

INNOV Care

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

Evaluation of the social and economic impact of the INNOV Care pilot

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Workshop on creating a sustainable environment for holistic & innovative care for rare diseases &
complex conditions
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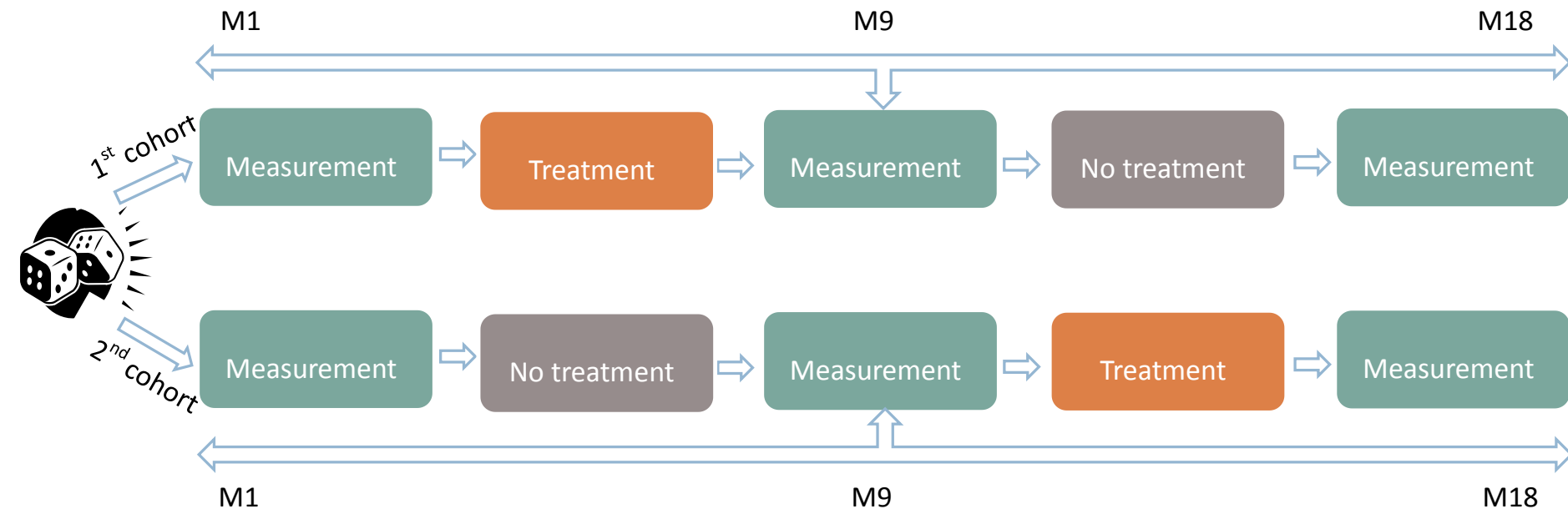


