **scarce and difficult to access**

Few experts, geographically **scattered**

Research is fragmented

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

First Europe-wide survey on social impact of rare diseases, involving 3000 rare disease patients & carers

Rare Barometer

Juggling care and daily life

The balancing act of the rare disease community

A Rare Barometer survey

May 2017

Report with full results

Serious impact on patients' everyday life

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

Complex & often invisible

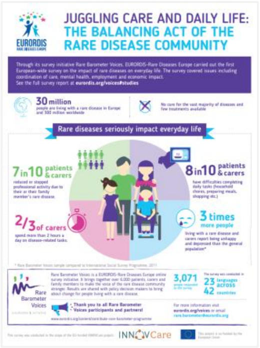
"The difficulty lies in the **impossibility of carrying a routine** (...). The problem arises when **one day you appear completely healthy, the next day you are sick**, and two days later you appear completely normal again. Many people find it difficult to understand the disease and the process, and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

Presentation of key results



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 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!

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

Infographics with key results

INTEGRATED CARE FOR RARE DISEASES: BRIDGING THE GAP TO IMPROVE THE LIVES OF 30 MILLION PEOPLE IN EUROPE

RARE DISEASES

Rare, complex, chronic, disabling

30 million people affected in Europe

Fewer than **1 in 2000** people affected by each rare disease

No cure for the vast majority and few treatments available

Expertise and knowledge on their consequences are scarce and difficult to access

PEOPLE LIVING WITH A RARE DISEASE AND THEIR CARERS FACE SERIOUS CARE BURDEN[1]

65% have to visit different health, social and local services in a short period of time

67% feel that these services communicate badly between each other

7 in 10 do not feel well informed about their rights

7 in 10 find that organising care is time-consuming; 6 in 10 find it hard to manage

INTEGRATED HEALTH AND SOCIAL CARE IS ESSENTIAL TO ENABLE PEOPLE LIVING WITH A RARE DISEASE TO

- **Overcome their care burden and to secure the services and support that they require**
- Achieve a **quality of life on an equal footing with other citizens**
- **Participate in society and in the job market** to their highest potential
- Fully **realise their fundamental human rights**

SHARE THIS FACTSHEET TO HELP RAISE AWARENESS OF THE NEED FOR INTEGRATED CARE FOR RARE DISEASES

#RareDisease | #INNOVCare

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Factsheet on integrated care for rare diseases with survey results

Survey performed via EURORDIS survey initiative

Rare Barometer Voices

and within the EU-funded INNOVCare project

Rare Barometer Voices

A EURORDIS INITIATIVE

First Europe-wide survey on social impact of rare diseases: 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

