

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

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Over 36 million people in Europe (patients and families) are affected by a rare disease (RD). These people are often not sufficiently supported by mainstream social systems and struggle to make the most of their potential throughout their life course. Additionally, caregivers assisting their spouse, patient or offspring may find providing care over the long term challenging, and absence from work or reducing work hours may be necessary.



The INNOVCare project is currently being tested in Salaj County, Romania and suggests:

- holistic, integrated and patient-centred care
- interdisciplinary approach
- linking health services to social and support services

In this pilot 4 case managers have been hired and each case manager support max 30 simultaneous "cases".

## Aim

Our study aims to analyse the social and economic impact, including both resource consumption and potential improvements in patients'/families' quality of life.

## Methods

120 patients with rare and complex conditions randomly assigned to case managers for nine months in two cohorts (Figure 1). The first cohort will receive case management support for nine months and the control group usual treatment. After nine months the groups will be rotated.

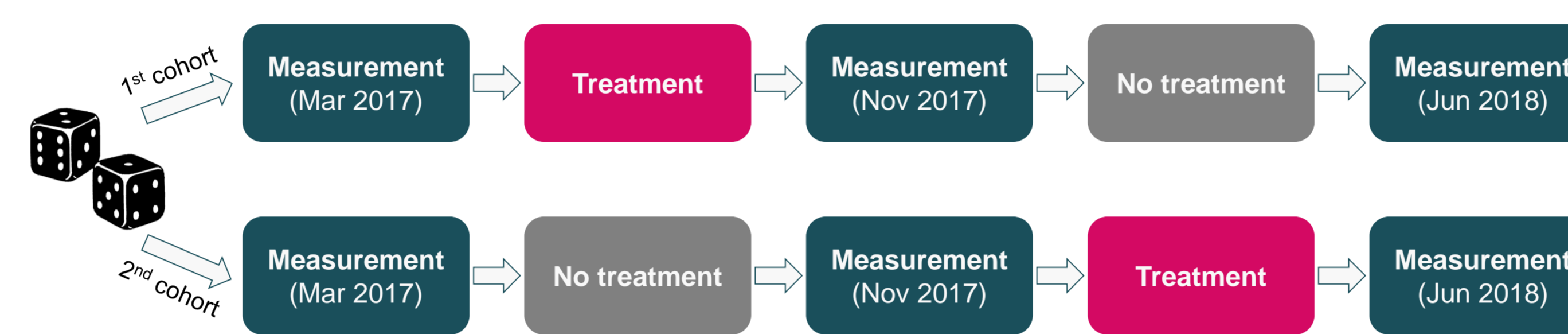


Figure 1. INNOVCare's evaluation model

## Data collection

Questionnaires covering socio-economic status; patients' condition, level of disability, and estimation of need; use of health, social and local services; health-related quality of life (DISABKIDS, EQ-5D-Y and EQ-5D-5L); work situation; and caregiver burden (Zarit Caregiver Burden Interview) were sent to patients and their families at baseline, after 9 months, and after 18 months.

## Background characteristics

Young (<8 years) and older patients with serious cognitive difficulties (n=60) were excluded from this analysis.

Mean age for patients in the 1<sup>st</sup> cohort was 56 years (range 21-76 years) and 43% were women. Mean age in the 2<sup>nd</sup> cohort was 50 years (range 15-77 years) and 68% were women. Among the caregivers, 80% were women.

## Preliminary results

Patients' mean EQ VAS score was 53.3 (SD 24.3) at baseline. The majority reported some or a lot of problems in all dimensions with mobility and pain/discomfort being the most prominent (Figure 2). After 9 months, the mean score was 61.3 (SD 19.3) and 66.2 (SD 18.8) for the 1<sup>st</sup> and 2<sup>nd</sup> cohort, respectively. Patients reported most problems in mobility and pain/discomfort (1<sup>st</sup> cohort) compared to usual activities and anxiety/depression (2<sup>nd</sup> cohort).