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 This project is co-funded by
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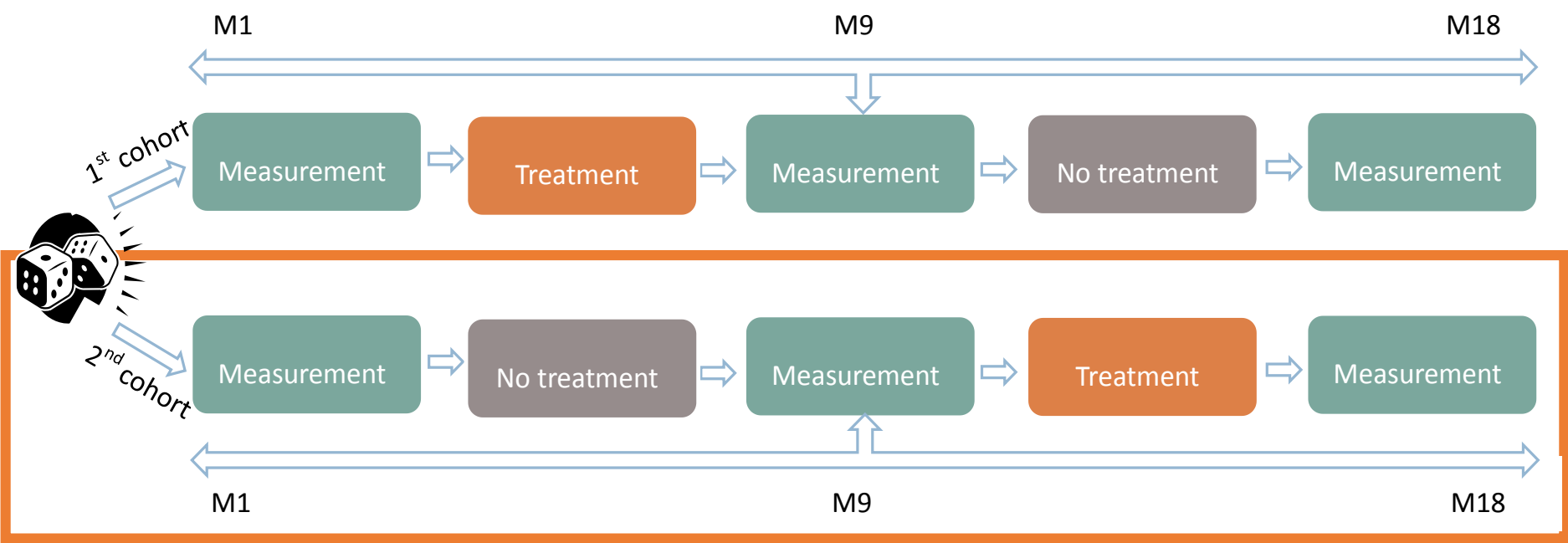
The INNOVCare evaluation design

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

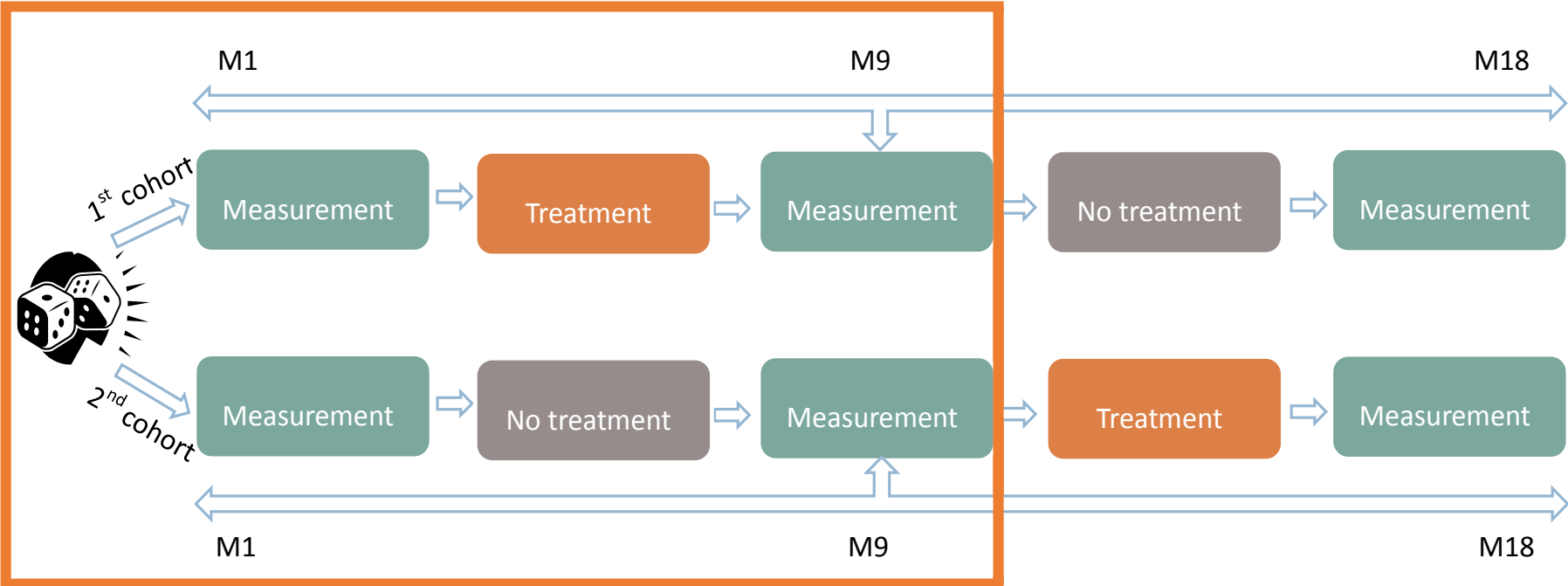


- Experimental design / randomised control trial rather than quasi-experimental designs
- Main difference: Randomisation → **golden standard**

