Social and economic impact of a case management approach for people with rare and complex conditions in Salaj, Romania

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Impact of rare and complex conditions

- 65% of people living with a rare disease have to visit different health, social and local support services in a short space of time*
- 67% of people living with a rare disease and caregivers say that different services communicate badly between them*
- 30% of caregivers for people living with a rare disease spend more than 6h per day on health-related tasks*
- 38% of patients and caregivers were absent from work due to health-related issues for over 30 days in the last 12 months*

*Survey conducted via Rare Barometer Voices in the scope of the INNOVCare project.
INNOVCare pilot in short

- **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
- Region of Salaj, Romania
- Four case managers employed by NoRo (resource centre)
- Profile of case managers: social worker and lawyer
- Max 30 simultaneous “cases” per case manager
- Service provision should be focused on a few key areas in order to have more meaningful results
The INNOVCare evaluation design

A basic two-condition repeated-measures design /rotation design

1st cohort

2nd cohort

Measurement → Treatment → Measurement → No treatment → Measurement

Measurement → No treatment → Measurement → Treatment → Measurement

M1  →  M9  →  M18
Methods

Questionnaires to patients and caregivers

Social impact

1. Information about disease
2. Information about rights as a patient
3. Self-management of care
4. Better communication skills
5. Knowledge of available services
6. Disease-related peer-to-peer learning
7. Understanding and acceptance in community
8. Coordination of care among stakeholders

Economic impact

- 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
Participants’ profiles

- **n=120**

- **n=65**

- **n=55**

### Disease:

- Undiagnosed
- Unknown
- ADHD
- Anaemia
- Autistic disorders
- Epilepsy
- Epidermolysis bullosa
- Kidney disease
- Mastocytosis
- Multiple sclerosis
- Muscular dystrophies
- Myeloma
- Neuropathies
- Pervasive development
- Prader Willi
- Ring chromosome 18
- Tetraparesis
- West Syndrome
- Myopathy

### Degree of disability

- No disability
- Severe functional deficiency (without personal assistant)
- Marked functional deficiency
- Moderate functional deficiency
- Severe functional deficiency (with personal assistant)

### Age groups:

- up to 3
- 4 to 7
- 8 to 17
- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65+
Preliminary results: Patients’ HRQoL measured by EQ-5D-Y

Mean EQ VAS score 49.3 vs 58.9 (1st cohort) and 57.0 vs 68.0 (2nd cohort)
Preliminary results: Caregivers’ HRQoL measured by EQ-5D-5L

Mean EQ VAS score 75.6 vs 83.5 (1st cohort) and 72.6 vs 81.2 (2nd cohort)
Preliminary results: Caregiver burden measured by Zarit Caregiver Burden Interview

Mean ZBI score 13.4 vs 12.3 (1st cohort) and 12.9 vs 12.0 (2nd cohort)
Preliminary results: 8 goals of the intervention

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<tr>
<th>Goal</th>
<th>T1 - 1st cohort</th>
<th>T1 - 2nd cohort</th>
<th>T2 - 1st cohort</th>
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4 point Likert scale: 0 'not at all', 4 'very well'

n=52
In summary...

- Intervention successful in terms of social impact e.g. patients are more empowered and informed, have higher self-confidence.
- No real impact on health-related quality of life among patients or caregivers but a positive impact on the reduction in caregiver burden.
- Significant improvement in 6 of the 8 related dimensions covered by the intervention.