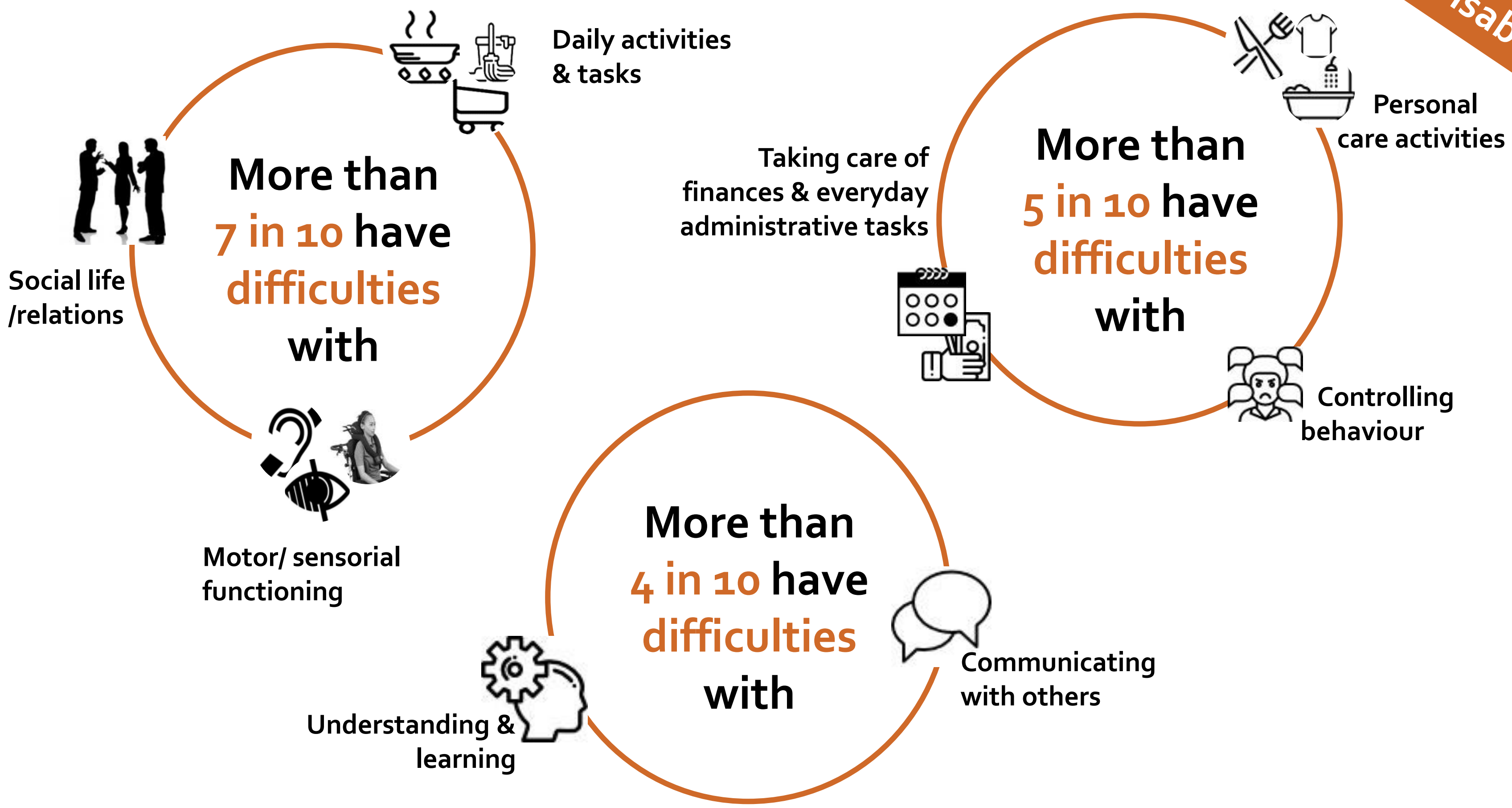
Patients and carers feel **badly informed about their rights** and **feel that social services are badly prepared to support them**

Rare diseases impact the mental health of patients and carers

Survey performed via EURORDIS survey initiative Rare Barometer Voices

People living with a rare disease have difficulties with several Activities of Daily Living

Disability



More than 7 in 10 have difficulties with

- Daily activities & tasks
- Social life /relations
- Motor/ sensorial functioning

More than 5 in 10 have difficulties with

- Personal care activities
- Taking care of finances & everyday administrative tasks
- Controlling behaviour

More than 4 in 10 have difficulties with

- Communicating with others
- Understanding & learning

Survey performed via EURORDIS survey initiative Rare Barometer Voices

Rare diseases are complex and often invisible

Discrimination

Symptoms vary & can be invisible in many ways

“**One day you appear completely healthy, the next day you are sick**, and two days later you appear completely normal again” Female, Spain

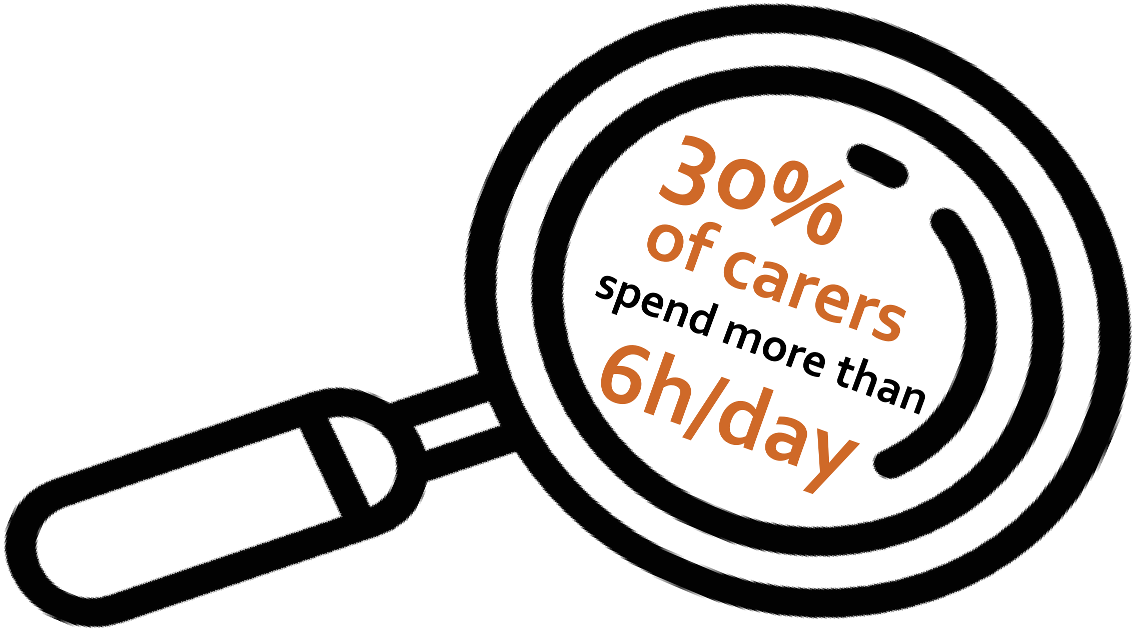
“**I don't look ill but am very ill** with a condition which no one understands or has heard of” Female, United Kingdom