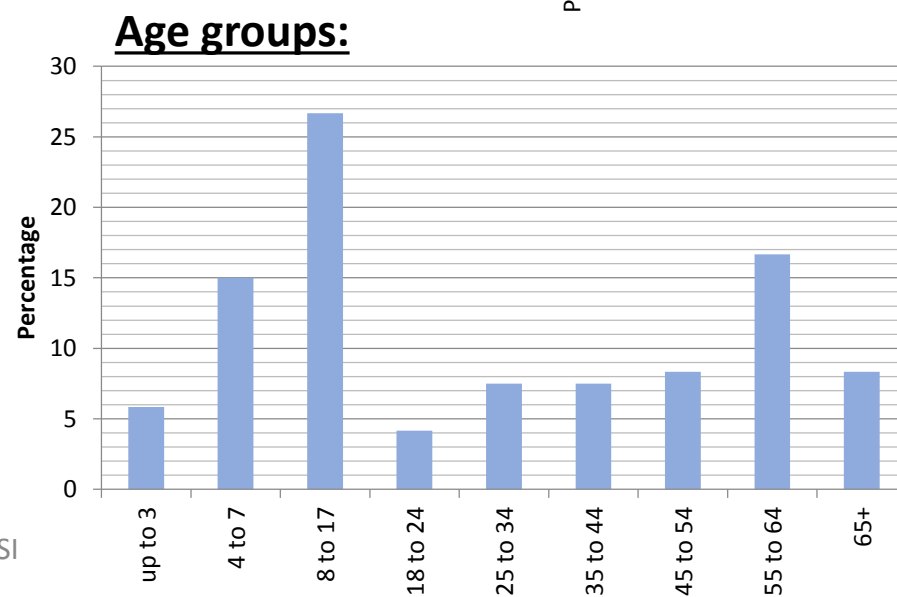
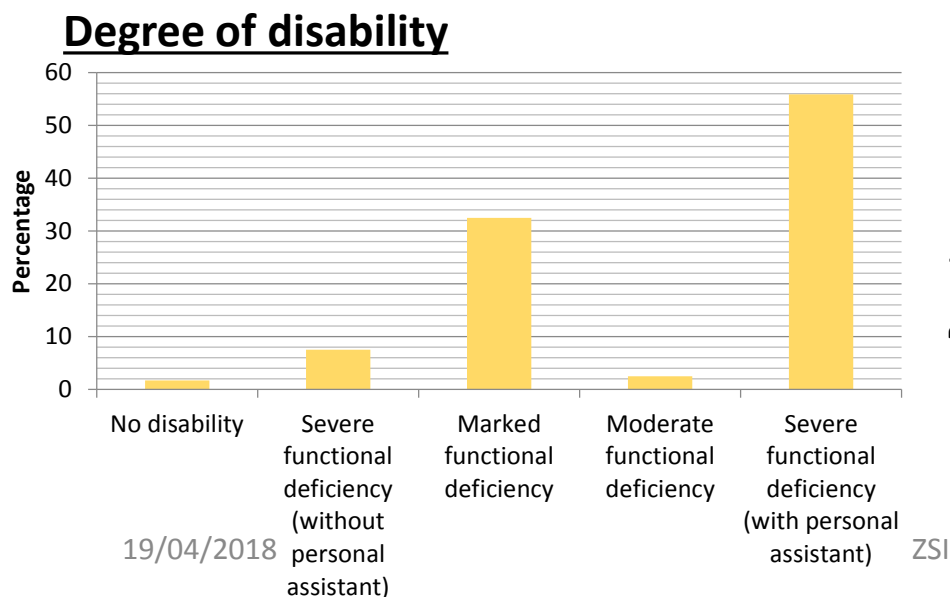
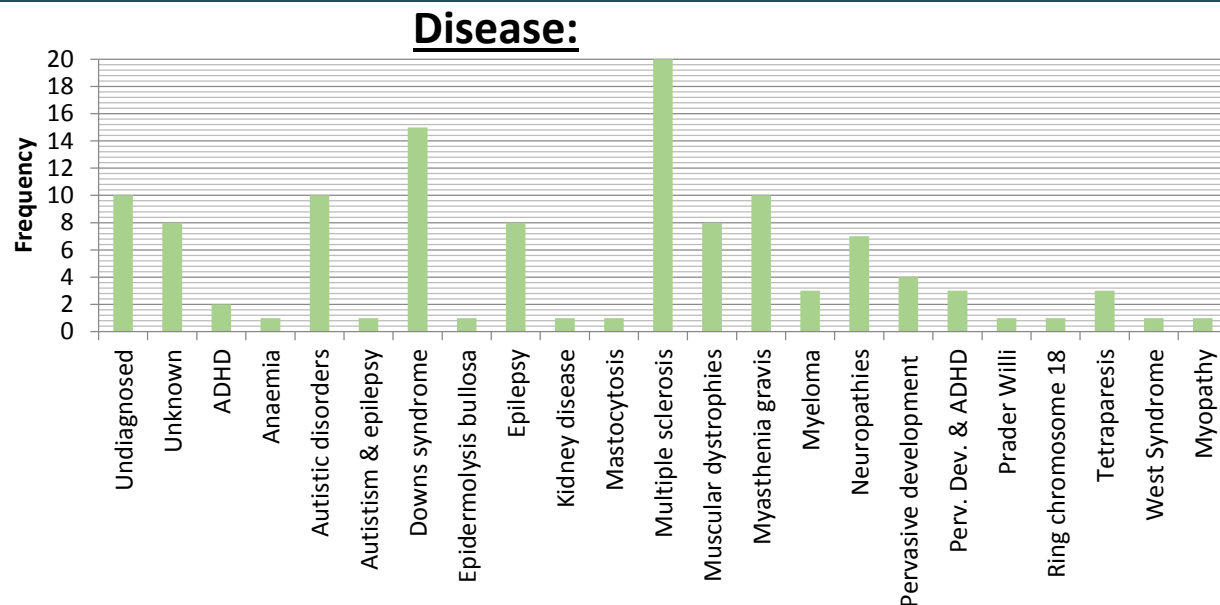
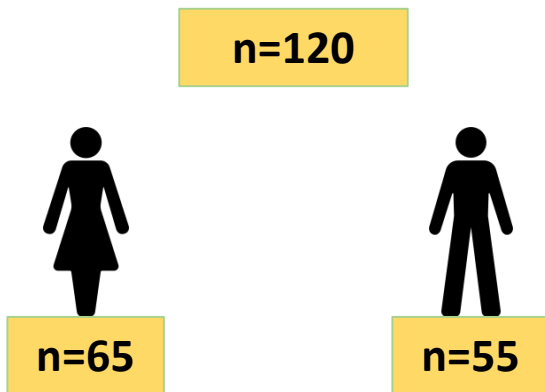
Comparison possibility : 2nd & 2nd cohort



