

INNOV Care

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

Evaluation of the social impact of the INNOVCare pilot

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Workshop on advancing holistic & innovative care for rare diseases & complex conditions
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www.creenfermedadesraras.es



www.cjsj.ro



www.apwromania.ro



www.eurordis.org



www.finovatis.com



www.ier.si



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Evaluation of the social impact of the INNOVCare pilot

- Method: social policy experimentation
 - Specification of the call for applications
 - Policy makers are increasingly interested in counterfactual impact evaluations

- Counterfactual impact evaluations:
 - measure the **causal effect** of an intervention
 - are useful to know **what works** and
 - **what doesn't** work
 - are useful to know whether **funding** is used **efficiently**

The essence of the counterfactual

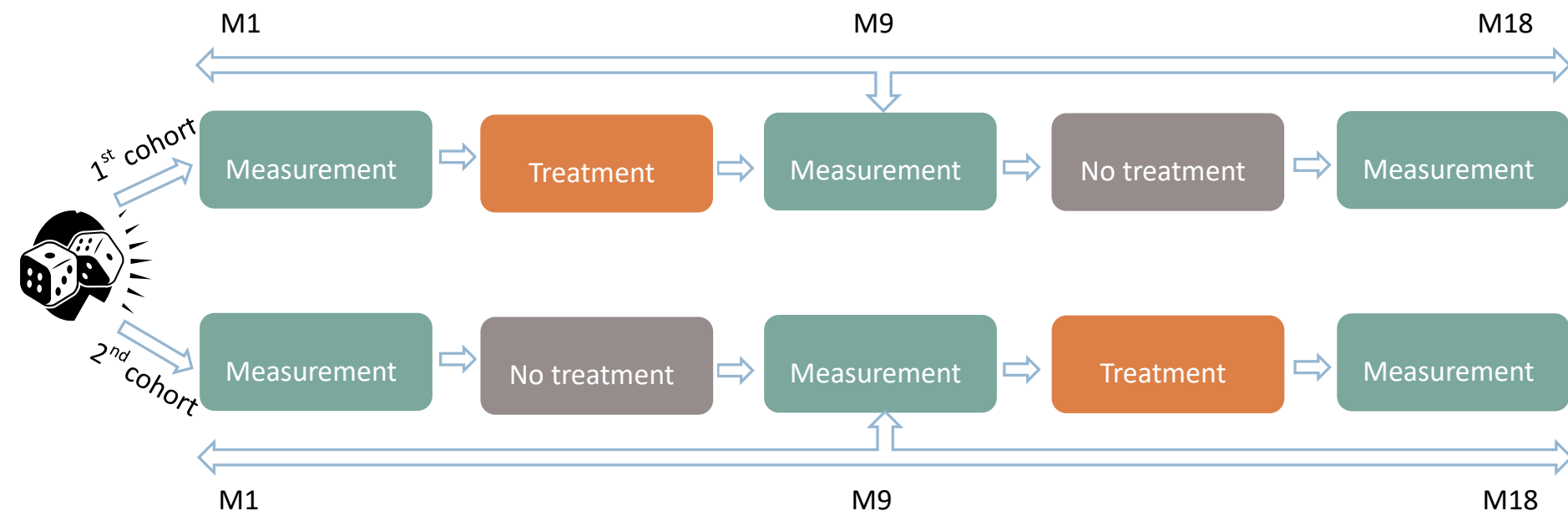
- The idea – an example:
 - **Research question:** what is the effect of a training programme on an unemployed individual?
 - The counterfactual approach conceives of two potential results:
 - the trainee's employment status subsequent to having taken part in training (**observed result**)
 - trainee's employment status had he or she not taken part in the training programme, all else being equal (**counterfactual result**)
 - **Impact of the training:** the difference between the observed and counterfactual results.

The essence of the counterfactual

- How do we obtain estimates of counterfactual results?
 - Measuring the **treatment effect**, i.e. the **causal effect** of an intervention = the difference between what you observe after the intervention, and what you would have observed had the intervention not taken place (the **counterfactual scenario**)
- In reality we cannot observe counterfactual results for individuals exposed to an intervention and we rely on ‘estimated’ counterfactual values.
 - Except **to some extent** in repeated measures designs like the basic two-condition repeated-measures design/rotation design used in INNOVCare where the 2nd cohort acts as its own comparison group.
 - Requires two groups (treatment and control group) as similar as possible in all respects including observable and unobservable characteristics. Only difference is the “treatment” or programme received to the treated group.

