



EU Action on Rare Diseases

European Recommendations support the incorporation of RD into Social Policies and Services

Gerhard Steffes

Policy Officer

DG Health and Food Safety, European Commission

Unit C.1, Programme Management and Diseases

Financing for social innovation

- *EaSI*, the *Employment and Social Innovation* programme
 - **Test ideas for reform on the ground, evaluate them and then upscale the best ones across Member States.**
- *EaSI* total budget is almost **920** million €.

The axis PROGRESS, which finances this call, is around 60% i.e. roughly 80 millions euro per year with 15-20% earmarked for social policy experimentation, i.e. €10-14 million a year for social innovation activities.

From around 100 applications, less than 30 were selected and only the first 7 could be financed.

Project INNOV-Care

- addresses the gap of insufficient social services for rare disease patients in the EU by developing, testing and promoting a holistic, personalised social pathway involving public, private and civil society organisations.

-innovative horizontal approach brings together national one-stop-shop services for rare diseases and regional case handlers, in partnership with public bodies. In addition, the project establishes a European Network.

Why a European strategy on rare diseases?

- 27 - 36 million people in the EU affected
- Highly specific public health area
 - limited number of patients
 - scarcity of knowledge and expertise
 - economics of scale at EU level
- High potential for effectiveness and efficiency
 - recognition and visibility of rare diseases
 - support rare diseases policies in the MS
 - cooperation, coordination and regulation at EU level

What is the EU doing?

Helping to pool scarce resources that are currently fragmented across individual EU countries. Joint action helps patients and professionals share expertise and information across borders.

Specific measures include:

- **improving** recognition and visibility of rare diseases,
- **ensuring** that rare diseases are adequately coded and traceable in all health information systems,
- **supporting** national plans for rare diseases in EU member countries,
- **strengthening** European-level cooperation and coordination Choose translations,
- **creating** European reference networks linking centres of expertise and professionals in different countries to share knowledge and identify where patients should go when expertise is unavailable in their home country,
- **encouraging** more research into rare diseases,
- **evaluating** current screening population practices,
- **supporting** rare diseases registries and providing a European Platform for rare diseases registration.

Policy framework

- Commission Communication on Rare Diseases: Europe's Challenge
- Council Recommendation on action in the field of rare diseases
- Implementation report on the Commission Communication and Council Recommendation on Rare Diseases

COMM(2008)679

2009/C 151/02

COM(2014) 548

(2008) Commission communication on Rare Diseases: Europe's challenges

Access to specialised social services

Centres of expertise may also have an essential role in **developing or facilitating specialised social services** which will improve the quality of life of people living with a rare disease.



Council recommendation of 8 June 2009 on an action in the field of rare diseases (2009/C 151/02)

Plans and strategies in the field of rare diseases

to elaborate and adopt a plan or strategy ...aimed at guiding and structuring relevant actions in the field of rare diseases within the framework of their health and **social system**

Research on rare diseases

Identify needs and priorities for basic, clinical, translational and social research in the field of rare diseases and modes of fostering them, and promote interdisciplinary co-operative approaches to be complementarily addressed through national and Community programmes.

Gathering the expertise on rare diseases at European level

Gather national expertise on rare diseases and support the pooling of that expertise with European counterparts in order to support:

(a) the sharing of best practices on diagnostic tools and medical care as well as education and **social care** in the field of rare diseases.

National plans and strategies

23 Member States have national plans or strategies adopted

before 2009 there were 4 countries with national plans in place

Governance and coordination at EU level

- **Commission expert group on rare diseases**
 - Composed of Member States representatives, patients' representatives, industry, scientific societies, individual experts
 - Seventh meeting in April 2016
 - Recommendation on ways to improve codification for rare diseases in health information systems
 - Addendum to previous recommendations on ERNs
 - Cross border genetic testing of rare diseases in the EU
 - Incorporation of rare diseases into social services and policies



Adoption of the Recommendations to support the incorporation of RD into Social Services

*- 7th meeting of the Commission Expert Group
5-6 April 2016*

Holistic care for rare diseases patients

Providing holistic care to people living with Rare Diseases (RD) is particularly challenging because:

- Expertise and knowledge on RD and their consequences are scarce and difficult to access;
- RD are often chronic, highly complex, severely disabling and frequently affect life expectancy;
- No specific treatment is currently available for most RD and existing treatments are not always able to minimise all the complex impairments generated by the disease;
- A high percentage of people with a RD are affected by motor, sensorineural or intellectual impairments, which can occur simultaneously;
- Even when they are not associated with a disability, RD will in many cases influence the person's health condition and impact on daily life in a disabling way.