Comparison possibility: 1st & 2nd cohort



The INNOVCare evaluation design: Participants' profile



INNOVCare survey methodology

- 2 main instruments:
 - Patient questionnaire
 - Family questionnaire

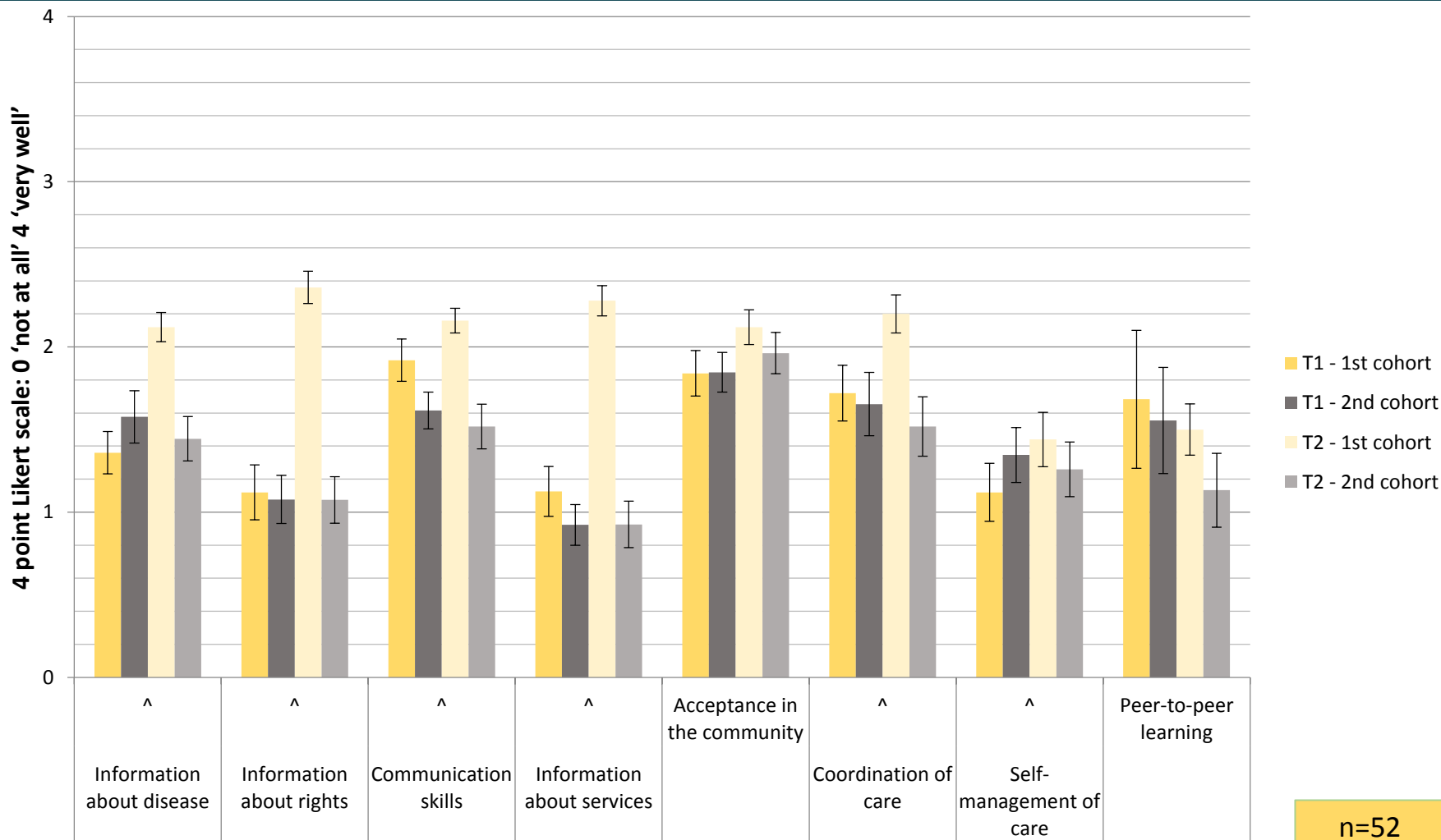
Whose quality of life is it anyway?
- Based on 8 main goals of the logic model of intervention:
 1. Information about disease
 2. Information about rights as a patient
 3. Self-management of care
 4. Better communication skills
 5. Knowledge of available services
 6. Disease-related peer-to-peer learning
 7. Understanding and acceptance in community
 8. Coordination of care among stakeholders

Preliminary results from the INNOVCare pilot: Quality of life

- Quality of life: The intervention seems to have had no significant impact on the quality of life per se

- Quality of life measures:
 - DISABKIDS-SMILEY: for children 4-7 years old and older persons with significant cognitive difficulties
 - DCGM-12: for patients aged 8 and older
 - EQ-5D-Y: for patients aged 8 and older