The INNOVCare evaluation design

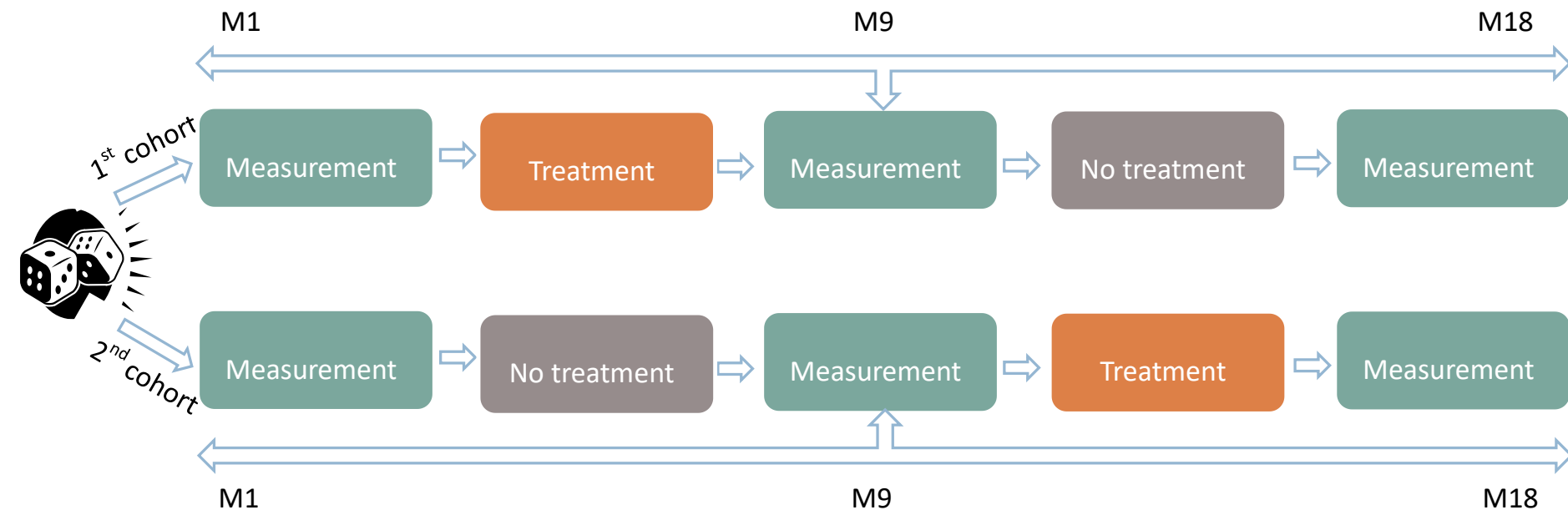
A basic two-condition repeated-measures design / rotation design



