



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

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*

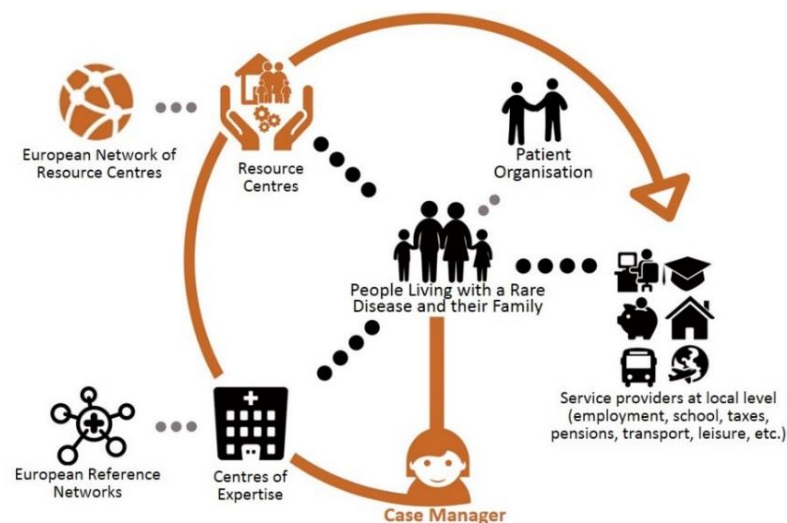
**Survey conducted via Rare Barometer Voices in the scope of the INNOVCare project.*



INNOVCare pilot in short

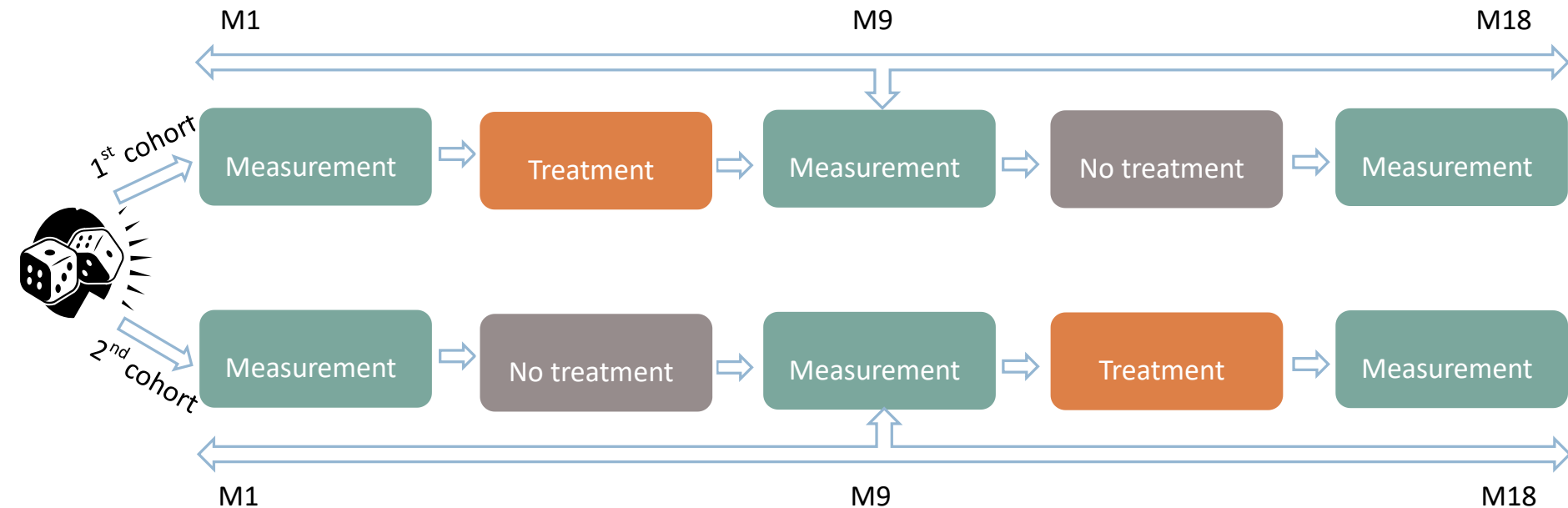
- **To bridge the gaps in coordination between health, social and local services**
- **To reduce care burden for patients and families**

