

Drivers and obstacles of integrated care in different national contexts

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Aim of the project

INNOV-Care aims to improve care systems for people with rare and complex needs by bridging the gap in the co-ordination between medical, social, educational and support services in the European Union Member States. It develops and tests a **holistic, person-centred care pathway, based on a case management approach**, and analyses its potentials to be scaled in different national contexts. Recent research on the social dimension of rare diseases showed that the problems patients and their families face are strikingly similar across the varied health and welfare systems in different European countries (EURORDIS 2017). However, ways to approach integrated care differ strongly as legal frameworks, awareness of policymakers and welfare traditions need to be taken into account. The poster focuses on **key elements of integrated care models, obstacles and drivers** to approach integrated care. It thereby takes a comparative perspective: based on the analysis of 30 expert interviews it gives insight into the situation and developments in four different EU member states.

Methods

To detect different approaches to integrated care a heterogeneous sample of European countries has been selected: Austria, Romania, Spain and Sweden. They are representing different types of welfare states and public administration systems, countries of different size, GDP per Capita, and have a diverse geographic representation across the EU. In a first step we interviewed different relevant stakeholders, who are involved in the provision of health and social care (i.e. policy makers, health and social care professionals, patient representatives, patients, main carers, families). Analysing the interviews we identified possible **aims of holistic care, approaches to reach the aims** as well as **obstacles and barriers** to improve the national care systems for patients with complex needs and their families. In a next step these findings will be discussed with the experts interviewed and other decision makers in order to commonly decide by which means and in which timeframe the next steps toward holistic care systems can be taken.

Key elements of integrated & holistic care

Holistic, integrated care models aim at reducing fragmentation and improving continuity and coordination of care. Yet, there is no consistent definition of integrated care model as focus and content of integrated, holistic care programs differ strongly (Ouwens 2005, 141). According to the experts interviewed the main components that are important to address in the context of RD are:

- ❖ patient-centred care
- ❖ care concepts involving the social surrounding and relatives of the patients
- ❖ Empowerment of the patients and patients' organizations
- ❖ Ensuring a low-threshold and encompassing access to health and social care

- ❖ Access to specialized knowledge on RD
- ❖ Continuity of care
- ❖ Collaboration and coordination on the political level
- ❖ Collaboration of health and social care professionals

Austria	Romania	Spain	Sweden
Universal system, doctor centered-care system giving little competences to other care professionals	Basic welfare state, scarce resources, access to social care is dependent on income, strong regional differences	Universal system with a strong autonomy of the regions that allows innovations of care systems	Inclusive, universal care system, based on universal rights
NAP on RD, little awareness of policy makers for the needs of RD patients and their families	NAP on RD, control of the use of the scarce resources, limited access even though there are special programs	NAP on RD, strong awareness of the needs of RD patients, regional care plans for RD patients	No NAP for RD – but: Inclusive rights for all citizens regarding the provision of health and social care

Obstacles

Enablers

Making RD visible

- Lack of awareness among key stakeholders
- Implementation of effective measures is strongly dependent on the support of individual policy

- Creating awareness among politicians and the public to make them understand the complex needs of a heterogeneous group of patients through information campaigns targeting traditional and social media
- Data bases that assess the health and social care needs on a local and on a national level to facilitate planning of its supply. Those data bases need to encompass information on the needs as well as on existing services
- Mainstreaming RD knowledge by integrating it into the training of care professionals and by setting up informative guidelines

Structural coordination & cooperation: Coordination between Political Bodies

- Federalism and regionalism hinder the exchange of knowledge and collaboration between services
- RD falls into responsibility of social ministry, health ministry and ministry of education
- Legal frameworks and funding schemes hinder stronger collaboration

- Stronger involvement and accountability of local administration
- Coordinated budget for health and social care provision
- Budget dedicated to the coordination of political bodies
- Qualified staff responsible for communication and mediation
- Learning how to collaborate – building on positive experiences

Structural coordination & cooperation: Collaboration between different care professionals

- Doctors-centred health care systems: Doctors are not used to collaborate with other health care professionals
- Failure to cooperate poses a risk for the continuity of care

- Public procurement to foster collaboration
- Recognizing the competences of health and social care professionals
- Training different professionals together (with patients)
- Intervention plans/protocol of treatments

Professionalization of coordination of care

- Best point of service for CM?
- Contradicting expectations towards the role of CM
- Professional working conditions need to be established (Training/ Supervision)

- Trainings for CM and training for doctors
- Networks and information on available services
- Legal frameworks and commissioning
- Building on existing resources (i.e. Community nurses who can be trained as CM)

Empowerment of patients & Engagement

- little information on the diseases
- No confidence in the patients abilities to organise care
- Limited access to social and health services for care giving relatives
- Limited resources for interest groups

- Case management/ holistic care systems
- Communication training for doctors and more time for counselling
- Guidelines for patients and professionals
- Involvement of interest groups into the legislative process

Support for the social environment of patients

- RD can impose a financial, physical, mental and emotional burden on families
- Lack of psychological support and social services for parents and siblings
- Time constraints of family carers limit their possibilities to make use of therapies and social services for them
- Lack of awareness of and support for teachers, day-care teachers, work colleagues and school mates are a potential barrier to the social inclusion of people with RD

- Psychological support and social services for family members must be organized in away that allows them to make use of it.
- Support for families in daily life activities (domestic work) and mobility
- Guidelines for teachers, social workers and other social care professionals to inform them on the RD and support measures that enable them to play an active role in the social inclusion of people with RD

Conclusion

The four countries in question differ in the way they finance and organize social and health care. Nevertheless, they are all confronted with similar obstacles when it comes to the establishment of a holistic, integrated and inclusive health and social care system for people with RD. In order to overcome these obstacles, it is important to build on existing resources as well as to look for innovative care models that have proved to be successful in other contexts. Improving the health and social care system for people with RD by making it more holistic, integrated and inclusive will not only be for the benefit of this patient group, but for other patient groups with complex conditions as well as to the general population.

Further steps

- Up scaling processes are engaging different relevant stakeholders. The process enables the involved experts and decision makers to
- detect innovative and inspiring solutions to holistic care tested and implemented in other contexts
 - It fosters awareness for the problem patients with complex needs and their families are confronted with in everyday life
 - It gives the stakeholders involved a possibility to get to know different perspectives on the problem
 - It provides a protected field where they can learn to collaborate and to develop a common vision of the problems that need to be addressed
- Up scaling in the health and social field therefore is a collective learning process without a predetermined conclusion, building on the experiences and insights created in the process.