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 and carers

Time burden

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



30% of carers spend more than **6h/day**

* *Hygiene, administration of treatments, helping with house chores, helping the patient to move*

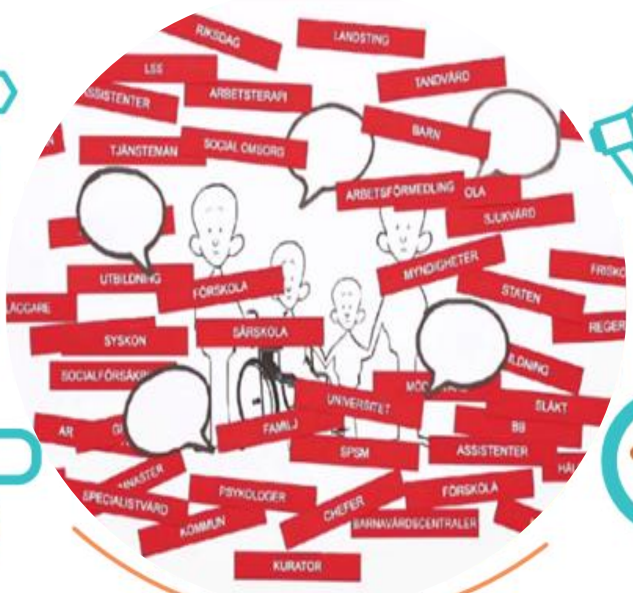
Survey performed via EURORDIS survey initiative Rare Barometer Voices

Care pathway is complex and hard to manage

Integrated care

65%
have to visit different health, social and local services in a short period of time

67%
feel that these services communicate badly between each other



7in10
do not feel well informed about their rights

7in10
find that organising care is time-consuming; 6 in 10 find it hard to manage

Image on care pathway used for illustration purposes.
Source: [Nationella Funktionen Sällsynta Diagnoser](), Sweden

Survey performed via EURORDIS survey initiative Rare Barometer Voices

Significant impact on professional life

Employment

7 in 10

People living with a rare disease & carers had to reduce or stop professional activity due to the disease