- 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



Methods

Questionnaires to patients and caregivers

WP7

Social impact

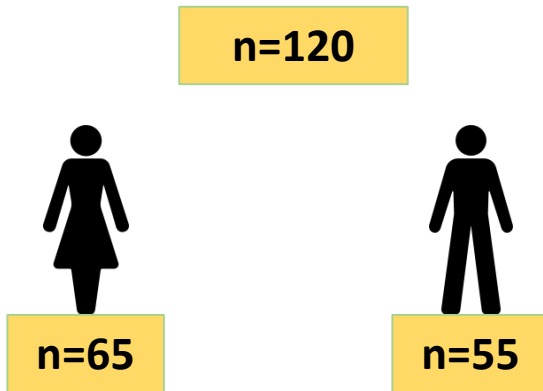
1. Information about disease
2. Information about rights as a patient
3. Self-management of care
4. Better communication skills
5. Knowledge of available services
6. Disease-related peer-to-peer learning
7. Understanding and acceptance in community
8. Coordination of care among stakeholders

WP8

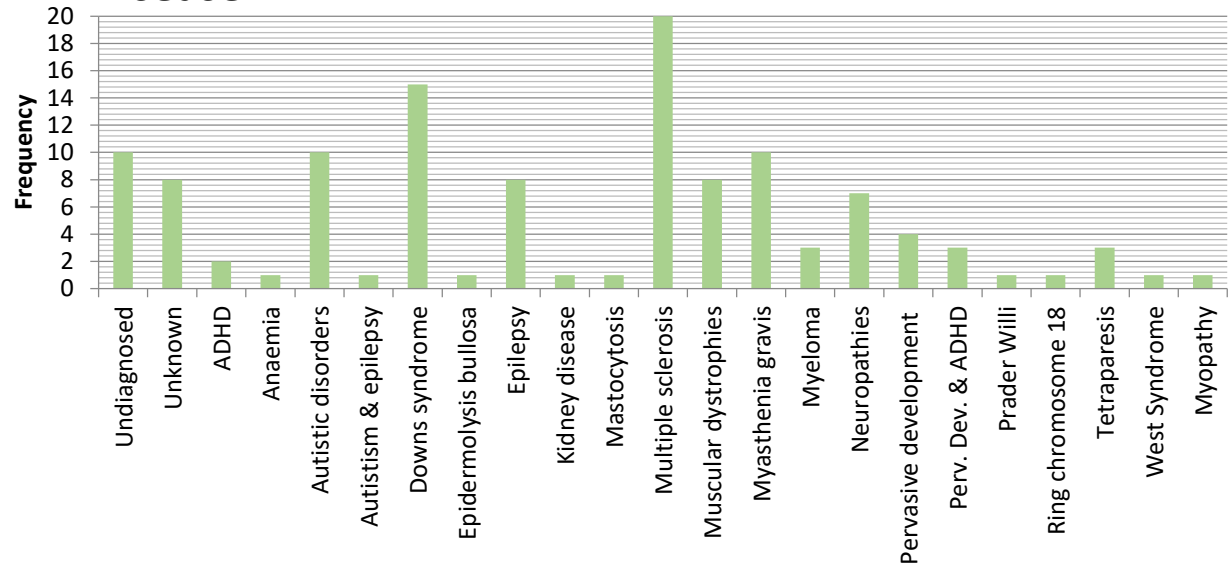
Economic impact

- 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

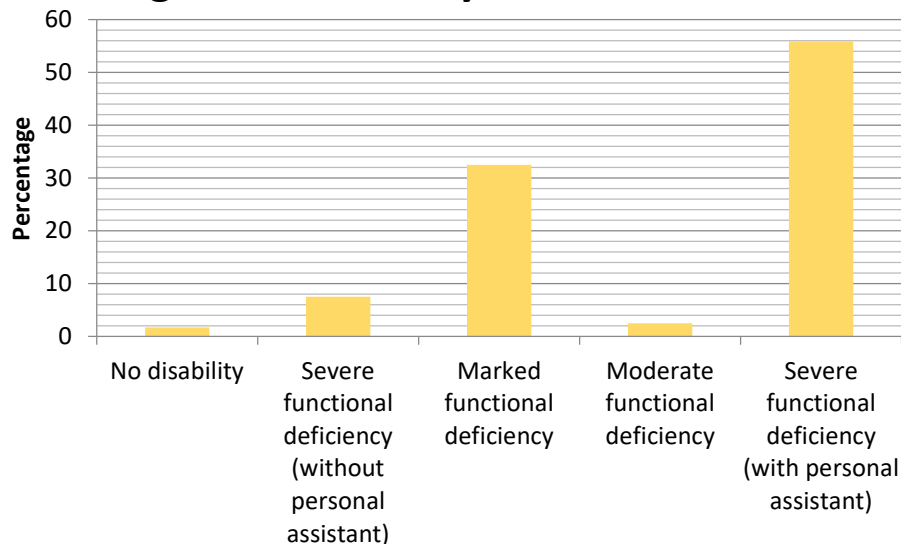
Participants' profiles



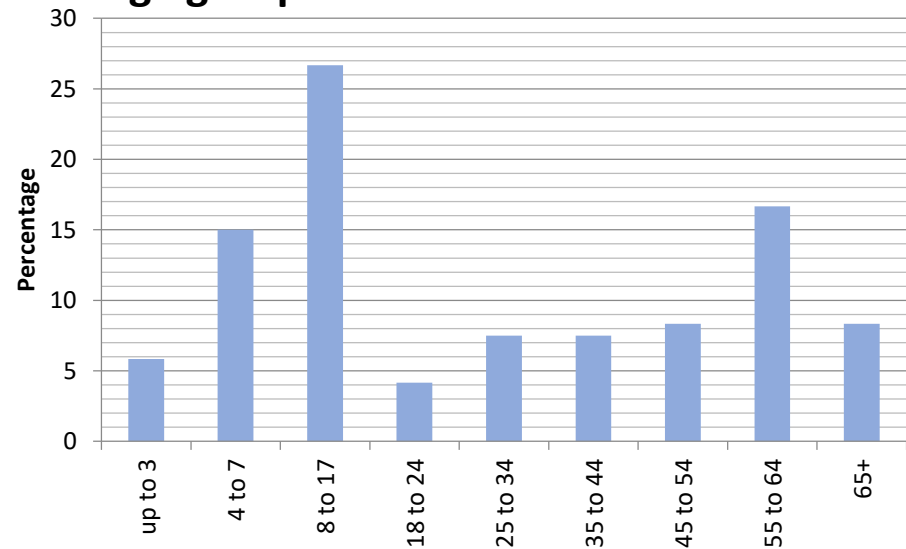
Disease:



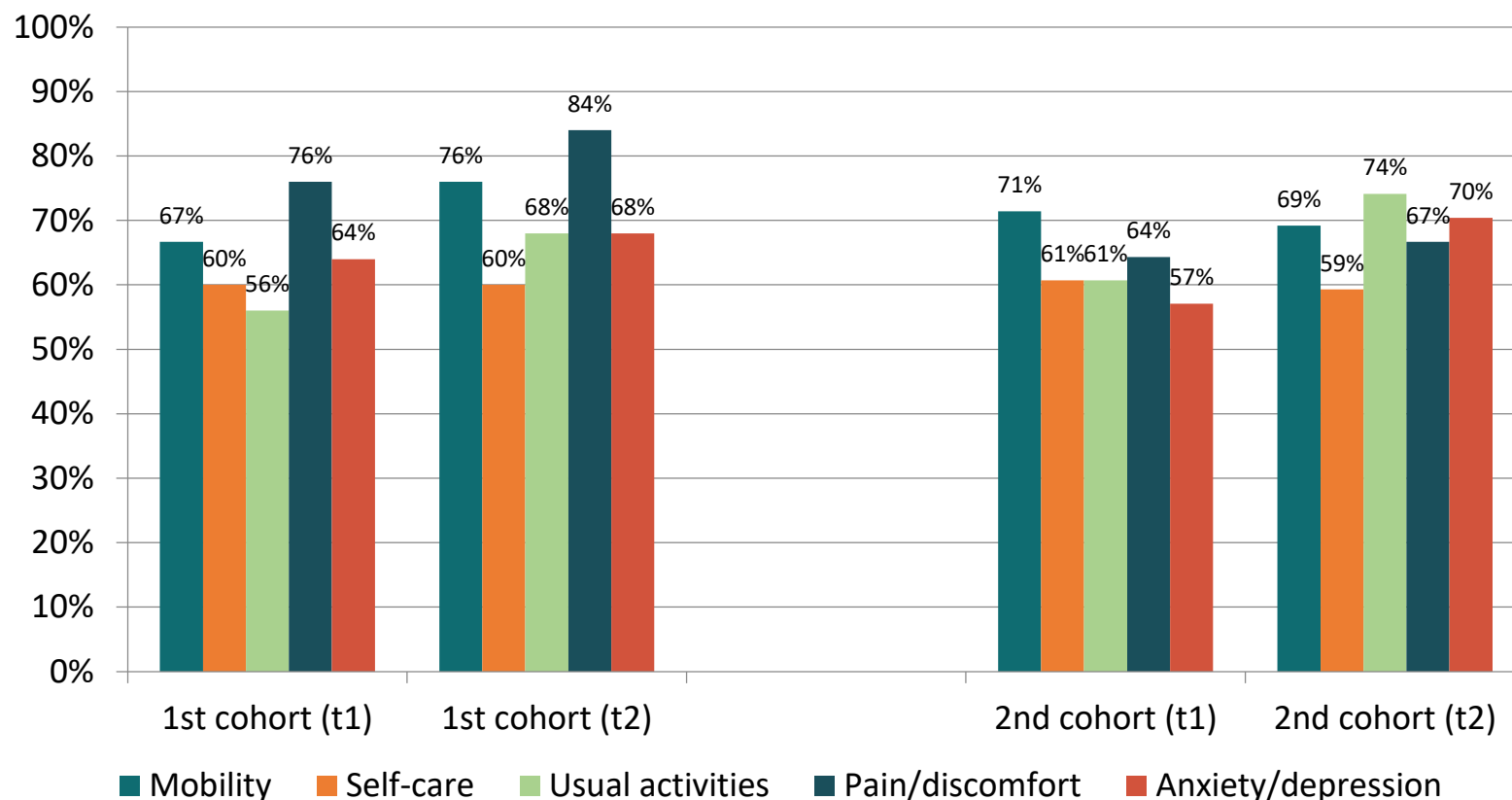
Degree of disability



Age groups:

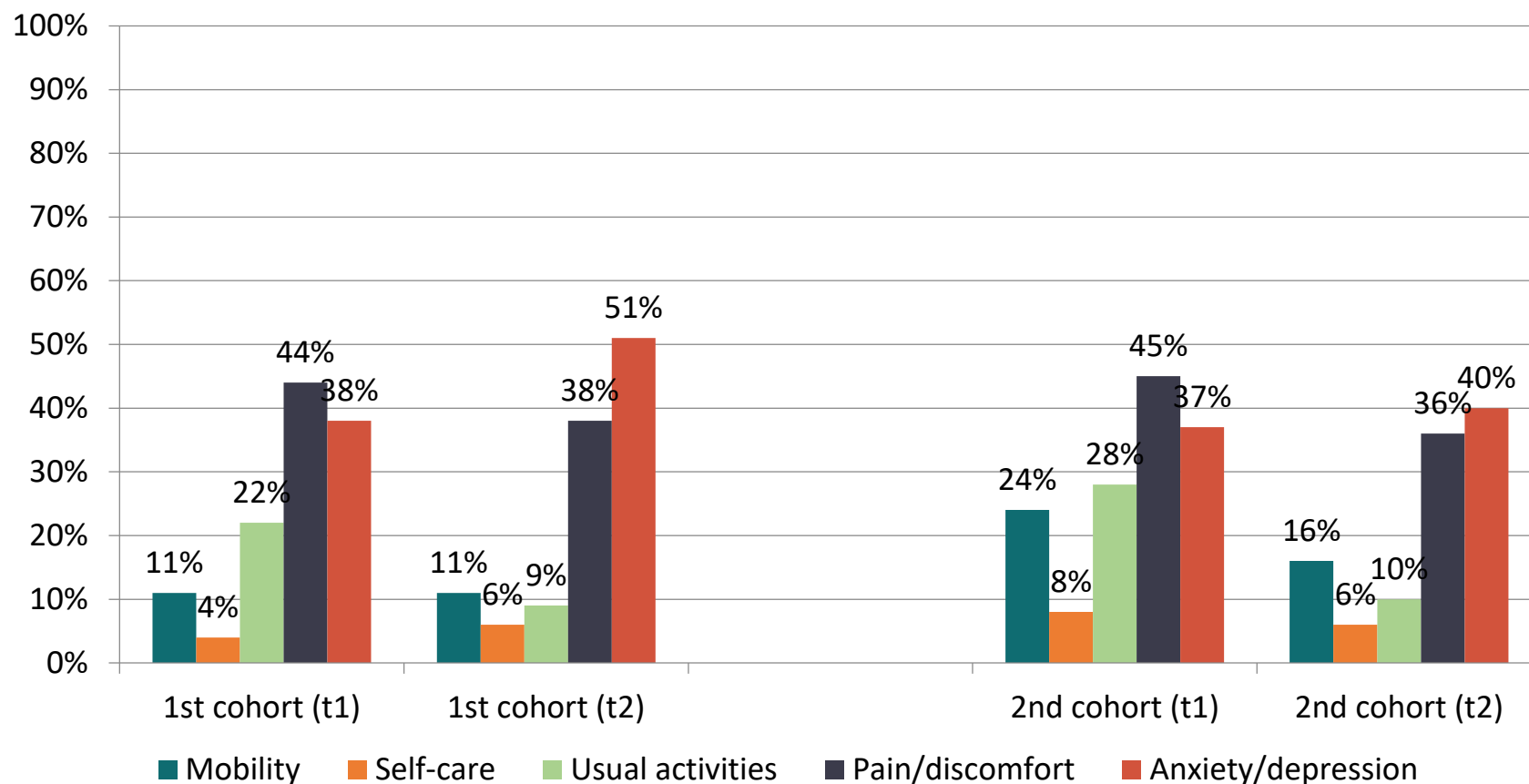


Preliminary results: Patients' HRQoL measured by EQ-5D-Y