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

The INNOVCare evaluation design: Objective

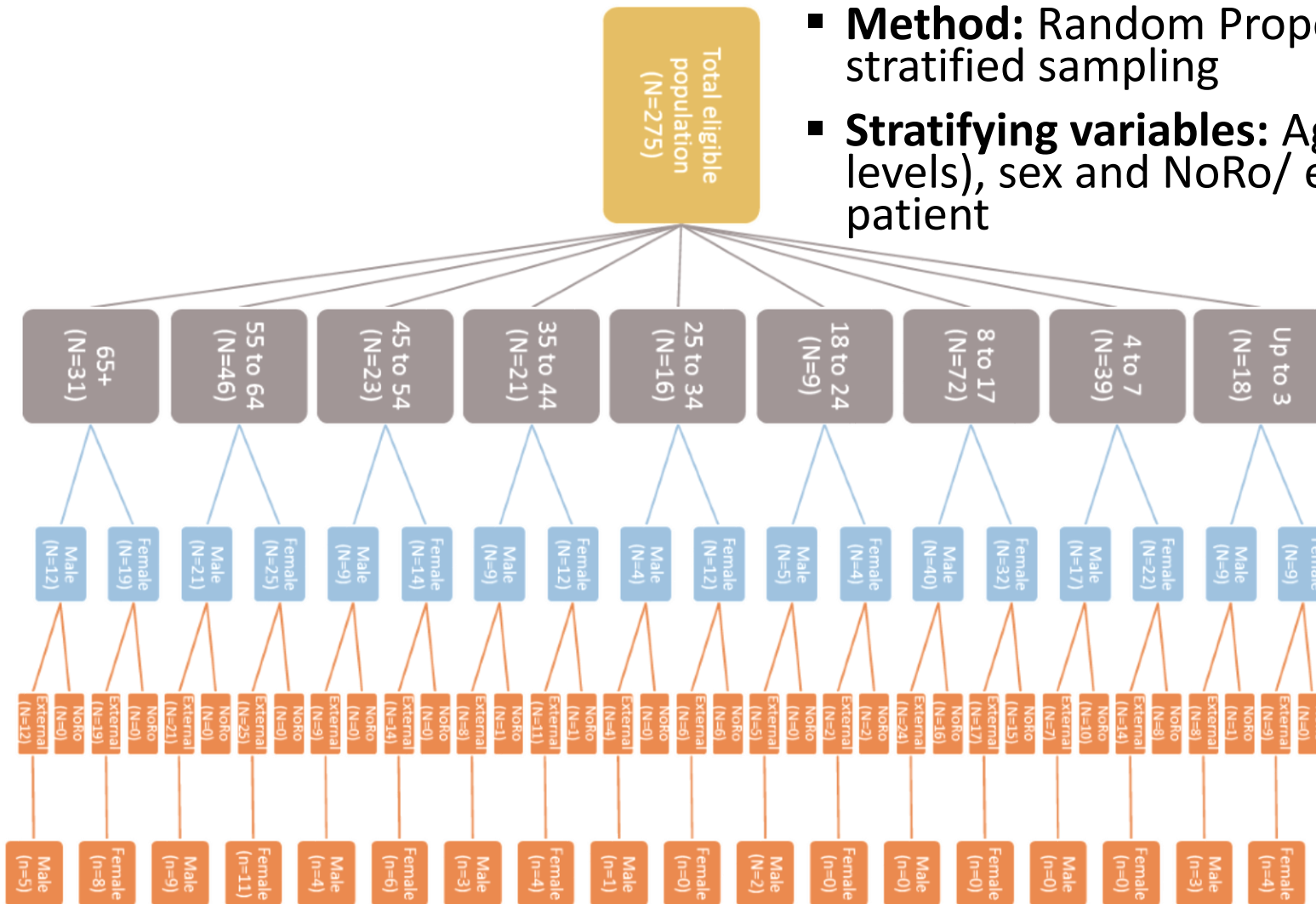
A basic two-condition repeated-measures design / rotation design



- How does the INNOVCare intervention impact the **quality of lives of those who benefit from it?**
- **“Those who benefit from it”** → 120 rare and complex disease patients and their families from the county of Salaj

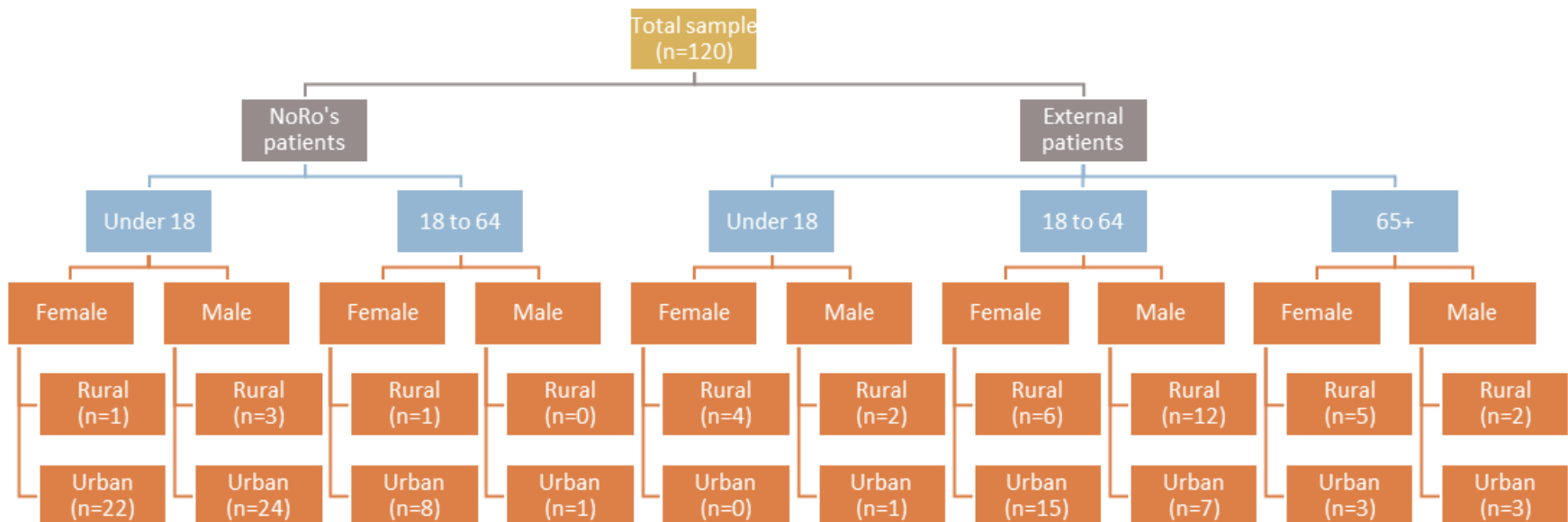
The INNOVCare evaluation design: Sampling