Preliminary results from the INNOVCare pilot: 8 goals of the intervention

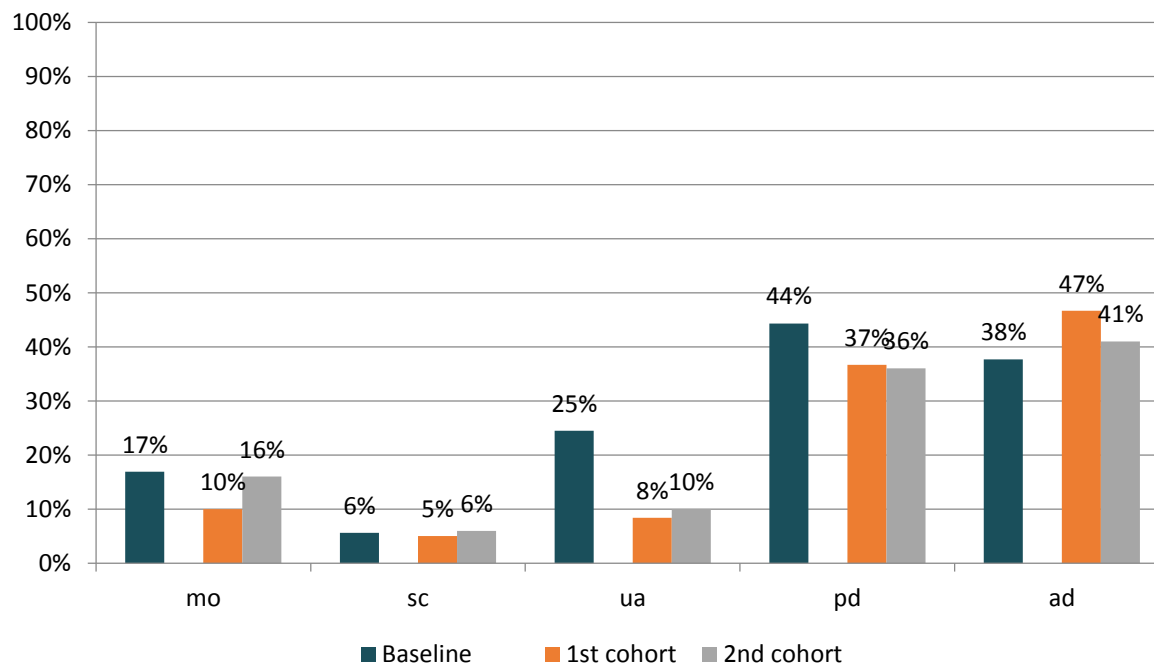


Costs for and impact on patients and caregivers

- Health care
 - Admitted to hospital
 - Emergency care
 - Visit to physicians or other healthcare professionals
 - Respite care
- Community and other services
 - Personal assistant, home aid, etc
 - Transportation services
- Healthcare insurance and cost-sharing
 - Insurance coverage
 - Out-of-pocket expenses for healthcare visits, tests, medicines or medical devices
- Health and well-being
 - EQ-5D-Y
 - EQ-5D-5L
 - Zarit Caregiver Burden
- Socio-economic differences
 - Level of education
 - Marital status
 - Employment status
 - Sick leave
 - Income