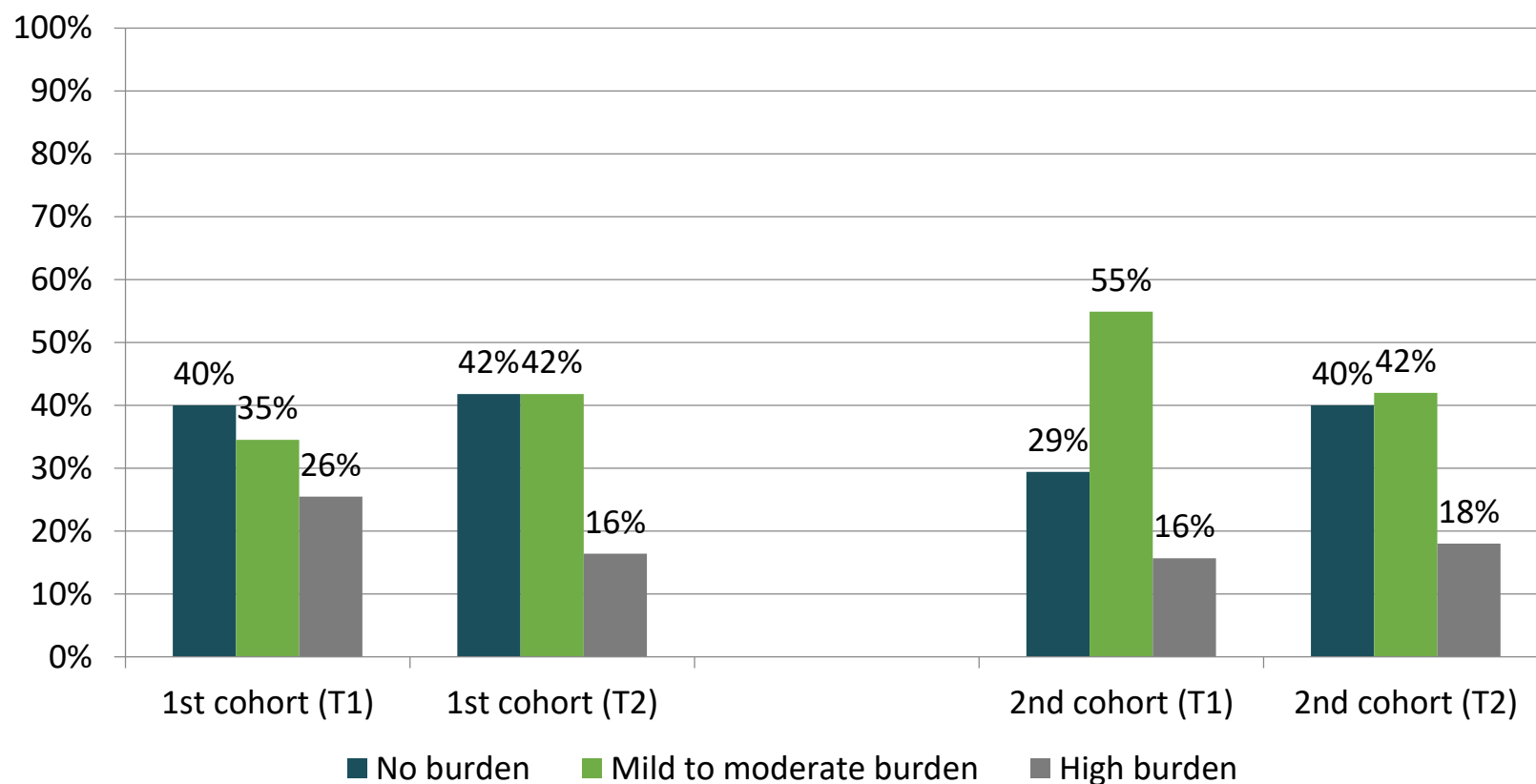
Mean EQ VAS score **49.3** vs **58.9** (1st cohort) and **57.0** vs **68.0** (2nd cohort)