- **Method:** Random Proportionate stratified sampling
- **Stratifying variables:** Age group (9 levels), sex and NoRo/ external patient



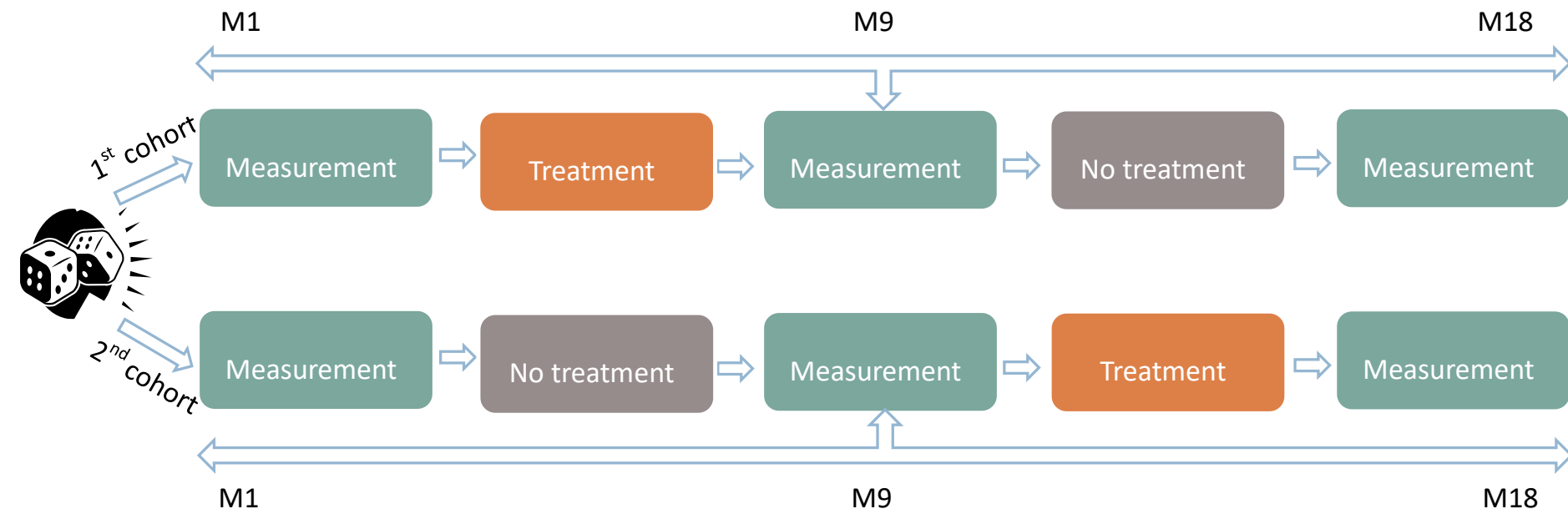
The INNOVCare evaluation design: Randomisation

- Allocation of participants into the 1st & 2nd cohorts → Method: **Stratified random assignment**
- Blocking variables:** NoRo/external patient; age group (3 levels → under 18, 18-64 and 65+); sex and location of patient (urban/rural)
- Allocation of participants to the case managers → Method: **Simple random assignment** and considering family connections and language
- Ex-post assessment of the randomisation procedure