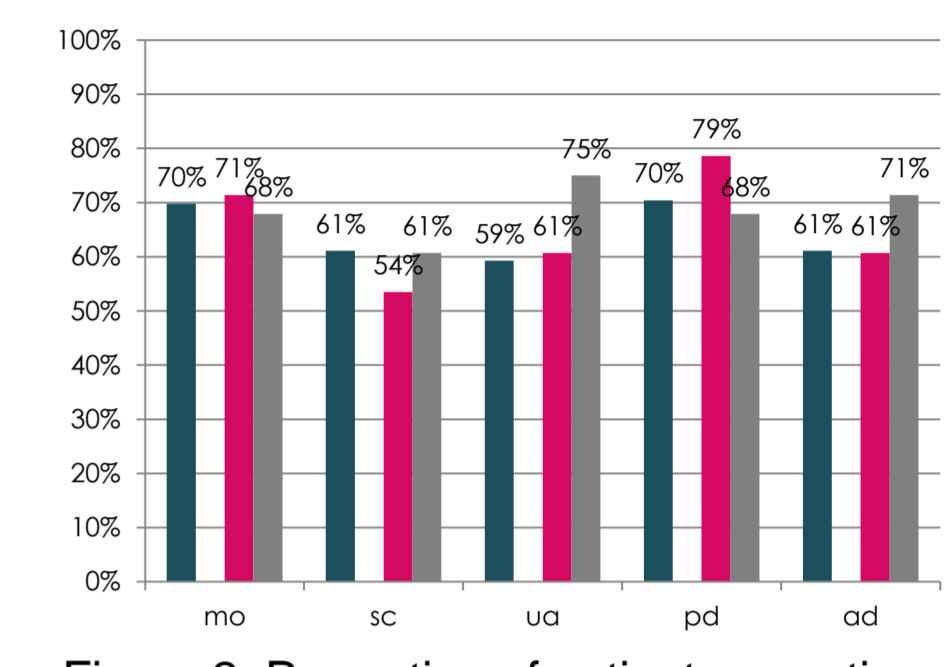


Figure 2. Proportion of patients reporting problems on the EQ-5D dimensions

Caregivers reported a mean EQ VAS score of 74.2 (SD 22.8) at baseline (Figure 3). At follow-up, the mean EQ VAS scores were 83.9 (SD 13.3) and 80.8 (SD 17.6) for the 1<sup>st</sup> and 2<sup>nd</sup> cohorts, respectively. Most problems were reported in pain/discomfort and anxiety/depression.

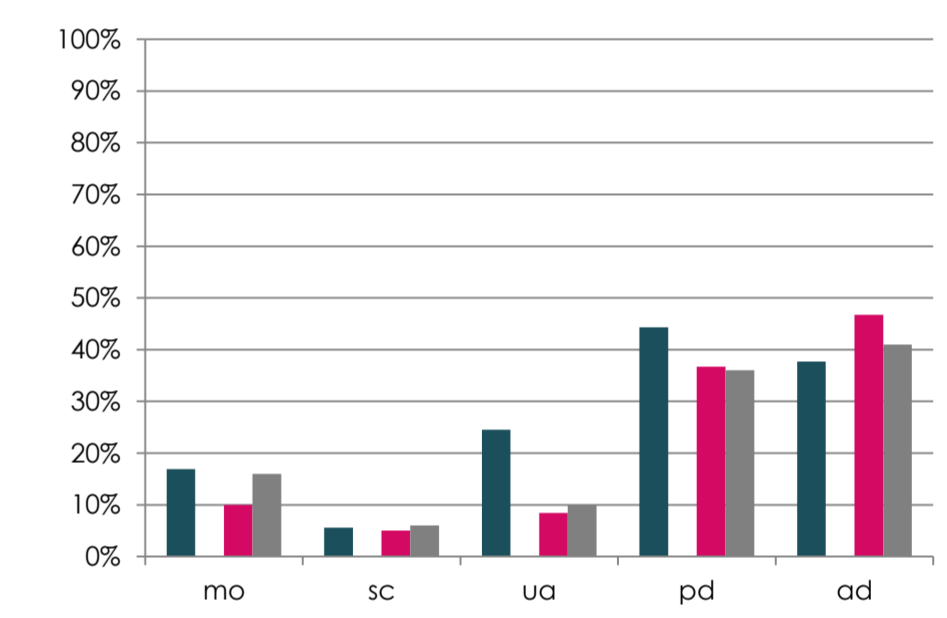


Figure 3. Proportion of caregivers reporting problems in the EQ-5D dimensions

ZBI scores showed a reduction from baseline to first follow-up (Figure 4). Mean ZBI was 13.2 at baseline compared to 12.0 (1<sup>st</sup> cohort) and 12.3 (2<sup>nd</sup> cohort) at follow-up.

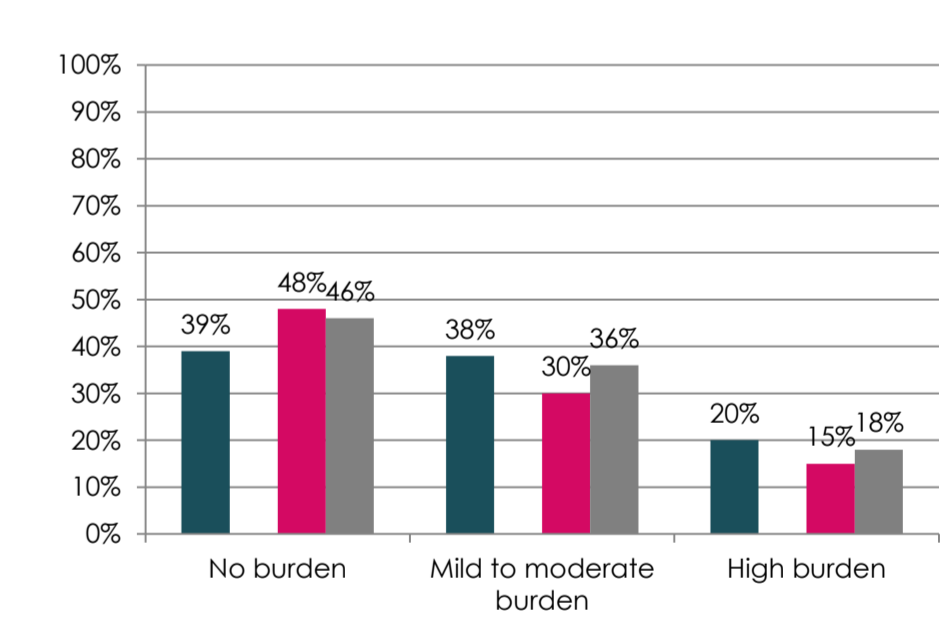


Figure 4. Proportion of caregivers reporting no, moderate or high burden of caregiving

## Next steps

Continued analyses of data to study if a coordinated and more person-centred care has improved the situation not only for the patients, but also for their caregivers in terms of a reduced caregiver burden and less anxiety, stress, and financial pressure.

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Our partners in the INNOVCare project:



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