

INNOV Care

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

Key issues for the implementation of integrated care for rare diseases

Preliminary results from expert interviews

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Detecting pathways to holistic care

- Detecting **regional and national potentials** to approach holistic care via **Expert Interviews** in four countries (Austria, Romania, Spain, Sweden)
- Identifying possible **aims of holistic care, approaches to reach the aims** as well as **obstacles and barriers** to improve the national care systems for RD patients and their families
- Discussing possible „next steps“ that can be taken to approach holistic care together with relevant **stakeholders and decision makers**

Experts interviewed

- Interview Partners in Austria, Romania, Spain and Sweden (30):
 - **Policy:** national and regional policy makers and administration (health and social)
 - **Service providers and care giving professionals:** Social and health care
 - **Patient representatives**
- Relevant criteria for the selection of interview partners:
 - Decision power and competence in the relevant policy fields
 - Continuity: People interviewed before
 - Expertise: Recommendations of interview partners
 - Diversity: Local and regional best practice examples as well as regional and national problems identified



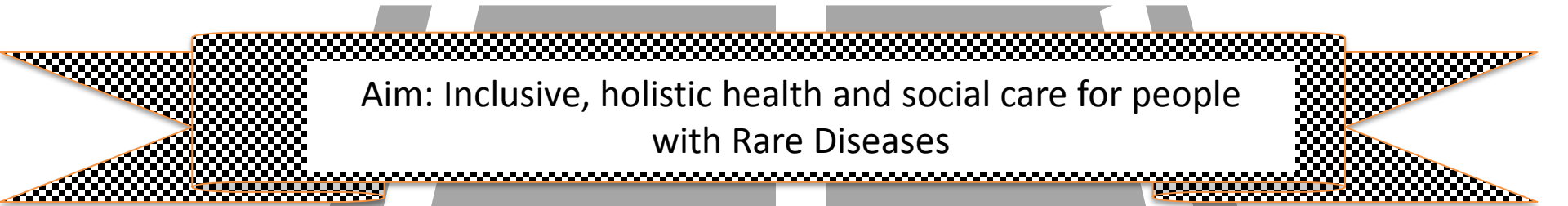
Aim: Inclusive, holistic health and social care for people with Rare Diseases



Obstacles and Enablers

Approaches to reach the aim

Starting Point: The current stages of the national health and social care systems



Aim: Inclusive, holistic health and social care for people with Rare Diseases

- Patient-centred care
- Including the social context of the patients
- Ensuring a low-threshold and encompassing access to health and social care
- Access to specialized knowledge on RD
- Collaboration of health and social care professionals
- Continuity of care
- Collaboration and coordination on the political level
- Empowerment of the patients and patients' organizations

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Obstacles and Enablers



Approaches to reach the aim

Starting Point: The current states of the national health and social care systems



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The current state of the national care systems

- Characterization of the current state of the national care systems **by the interview partners**
- Additional information on the national care systems was added by **literature research**

To **compare different national care systems** regarding the inclusion of patients with complex needs means:

- To focus on differences between the systems to identify local peculiarities, advantages, disadvantages and innovative solutions
- An in-depth analysis of the national system is not possible

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The current state of the national care systems

Austria	Romania	Spain	Sweden
Universal system, doctor centered-care system giving little competences to other care professionals	rudimentary 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, regionals care plans for RD patients	No NAP for RD – but: Inclusive rights for all citizens regarding the provision of health and social care

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Obstacles and Enablers



Approaches to reach the aim



Starting Point: The current stages of the national health and social care systems

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Potential Approaches

- Making RD visible
- **Coordination and cooperation in social and health care**
- **Professionalisation of the coordination of health and social services**
- **Empowerment of the patients**
- Support for the social environment of RD patients

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Obstacles and Enablers



Approaches to reach the aim

Starting Point: The current stages of the national health and social care systems

Structural coordination & cooperation: Coordination between Political Bodies

• Barriers



- 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

• Enablers

- 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

• **Barriers**



- Doctors-centred health care systems: Doctors are not used to collaborate with other health care professionals
- Risk for the continuity of care

• **Enablers**

- 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



Professionals have to accept that they are cannot be ,experts for everything‘

Professionalization of coordination of care

Counselling, personal support and contact point for patient and families, coordination of services, coordination of professionals, guarantee continuity of care

• Barriers



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

You need to have the right personality

• Enablers

- 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

• Barriers



- 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

• Enablers

- 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



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Thank you!

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