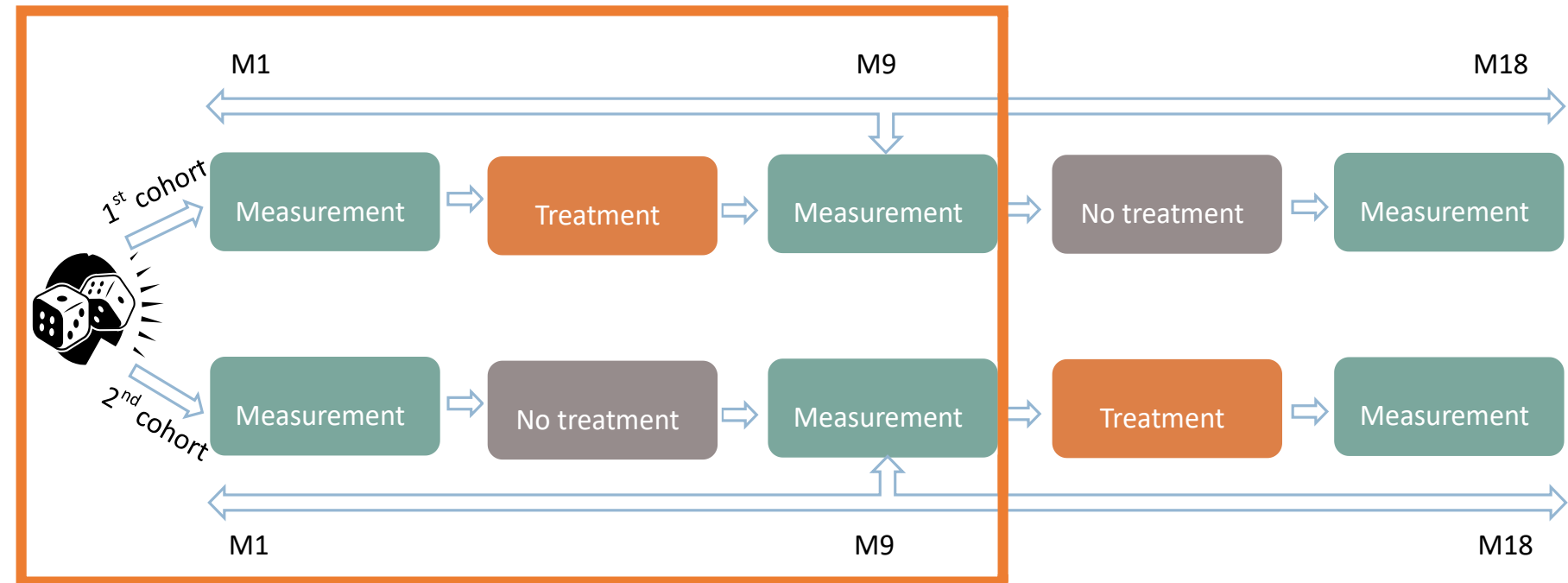
The INNOVCare evaluation design: Challenges

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



- **Requirement of the treatment effect to be short term:** Difficult for the 1st cohort to act as its own comparison BUT provides medium-term impact.
- **Lag between treatment and detection of effect:** How long does the intervention need to be for the effects to mature and become detectable?
- **Practice effects:** Identical questionnaires at 3 points in time.
- **Social desirability:** Familiarity with the testing situation; human interaction between participants and case managers → falsely believe questionnaires are assessing the performance of the case managers.