The rare disease led to an **income decrease for 69%**

Survey performed via EURORDIS survey initiative Rare Barometer Voices

Significant impact on professional life

Work-life Balance

58% absent from work over 15 days/year

41% asked for special leave from work but could not obtain it

Survey performed via EURORDIS survey initiative Rare Barometer Voices

Deteriorated mental health

Mental Health

3 times more people

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

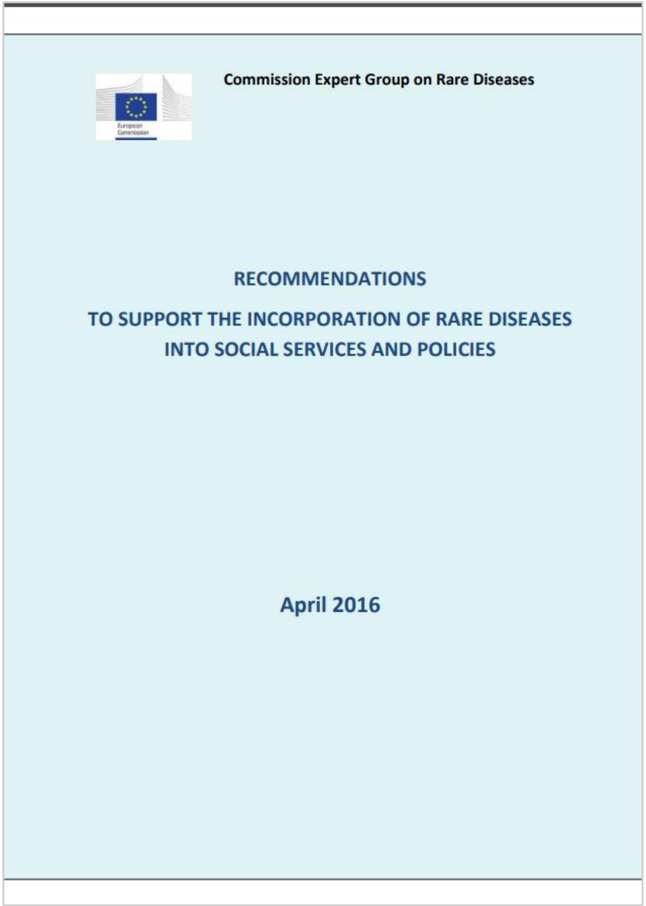
* Rare Barometer Voices sample compared to International Social Survey Programme, 2011

Survey performed via EURORDIS survey initiative Rare Barometer Voices

> “*The serious unmet social needs of people with a rare disease and their families affect their dignity, autonomy and other fundamental human rights*”

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

Addressing these needs: EU-level recommendations



Commission Expert Group on Rare Diseases

RECOMMENDATIONS

TO SUPPORT THE INCORPORATION OF RARE DISEASES
INTO SOCIAL SERVICES AND POLICIES

April 2016

1. Integration into national plans for rare diseases

2 & 3. Role of Centres of Expertise and of European Reference Networks, as per previous EU-level recommendations

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**

See all the recommendations here

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



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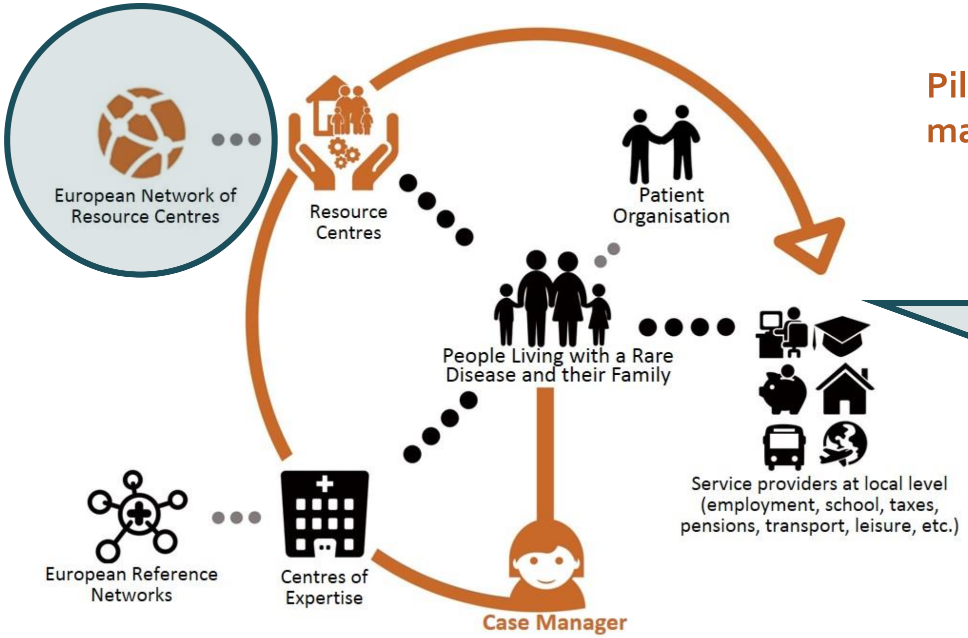
1st Europe-wide survey on the social impact of RD

Patients' & families' needs

Creation of RareResourceNet



Pilot of case management for RD

Good practices

Social Impact

Economic Impact & cost-benefit

Multi-stakeholder Workshops

Good practices

Roadmaps to up-scale model

Key contacts for advocacy

- ✓Recommendations
- ✓Good practices
- ✓Case studies

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

Events

05 SEP 2018 Conference on Advancing person-centred & integrated care for rare diseases & complex conditions across Europe