Preliminary results: Caregivers' HRQoL measured by EQ-5D-5L



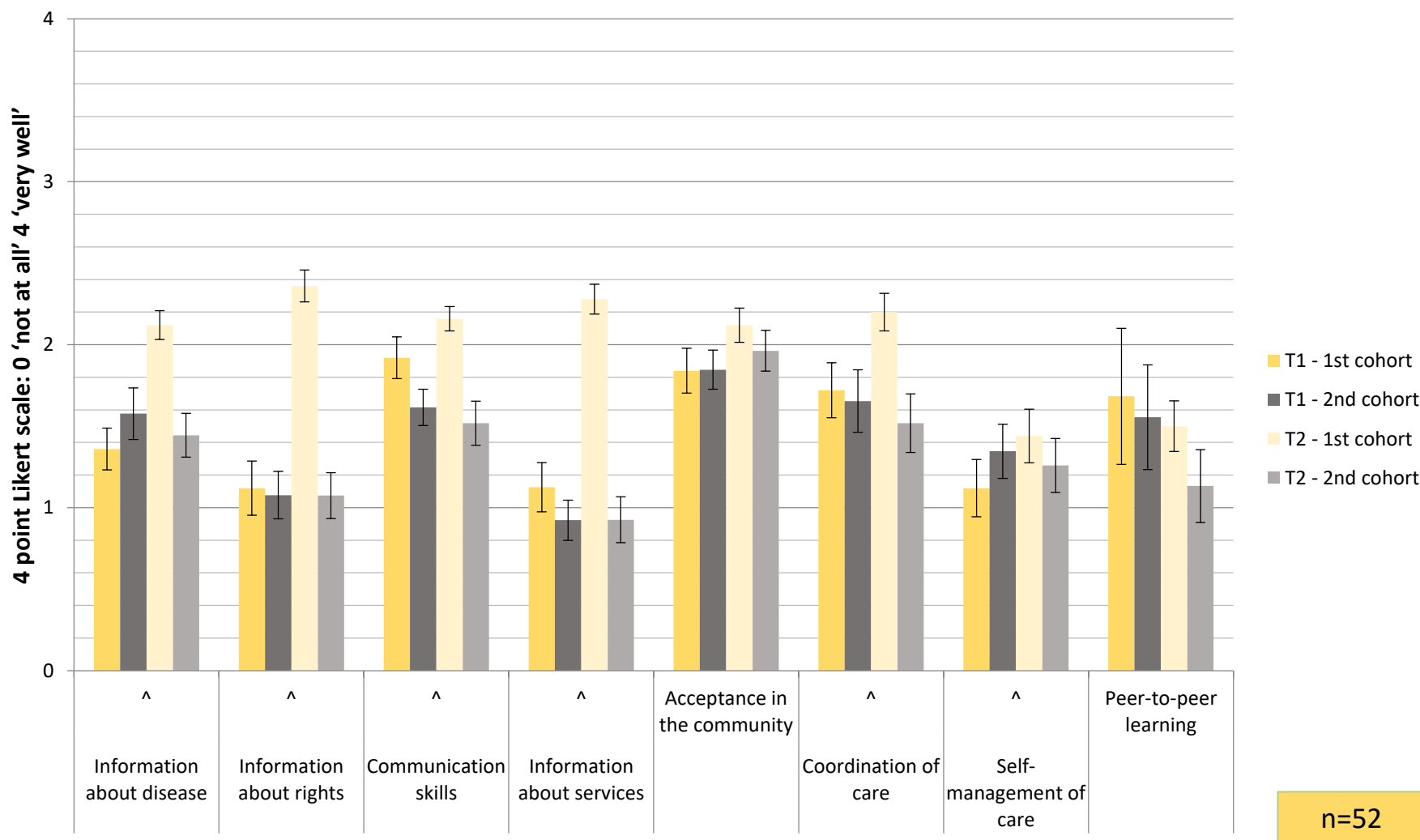
Mean EQ VAS score **75.6** vs **83.5** (1st cohort) and **72.6** vs **81.2** (2nd cohort)

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



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

