

HOW TO GET EU ACTIONS ON RARE DISEASES (RD) CLOSER TO RD PATIENTS AND THEIR RELATIVES?

From local and cross-border developments to European solutions

RARE DISEASES DO NOT STOP AT BORDERS.

European cooperation and coordination on rare diseases is essential to allow RD patients access to the best expertise available irrespective of the Member States.

Developing local and cross-border solutions for the persons living with a rare disease and their relatives is also of high importance to improve their quality of life close to their home.

Both approaches are complementary.



30 million citizens affected in the EU



6000-8000 different rare diseases



For each RD, **fewer than 1 out of 2000** people affected



Important needs and complex care of patients



Geographically **scattered** expertise

THE EMRaDi PROJECT PARTNERS PROPOSE 3 RECOMMENDATIONS TO SPECIFICALLY IMPROVE THE SITUATION:

1

HOLISTIC CARE: ORGANIZING THE CARE TO TAKE INTO ACCOUNT ALL THE NEEDS OF PEOPLE LIVING WITH A RARE DISEASE

Holistic care covers the 360° spectrum of the health, social and everyday needs of people living with a rare disease and their families.

2

DEVELOPING REIMBURSEMENT OF TELEMEDICINE FOR RD PATIENTS IN ERNS AND IN A CROSS-BORDER CONTEXT

To support easy access to the best available expertise for RD patients.



3

STRUCTURING THE COORDINATION AND THE SOLIDARITY FOR RD AT EU LEVEL

Create an EU agency to guarantee the sustainability of existing policies and initiatives on RD and to ensure implementation of the European pillar of social rights principles and social protection for RD patients.

Share this factsheet to help to develop local solutions for people living with a RD and a more coordinated approach at an EU level.

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RECOMMENDATIONS



1

HOLISTIC CARE

ORGANIZING THE CARE TO TAKE INTO ACCOUNT ALL THE NEEDS OF PEOPLE LIVING WITH A RD

- Holistic care covers the 360° spectrum of the health, social and everyday needs of people living with a rare disease and their families. The holistic approach empowers and supports people with a rare disease and their carers to live their lives in the most fulfilling and independent manner possible, and to fully enjoy their fundamental human rights.¹
- **The EU should support** health care providers and health insurance funds to develop **holistic care and care coordination services** for RD patients. These stakeholders have to be recognized as services of general interest at the EU level and the EU should create a supportive legislative frame for their actions.
- **At cross-border and local levels:** with the support of the European regional development fund, the EMRaDi partners plan to continue pilot projects that will
 - implement **new "RD Case Managers"** to provide more support to RD patients and improve care coordination
 - provide additional **training (incl. eLearning instruments) and tools for general practitioners** to raise awareness and to reduce time to diagnosis
 - increase **data-sharing** between interested centres in the Euregio Meuse-Rhine (EMR), including projects to harmonize the coding of RD



2

TELEMEDICINE

DEVELOPING REIMBURSEMENT OF TELEMEDICINE FOR RD

- European Reference Networks (ERNs) and cross-border telemedicine are complementary solutions to support the RD patients and the experts: complex patient cases benefit from multidisciplinary teams/ panel of experts through the ERNs, while other patient cases may require the consultation of a single expert across the border.
- **EU should support:**
 - the establishment of **clear rules for reimbursing telemedicine** for RDs in ERNs and in a cross-border context, and an **easy access to the best available expertise** for RD patients with priority rule and price-safety, in coordination with the health insurance funds
 - **the training of National Contact Points (NCPs)** and health insurance funds to better inform the RD patients and to facilitate their access to cross-border healthcare (CBHC) possibilities
- **At cross-border and local levels:** the EMRaDi partners recommend the development of pilot projects that will **provide reimbursed telemedicine** for RDs (tele-expertise and tele-consultation)

¹ <https://innovcare.eu/social-services/rareresourcenet/>



3

EUROPEAN SOLIDARITY

STRUCTURING THE COORDINATION AND THE SOLIDARITY FOR RD AT EU LEVEL

- **Structuring the coordination and the solidarity for RD at the EU level** is essential in order to guarantee the sustainability of existing policies and initiatives on rare diseases and to ensure the implementation of the European Pillar of Social Rights (EPSR) principles and social protection for people living with a rare disease.
- **The EU should support** the creation of a **European agency for RD** that would be mandated to create sustainable ecosystems around RD with the core value of European solidarity in a Triple A approach:
 - **Raising the Awareness** of the public at large and dialogue within the RD community
 - **Increasing Accessibility** to health and social services, affordability /sustainability of the health system throughout EU
 - **Advancing academic and medical research** and cooperation in RD
- **Next steps:** the EMRaDi partners advocate for:
 - continued dialogue between citizens, the EU, the Member States and the other stakeholders
 - cooperation with the Rare 2030 project on the future policy on RD, which will culminate with a presentation to the EU Parliament at the end of 2020

The EMRaDi (Euregio Meuse-Rhine Rare Diseases) project is an INTERREG-funded cross-border initiative whose goals are to increase the transparency of needs and availability of services, develop models of patient pathways, improve the network of stakeholders and draw up recommendations in order to improve the quality of life of patients with a rare disease.

