

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

The EU-funded [INNOVCare project](#) supported the implementation of the European Commission Expert Group on Rare Diseases [Recommendations to Support the Incorporation of Rare Diseases into Social Services and Policies](#).

The project **voiced the everyday challenges faced by people living with a rare disease and aimed at bridging the gaps in the co-ordination between medical, social and support services in the European Union Member States.**

The first European-wide survey on the everyday impact of rare disease was conducted within the project by EURORDIS survey initiative (Rare Barometer Voices). The results of the survey "[Juggling care and daily life: the balancing act of the rare disease community](#)" (3000 respondents, patients and carers) **provide evidence on the serious impact of rare diseases and complex care pathways on daily life, mental health and work-life balance.**

INNOVCare also developed and evaluated a pilot of a holistic and integrated care pathway, using a [resource centre for rare diseases](#) and **regional case managers**. This **case management implementation led to various positive outcomes within important daily life and care areas for people living with a rare disease and their families, while also bringing efficiency gains to the care system.**

Additional research done within the project and the project's multi-stakeholder workshops (100 experts from 24 countries involved) aimed at identifying **key priorities that EU Member States and other European countries need to address to implement mechanisms that ensure integrated health and social care.**

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The INNOVCare partners RECALL:

- The Universal Declaration of Human Rights;
- The United Nations Convention on the Rights of Persons with Disabilities;
- The European Charter of Fundamental Rights;
- The European Pillar of Social Rights, in particular principles 9. Work-life balance, 16. Health care, 17. Inclusion of people with disabilities, 18. Long-term care; The European Commission's proposal for a Work-Life Balance Directive;
- The Commission Expert Group on Rare Diseases Recommendations to Support the Incorporation of Rare Diseases Into Social Services and Policies, in particular recommendation 4 on holistic care provision.

Only by implementing mechanisms that ensure integrated care and integrated service delivery, coordinated between health, social and community services can the EU, its Member States and other European countries ensure that the principles set by these important policies are effectively achieved.

**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 gather and share of knowledge/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, Orphanet and other multi-stakeholder platforms that can further 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.**