12 APR 2018 Workshop on Creating a Sustainable Environment for Holistic & Innovative Care for Rare Diseases & Complex Conditions

01 JUN 2017 Workshop on Advancing Holistic & Innovative Care for Rare Diseases & Complex Conditions

06 OCT 2016 Workshop on Scaling Innovative Care Delivery for Rare Diseases & Complex Conditions

08 SEP 2016 Workshop on Improving Integrated Care for People Living with Rare Diseases & Complex Conditions

Bridging the gaps of p

Resources

INNOVCare Recommendations (2018)

Factsheet on Integrated Care for Rare Diseases (2018)

Poster presented at SHEA 2018: Social and economic impact of a case management approach for people with rare and complex conditions in Salaj, Romania (2018)

Poster presented at ECRD 2018: Measuring the effects of a case management approach on the quality of life of rare and complex disease patients (2018)

- ✓4 workshops
- ✓100+ participants
- ✓24 countries

https://innovcare.eu/events/
https://innovcare.eu/resources/

Recommendations from all project partners

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Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions *www.innovcare.eu #INNOVCare*

Based on the INNOVCare project's outcomes,
the project partners RECOMMEND that:

1. **The EU, its Member States and other European countries continue to implement the Commission Expert Group on Rare Diseases Recommendations to Support the Incorporation of Rare Diseases into Social Services and Policies.**
   - The report on the **State of the Art of Rare Disease Activities in Europe**, previously issued by the European Joint-Action on Rare Diseases (RD-Action) **should be continued and used as a monitoring mechanism to assess the implementation of the recommendations** and the sharing of good practices across countries;
2. **The Work-life Balance Directive takes into account the specific needs of persons with rare diseases and their carers as well as of those with other complex chronic conditions and disabilities;**
3. **National and European bodies must allocate financial and structural support to ensure the continuity and the sustainability of Europe-wide platforms that are essential for the development and sharing of good practices** on integrated care for rare diseases and other complex conditions/disabilities.
   - These include **the European Reference Networks, the European Network of Resource Centres for Rare Diseases and other multi-stakeholder platforms that can further discuss and develop these topics** following the secession of the Commission Expert Group on Rare Diseases and the conclusion of the European Joint-Action on Rare Diseases;
   - The **European Commission Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable diseases must embrace and respond to the challenges of people with rare diseases and their carers.**
4. **National Strategies and Plans for Rare Diseases include the provision of integrated care and services for people living with a rare disease**, in coordination between specialised and mainstream services;
5. **Specific integrated care measures are implemented at national level** such as:
   - **Inter-Ministerial working groups and shared budgets**;
   - **Training of service providers**, including case management training;
   - Support to the **implementation of services and of expert networks** that support person-centred care coordination such as **Resource Centres** and **case management** for rare diseases and other complex conditions/disabilities;
6. **Patient/person-engagement in the design and implementation of services and patient empowerment become a requisite for health and social care provision,** in order to guarantee person-centred, participative care;
7. **Pilot projects continue to be supported, as generators of good practice and innovative services,** and that **due time is allowed for their design, implementation and long-term impact assessment.** Systematic and long-term evaluation is necessary to gather quality evidence on the direct and societal impact of the service.
8. **Sustainability mechanisms are put in place and accessible to public bodies, civil society organisations and service providers** involved in the implementation of integrated care services:
   - The new **Multi-annual Financial Framework** must continue to bring **support to EU-wide platforms and innovative projects** that allow Member States to develop and transfer good practice and evidence;
   - **The European Structural Funds must act as an accessible and adequate mechanism to support** Member States to **up-scale** innovative pilots into mainstream services;
   - **The European Semester must be used as a vehicle to implement integrated care** for people living with a rare disease and other complex conditions **at national level**.

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EU-wide and national measures to guarantee integrated care for rare diseases is implemented and sustainable across Europe. Linking to:

- ✓ EU-level recommendations
- ✓ Work-life Balance Directive
- ✓ European Networks
- ✓ National policies for rare diseases
- ✓ Specific integrated care measures
- ✓ Support and funding mechanisms

https://innovcare.eu/recommendations/
Pick your copy at the registration desk

INNOVCare

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

Thank you

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EURORDIS would like to thank all Rare Barometer partners for their support to co-fund the surveys conducted via EURORDIS survey initiative Rare Barometer Voices

Rare Barometer Voices

A EURORDIS INITIATIVE
eurordis.org/voices

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