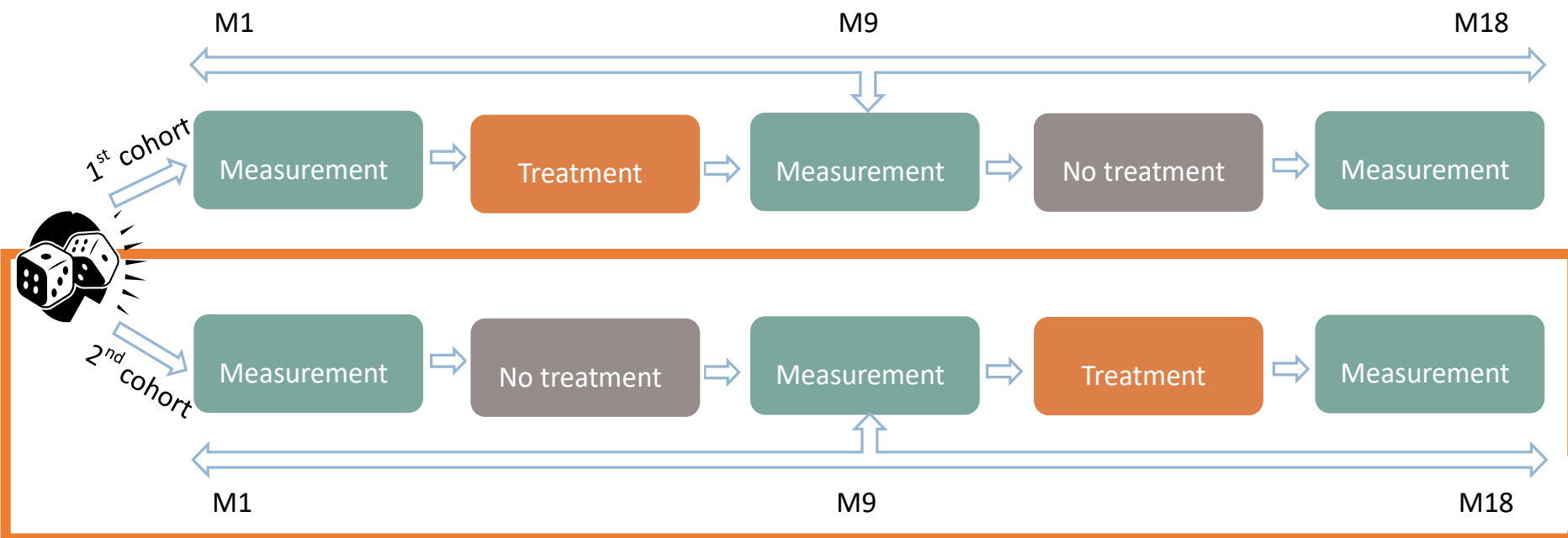
1st comparison: 1st & 2nd cohort



■ Challenges:

- **Anticipation effect:** Participants may behave differently or answer questionnaires inaccurately anticipating end of intervention.
- **Spillover effect:** (Social) interaction among participants in the 1st and 2nd cohort may cause change in behaviour.

2nd comparison: 2nd & 2nd cohort



■ Challenges:

- **Anticipation effect:** Participants may behave differently or answer questionnaires inaccurately anticipating receiving the intervention
- **Spillover effect:** (Social) interaction among participants in the 1st and 2nd cohort may cause change in behaviour.

INNOVCare survey methodology

- 2 main instruments:
 - Patient questionnaire **Whose quality of life is it anyway?**
 - Family questionnaire
- Cooperation with KI to synergise activities of social and economic impact analysis.
- 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

Patient questionnaire

Name of questionnaire	Components	Target group
Patient-SMILEY	DISABKIDS – SMILEY (self-reported)	<ul style="list-style-type: none"> Patients aged 4 to 7 Patients older than 7 with serious cognitive difficulties
Patient-8+	<ul style="list-style-type: none"> DCGM-12 (self-reported) EQ-5D-Y (self-reported) 'Soft' items 	<ul style="list-style-type: none"> Patients aged 8 and above
Patient-SOLO	<ul style="list-style-type: none"> DCGM-12 (self-reported) EQ-5D-Y (self-reported) 'Soft' items 'Hard' items 	<ul style="list-style-type: none"> Adult patients, living alone and managing their own care

- “Soft” items based on the 8 goals of the intervention
- “Hard” items based on demographical information of household and use of healthcare resources
- Cognitive pretesting

Family questionnaire

- Target group:
 - If the patient has a personal assistant and this is one of his/her relatives, then this person should complete this questionnaire.
 - If the patient has a personal assistant but this person is not a relative, then the relative most closely involved or informed about the patient's care should complete this questionnaire (for example: parents, spouses, children etc.).
 - If the patient does not have a personal assistant, then the relative most closely involved in the patient's care should complete the questionnaire.
 - If the patient lives alone and is his or her own main caregiver, then the patient should complete the 'Patient-SOLO' questionnaire. In this case, no family member would complete the family questionnaire.
- “Soft” items based on 8 main goals
- “Hard” items based on demographical information of household and use of healthcare resources
- Cognitive pretesting