Key principles



Health is a state of complete physical, mental and social well-being;

- Social dimension, and with it, social services contribute to core values and objectives of the EU Member States and of the European Union, such as achieving a high level of employment, social protection, health protection, gender equality, and economic, social and territorial cohesion;*

- Social services aim at improving citizens' quality of life and at providing social protection. They assist vulnerable individuals and persons who have a range of special needs and risks, such as those needing long term care or facing disability, poverty and those at risk of social exclusion;*

Key principles



- Social care consists of helping people to participate fully in all aspects of life, particularly those who require extra help. Social care workers contribute to help individuals maintain their independence, which increases their quality of life and helps them lead fuller more enjoyable lives;*
- Social services are often closely interlinked with health services. Experts consider that there is a need for a chain of actors and providers to take care of individual needs and to provide solutions in an integrated and coordinated manner*

«These recommendations mainly focus on empowering health services attempt to facilitate integrated care provision to enable them to play the role they need to play in supporting the integration of RDs' specificities into mainstream social and support services, within a holistic and person-centred approach and a human rights perspective.»

Target



«These recommendations aim at advising Member States and the European Commission on issues that should be considered when organising the holistic care of RD patients within national health and social care systems.

EU funding programmes should be mobilised to support the implementation of these recommendations.

The recommendations mainly focus on rare and very complex conditions which ... have specific needs. »

***1.** The incorporation of RD specificities into mainstream social services and policies is a necessary element to be considered in future National Plans and Strategies (NP/NS) for RD and should be incorporated when existing NP/NS are evaluated and revised. In particular:*

- Training of professionals should be promoted;**
- High quality information should be made available.**

2. Centres of Expertise have a key role in facilitating integrated care provision in line with the EUCERD recommendations on Quality Criteria for Centres of Expertise on Rare Diseases²² (4, 9, 10):

- **Centres of Expertise (CEs) bring together, or coordinate, within the specialised healthcare sector multidisciplinary competences/skills, including paramedical skills and social services;**
- **CEs provide education and training to (...) non-healthcare professionals (such as school teachers, personal/homecare facilitators);**
- **CEs contribute to and provide accessible information adapted to the specific needs of patients and their families, of health and social professionals.**

3. *European Reference Networks for RD have a key role in facilitating integrated care provision in line with the EUCERD recommendations on European Reference Networks for Rare Diseases (10)23 and the Directive on patients' rights in cross-border healthcare (Article 12, 4-ii):*

- Rare Disease European Reference Networks (RD ERNs) need to collaborate with each other, as well as with patient groups, health and social care providers;**
- RD ERNs follow a multi-disciplinary approach;**
- RD ERNs could function as a platform to share experiences and promote cooperation between MS, to develop precise descriptions of the services required and elaborate common guidelines.**

4. 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. In particular:

- MS should ensure that people living with a RD are afforded the same standards of care and support as the ones available to other citizens with similar requirements;**
- MS should recognise the particular challenges posed by rare and complex conditions.**

5. MS should promote measures that support patients/families affected by RD to participate in decisions regarding their care plan and their life project:

- MS should develop information and training tools for patients and families affected by a RD which empower them and increase their capacity to undertake a participative role in care provision;**
- Care providers should be prepared to give non-directive assistance and support patients and families to express their wishes, set priorities, take decisions and direct their own services if they wish to do so.**



6. *Transfer of information between care providers, within the limits of data protection legal frameworks, should be promoted to support holistic care provision.*

7. *MS should promote coordination and networking between all parties involved in the care provision of persons affected by RD, including public, private and civil society organisations as well as between providers and patient/disability organisations.*

8. *RD specificities should be integrated into national systems assessing a person's level of functioning, in line with the United Nations Convention on the Rights of Persons with Disabilities.*



9. *The elaboration and dissemination of good practices for social care in RD should be encouraged.*

10. *Socio-economic research in the field of RD care provision/organisation should be supported both at MS level and at European Union level. Support should be provided for research on the following topics:*

- Socio-economic burden of RD;**
- Accessibility and appropriateness of healthcare services, including social services, for people living with a RD and their families;**
- Effectiveness and cost-effectiveness of social services and support, as well as rehabilitation and assistive technologies for people with a RD;**
- Innovative care practices in health and social services and their impact on the quality of life of people living with RD.**

Thank you!

