

INNOVCare

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

INNOVCare's pilot implementation in Romania

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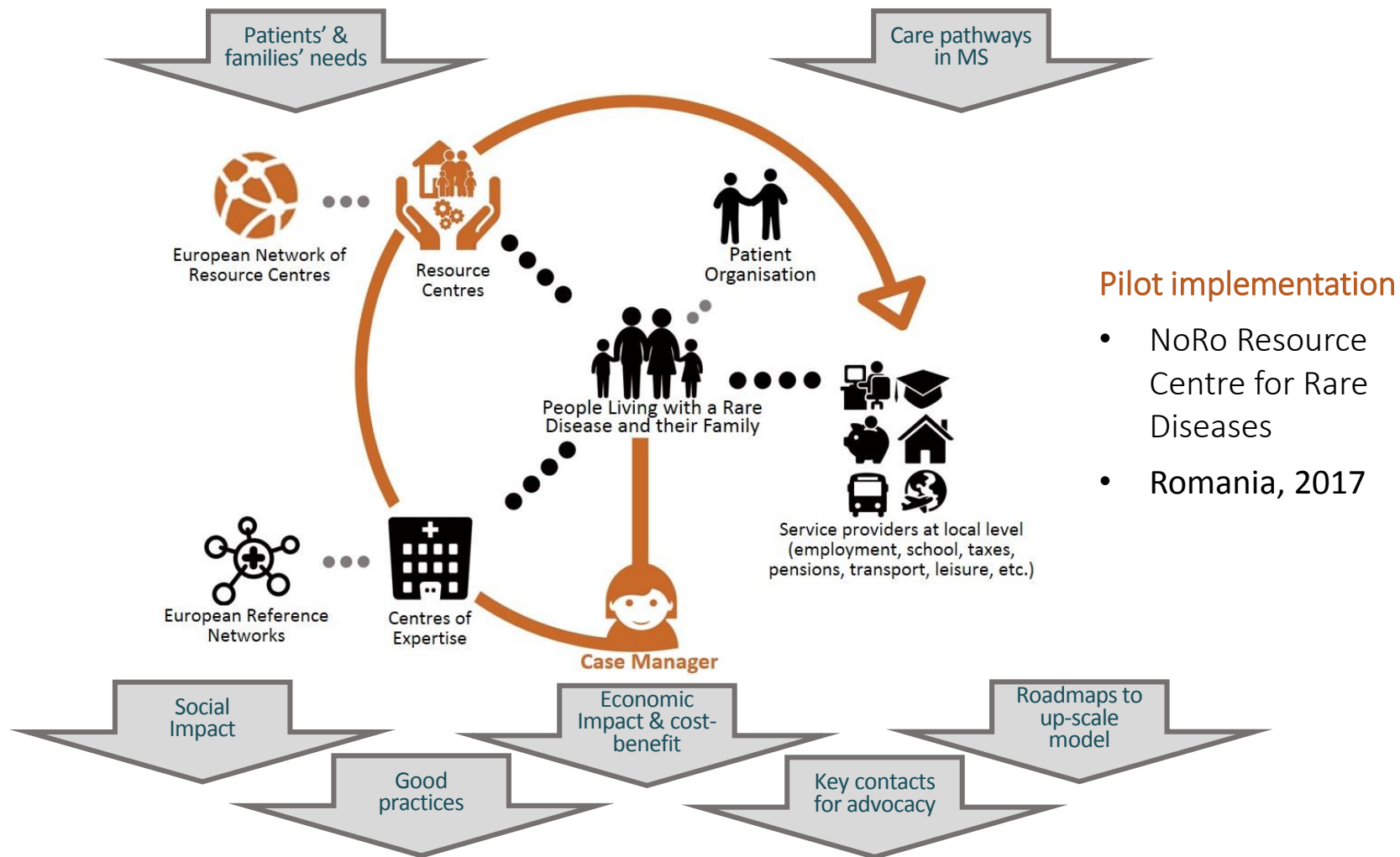
INNOVCare Workshop on Improving Integrated Care for People Living with Rare Diseases and Complex Conditions—Gothenburg—8-9 September 2016

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Pilot implementation

- NoRo Resource Centre for Rare Diseases
- Romania, 2017

Needs of people living with a rare disease

- ✓ **Rare diseases have significant impact on the daily life of patients & families**
 - ✓ **Access to services and support is limited**
- ✓ **Patients' access to information on relevant specialists, services, rights and financial support is limited**
 - ✓ **Significant time is invested on illness related tasks;**
 - ✓ **Difficulties to manage time spent organising care**
 - ✓ **Difficulties managing their health related administrative procedures**
- ✓ **Difficulties with managing the time spent explaining the disease to different experts and professionals**
- ✓ **Difficulties to handle their visits to health and social support services/specialists in a short period of time**
 - ✓ **Communication/exchange between different service providers is not good**
 - ✓ **Professionals' knowledge of consequences of the disease is limited**
- ✓ **Professionals not prepared to support in dealing with the consequences of the disease**