Social network analysis

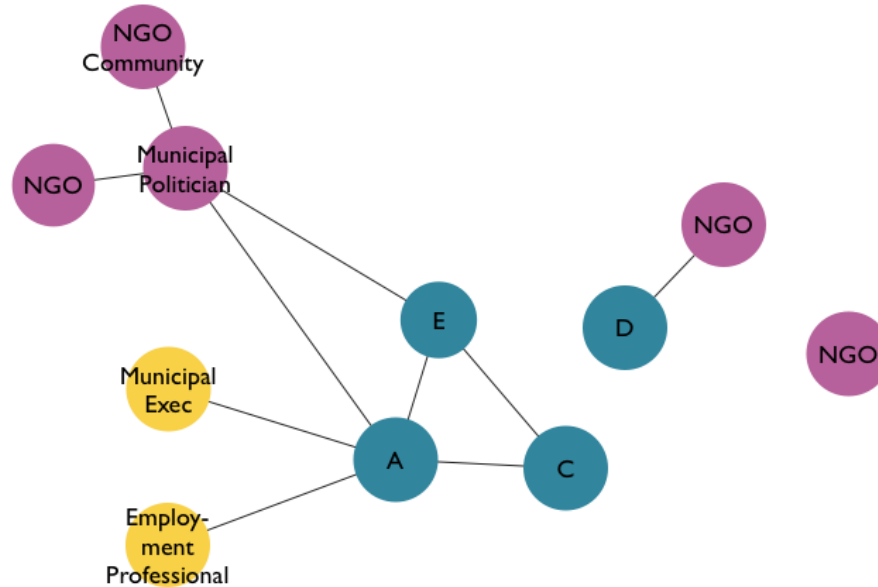
■ **Goals:**

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

• **Instruments:**

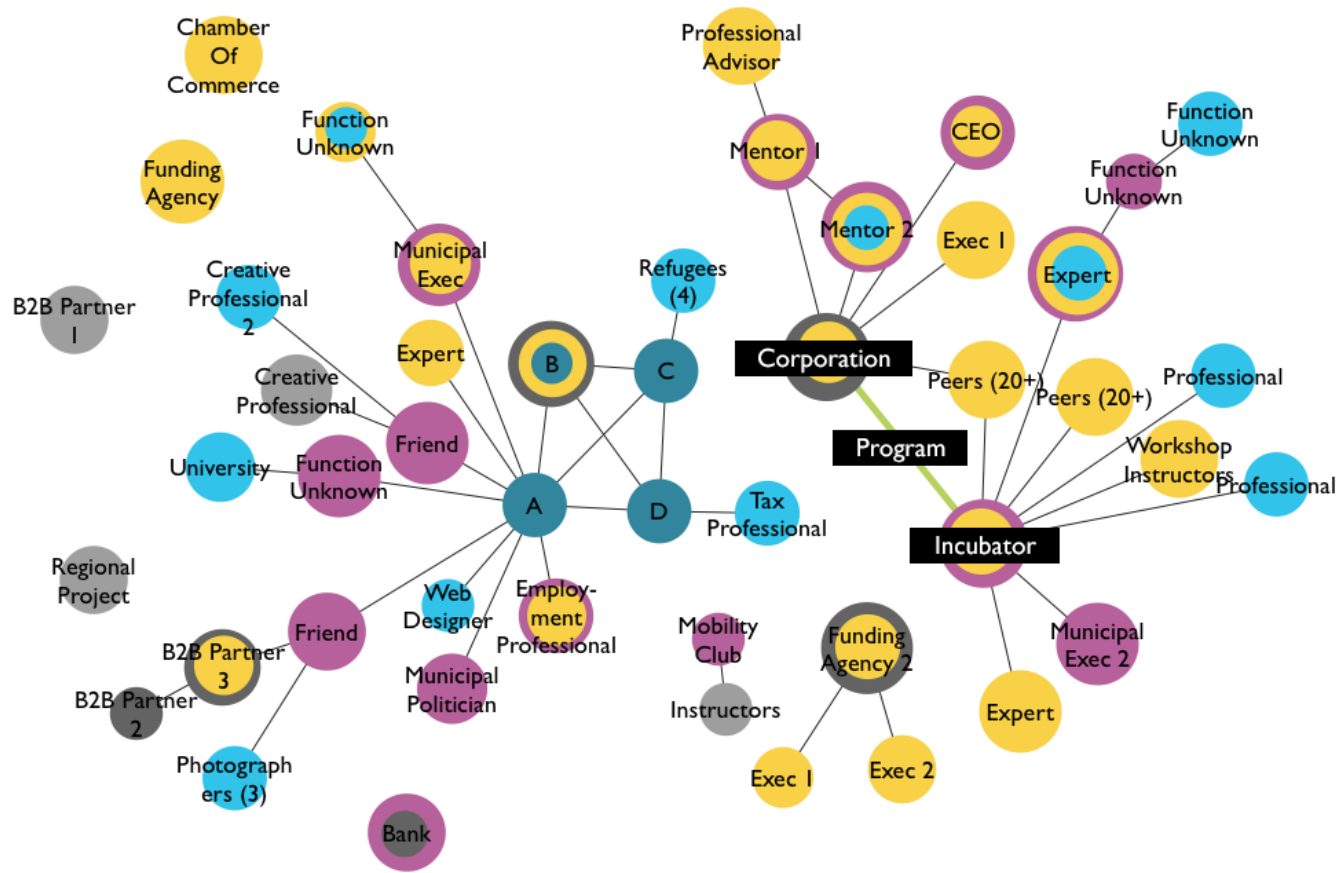
- Questionnaire for case managers on organisations involved in individual patients' care and quality of cooperation between them
- Interviews with case managers

