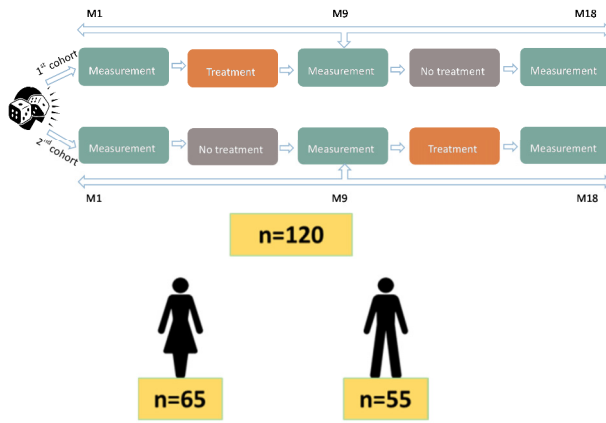


### Measuring the effects of a case management approach on the quality of life of rare and complex disease patients

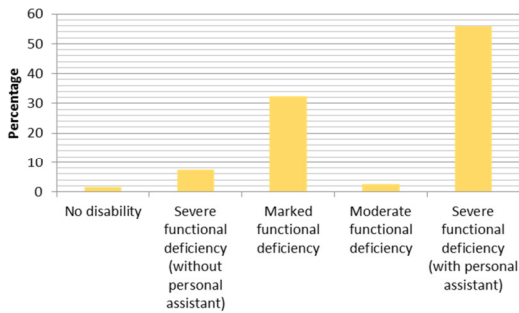
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#### A basic two-condition repeated-measures design / rotation design

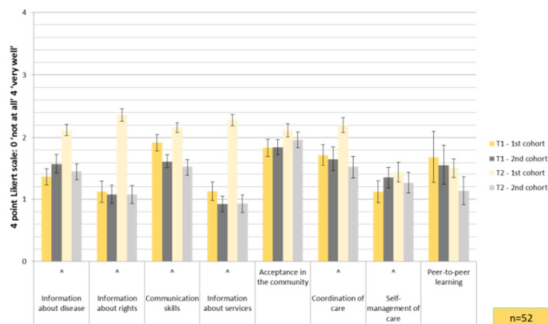
- Experimental design / randomised control trial rather than a quasi-experimental design
- Comparison possibilities:
  - 1<sup>st</sup> vs 2<sup>nd</sup> cohort between M1 and M9
  - 2<sup>nd</sup> cohort between M1 and M9 with the 2<sup>nd</sup> cohort between M9 and M18
  - Mid-term effects of the intervention on the 1<sup>st</sup> cohort (M9 – M18)



#### Degree of disability



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



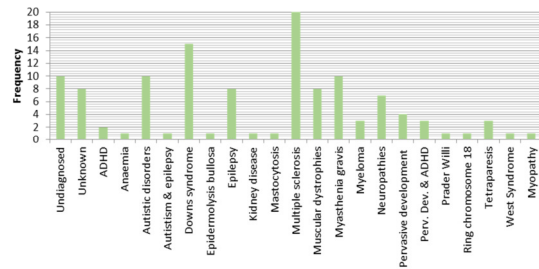
#### 2 main instruments with tailored items as well as involving validated quality of life measures e.g. DISABKIDS-SMILEY, DCGM-12 and EQ-5D-Y:

- Patient questionnaire
- Family questionnaire

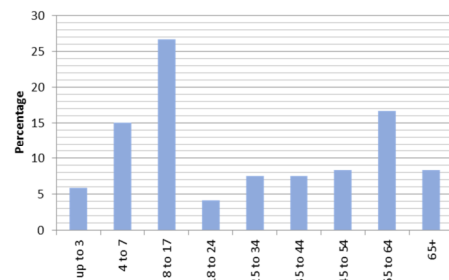
#### Based on 8 main goals of the logic model of intervention:

- Information about disease
- Information about rights as a patient
- Self-management of care
- Improved communication skills
- Knowledge of available services
- Disease-related peer-to-peer learning
- Understanding and acceptance in community
- Coordination of care among stakeholders

#### Disease

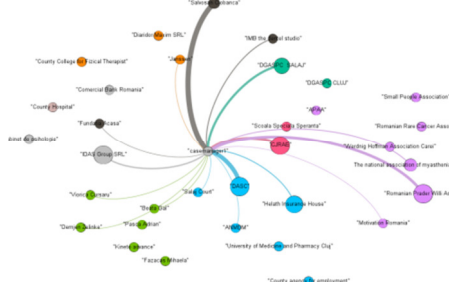


#### Age group



#### Social network analysis

- 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



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