Based on preliminary results of ongoing study conducted by EURORDIS, via [Rare Barometer Voices](#), in European Countries:
1200+ respondents across Europe and diseases - 63% patients, 35% parents, 2% spouses, 2% grand-parents

National context in Romania

- Rare Diseases in Romania: declared a national priority, too often forgotten, considered costly and patients with NO real chance for cure...



- *Lack of integrated services addressed to those affected by rare diseases, to facilitate the diagnose and to give the power to go forward and look for treatments, therapies, rehabilitation, inclusion in school and community...*

NoRo Resource Centre for Rare Diseases



NoRo Resource Centre for Rare Diseases

- Opened in June 2011 through a project of the Romanian Prader-Willi Association, funded by Norway grants (Frambu as partner)
- NoRo is:
 - **A Resource Centres for Rare Diseases** in Romania
 - Recognized as a healthcare provider and Centre of Expertise, involved in European Reference Networks;
 - **One-stop-shop style of service**, specifically designed for people living with a rare disease, **combining health, social and educational services**;
 - Creating a **bridge** between patients/families and various professionals and services involved in patient care;
 - **Involving patients** at local, county and national level in our services;

NoRo Resource Centre – Beneficiaries

- People affected by rare diseases in Romania and their families;
- Professionals involved in the diagnosis and management of these diseases.



NoRo Resource Centre – Services

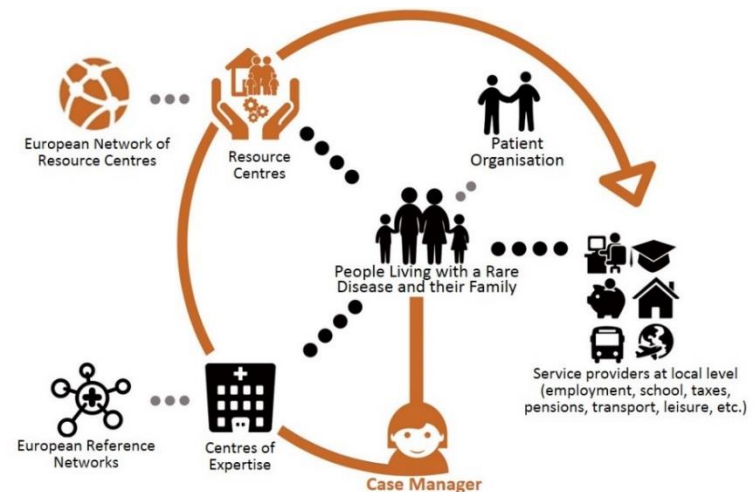
- Day care centre for children: therapies, educational and entertainment activities
- Therapeutic education/counselling on disease management for patient/families
- Trainings - eUniversity
- Conferences
- Helpline for rare diseases: information and counselling
- Multidisciplinary evaluation (medical, social, kinetic, psychological)
- Rehabilitation services and therapies
- Information and connection with local social services
- Patient registry
- Health services: psychiatry, genetics, paediatrics, neurology
- Information and training for professionals
- Research
- Advocacy



INNOVCare pilot - summary

Regional case managers to be hired by NoRo:

- **To bridge the gaps in coordination between health, social and local services**
- **To reduce care burden for patients and families**
- Time frame: 18 months, 01/2017-06/2018
- Target population:
 - Patients with rare/complex conditions (children and adults) and their families;
 - Current beneficiaries of NoRo and new ones;
 - 120 cases; each case includes patient + family;
 - Each case has access to the service for 9 months;
- Geographical scope: region of Salaj, Romania;
- Number of case managers employed: 2;
- Profile of case managers: social worker and lawyer;
- Nr. of simultaneous “cases” per case manager: 30;
- Service provision focused on a few key areas in order to have more meaningful results.