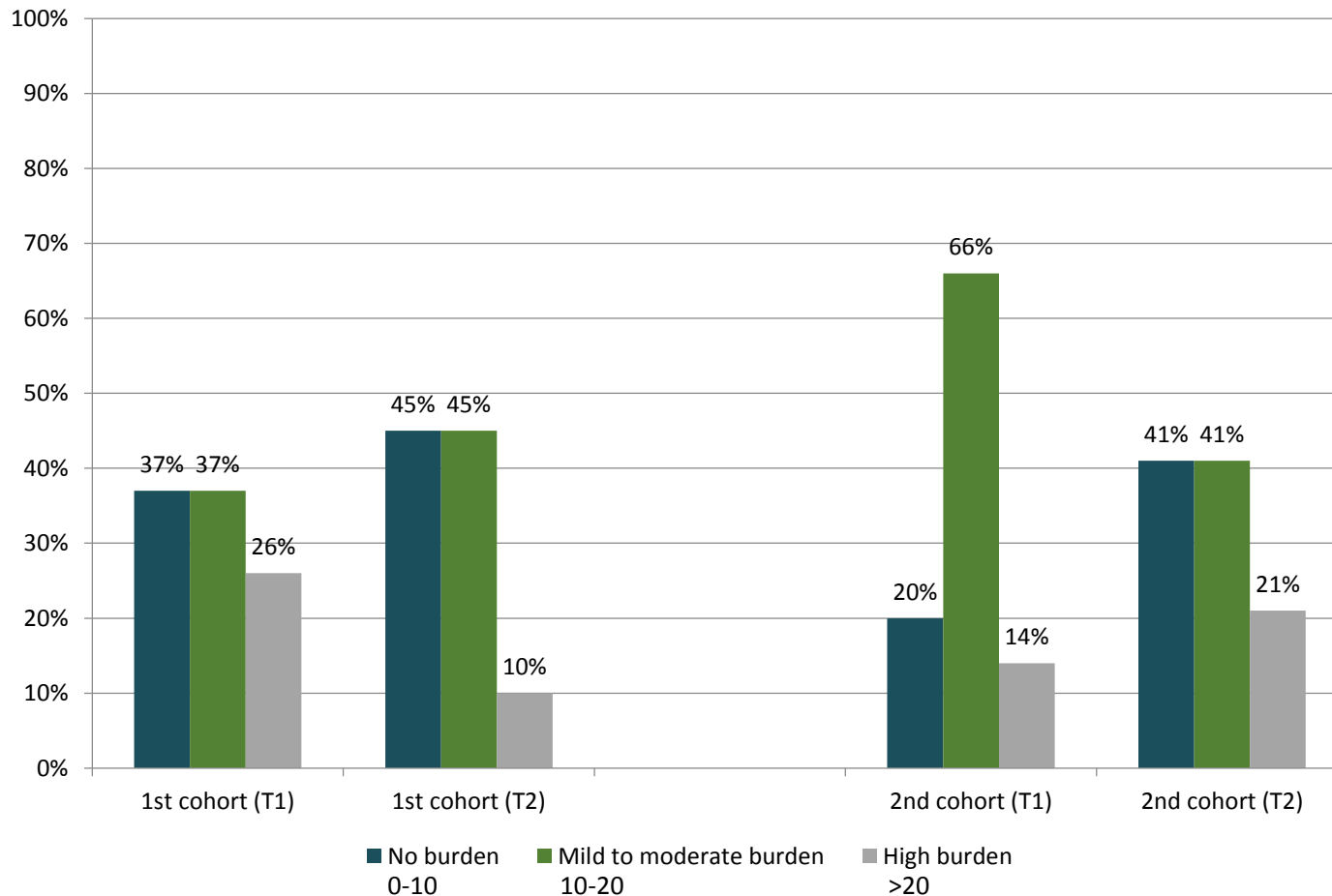
Preliminary results – caregivers' HRQoL

- Most problems were reported in the dimensions pain/discomfort and anxiety/depression.
- Mean EQ VAS score **74.8** vs **80.9** (1st cohort) and **71.0** vs **81.8** (2nd cohort)