Network BEFORE the incubator programme



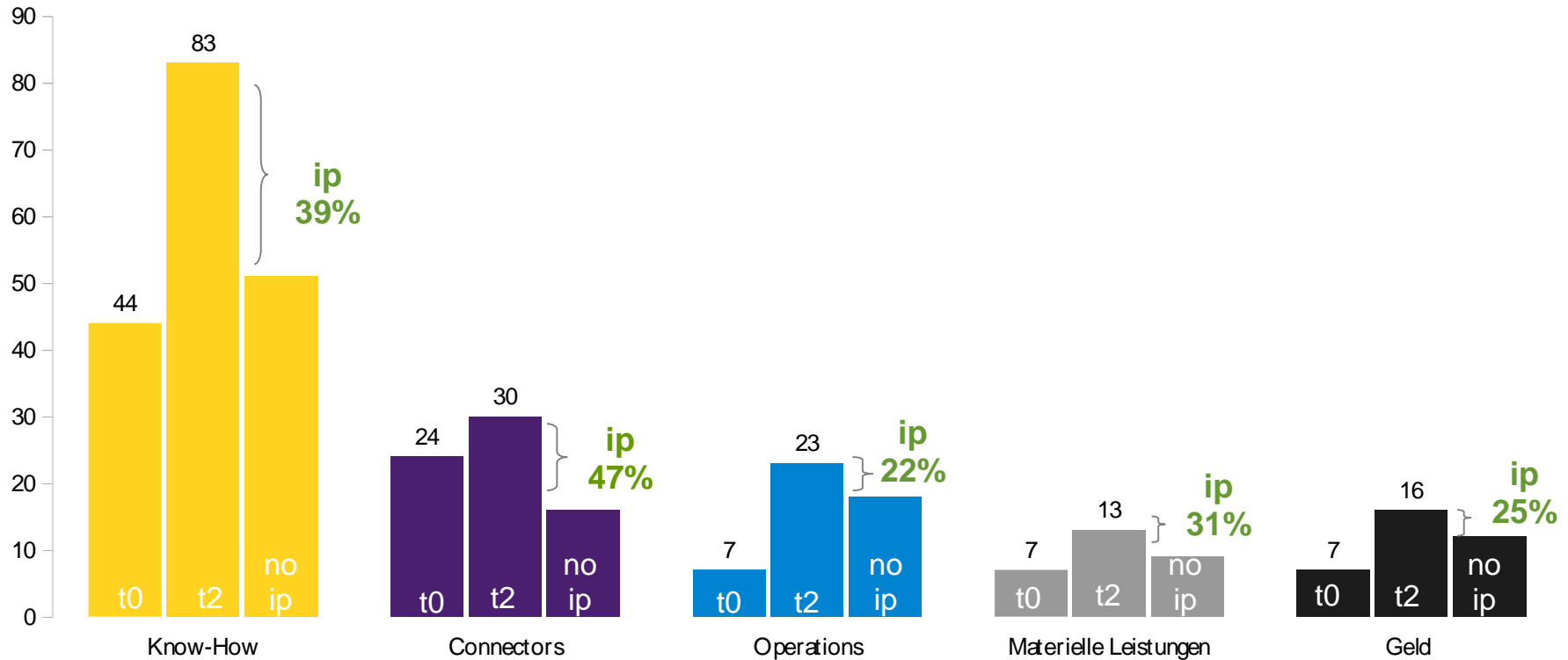
Information/Knowledge Connectors Operations Material support Financial funding Team

Network AT THE END of the incubator programme



Information/Knowledge Connectors Operations Material support Financial funding Team

The role of the incubator



- Aggregated number of contacts of participants of the incubator programme from October 2016 (t0) to March/April 2017 (t2), not including team members.
- For the „no ip“-columns, contacts found via the incubator program were excluded.

Extension of social network analysis

- Explore the impact of INNOVCare's pilot on:
 - ☑ ...support network of **patient and family**
 - ...on expert networks of individual **case managers**
 - ... on the entire expert network of **the pilot**

Overall result → Impact of the network on the target group's quality of life.

Ethical Reviews and Data Protection

- Evaluation model reviewed and approved by the ethical commissions in Romania and in Austria (ZSI)

- Recommendations by the ZSI Ethical Commission:
 - Confidentiality agreements
 - Informed consent forms (integrated in NoRo's official contracts)
 - Anonymity (participant codes)
 - Restricted data handling

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Thank you

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