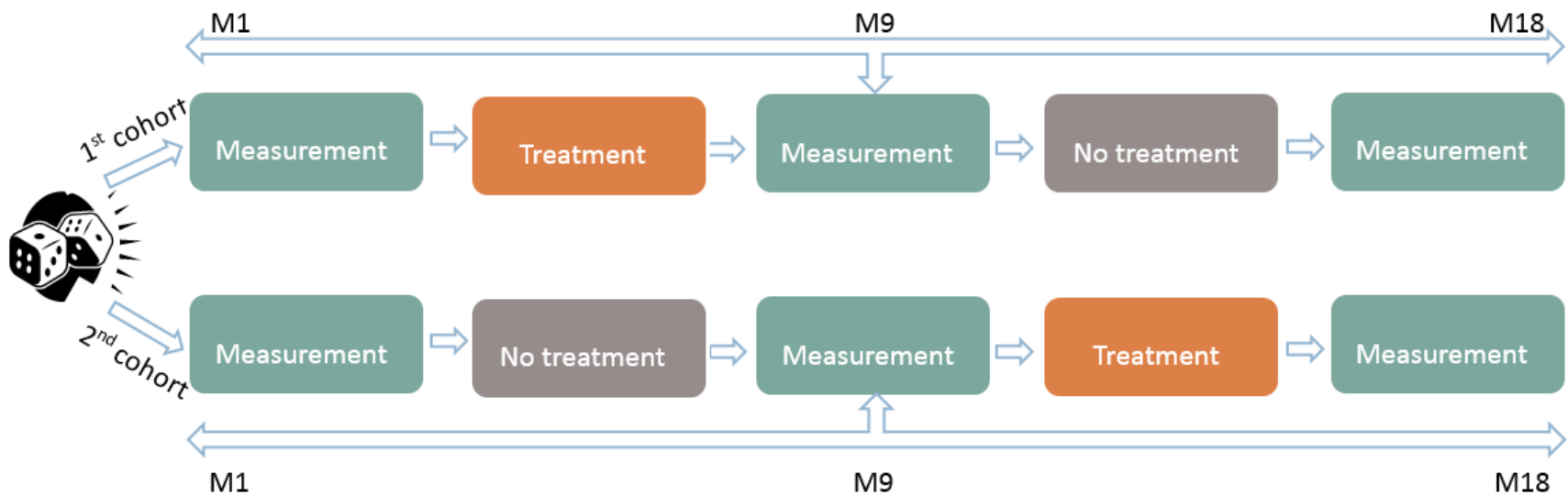


INNOVCare pilot – possible role of the case manager

- **Single and stable point of contact**
- **Listen, inform, support and empower patients and families**
 - Providing knowledge/tools & informing about existing resources
 - Encourage health literacy and compliance to treatments
 - Relief the burden of care provision for patients and families
- **Assessment/monitoring of needs & being an observatory of those needs**
- **Holistic and patient-centred care planning and care co-ordination:**
 - Identify resources available in the territory - services and support
 - Referral to and speed up access to services and support
 - Simplify care pathways, ensure continuous support, support navigation for patients/families and professionals
- **Hub of information and knowledge**
- **Inform, support and empower professionals involved in care provision**
- **Facilitating coordination between services and networks of service providers**
- **Prevention of avoidable high risk situations & limit over-use of health services if not needed**
- **Develop working methods that support empowerment of patients and families**



Proposed method to evaluate impact the INNOVCare pilot - case management at NoRo



A two-condition repeated-measures design

Proposed method to evaluate impact the INNOVCare pilot - case management at NoRo

Randomised control trials (RCTs) - quasi-experiment

- most powerful research design to establish **causality** as well as **effectiveness** of interventions.
- **randomisation**
 - experiment group which receives the intervention
 - control group
 - as similar as possible
 - no systematic differences
- INNOV-Care: **quasi experiment**
 - Limited no. of patients
 - Ethical problem withholding intervention
 - Time and practical constraints

Proposed method to evaluate impact the INNOVCare pilot - case management at NoRo

This model solves 3 challenges

- Ethical factor:
 - delay
- Limited group
 - 60 current + 60 new patients
 - 2 case managers.
 - 30 patients max realistic
- Time
 - 9 month intervention expected to have some effect
 - Group 1: Longer-term benefits possible after 18 months
- Option: 3rd control group outside region

Challenges of this model

Challenges of this model

- Spill-over effects: experiment group → control group
- Anticipation effects
 - Patients
 - Case managers (when working with 9month time constraint)
 - Organisations (learning curve – hopefully!)
- External validity: *representative of the target population in general?*
 - not random sampling
 - Possibly with new recruits
 - But generally limited size and internal variety of group

Evaluating the economic impact of the care model

- Literature review
 - Definition of resource components and measures of benefits
- Mapping of care pathways from WP6 as a structure for the economic model
- Data collection
 - Costs for the care model
 - Costs for and impact on patients and caregivers, e.g.
 - Health care utilisation (different levels of care)
 - Use of prescription medication
 - Health care insurance and cost-sharing
 - Health and general well-being
 - Information about caregivers
 - Impact on caregivers

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Thank you

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