Preliminary results – Caregiver burden

- Zarit Caregiver burden



Social network analysis

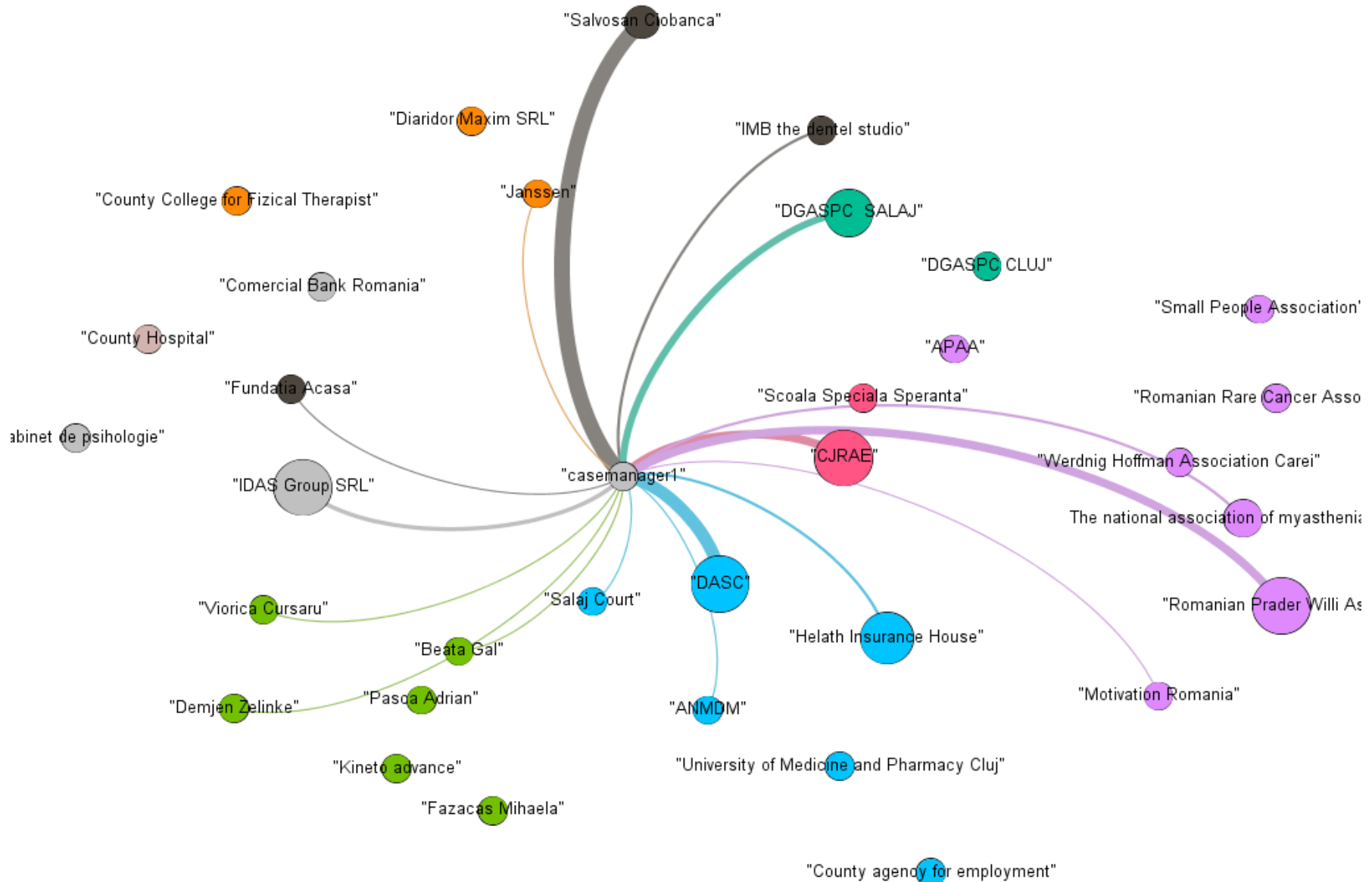
■ **Goals:**

- to explore the effect of the intervention on the networks of the case managers and
- the development or change in the communication among different health and social care professionals and organisations involved

• **Instruments:**

- Questionnaire for case managers on organisations involved in individual patients' care and quality of cooperation between them
- Interviews with case managers
- Questionnaire for organisations involved in the INNOVCare pilot patients' care

Social network analysis



Social network analysis

- **New connections since INNOVCare?** – Mix between old and new contacts
- **Ease of establishing contact:** NGO's and private service providers easier and stronger than public organisations as they understand needs of the patients better and are less hierarchic
- **Difference between case management and previous tasks:** CM allows to see a different, broader perspective of the patients and the environment they live in; more time for patients and widening of personal networks of the case managers

Social network analysis

■ Well-working aspects:

- Patient-centred approach
- Counselling patients
- Empowering patients
- Establishing new contacts
- Good, working collaboration with institutions

■ Challenges:

- “Hopelessness” with regards to solving needs
- Services (e.g. Rural areas closed off, unequal availability and distribution of services for different target groups, poor communication)
- Discrimination of people with disabilities in the labour market
- Legislation regarding access to treatment
- Distance

In summary...

- Based on these results, the intervention can be considered successful in terms of its social impact e.g. patients are more empowered and informed, have higher self-confidence.
- In relation to exchanging experiences with other people in a similar situation, new contacts were developed, however, there is no measurable effect possibly due to a small sample size.

In summary...

- No measurable effects regarding the overarching goal of the intervention: improving the general quality of life of the patients
- Reduced caregiver burden for the family members connected to the patients that have received the case management service
- However, quality of life:
 - can only be affected indirectly,
 - needs a long time to improve considerably and
 - is affected by several dimensions which cannot be influenced by the intervention e.g. type of disease, degree of disability, relationships
- BUT significant improvement in 6 of the 8 related dimensions covered by the intervention

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Thank you

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