

INNOVCare

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

Evaluation of the social impact of the INNOVCare pilot

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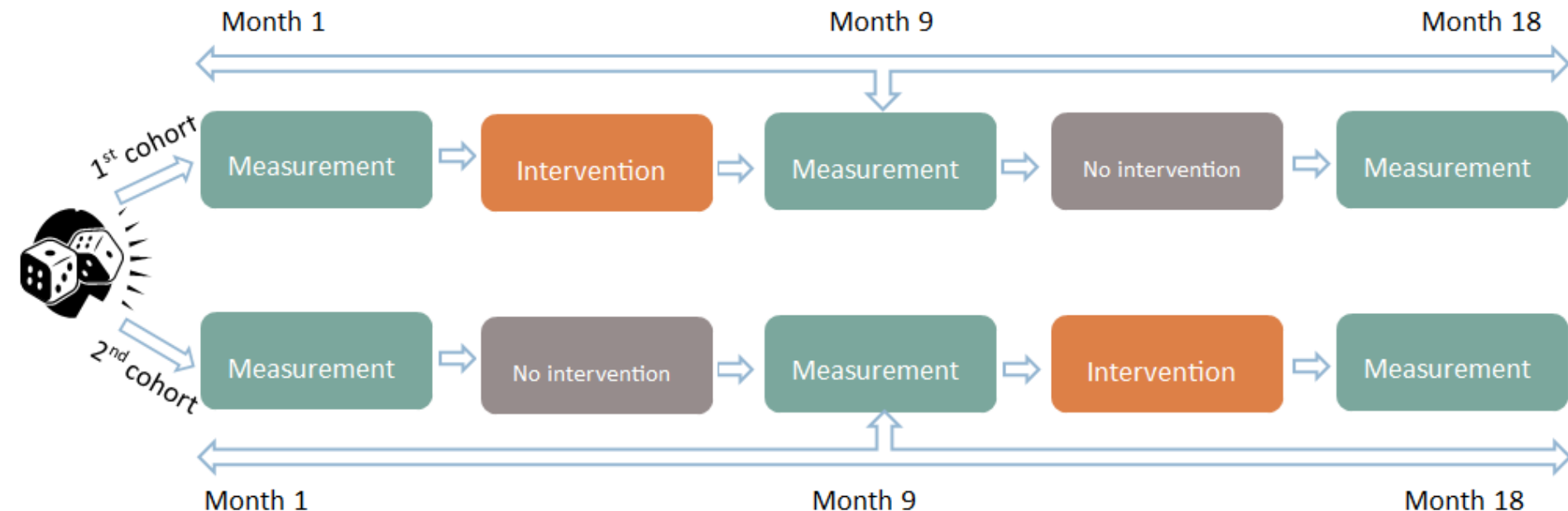


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 This project is co-funded by the European Union

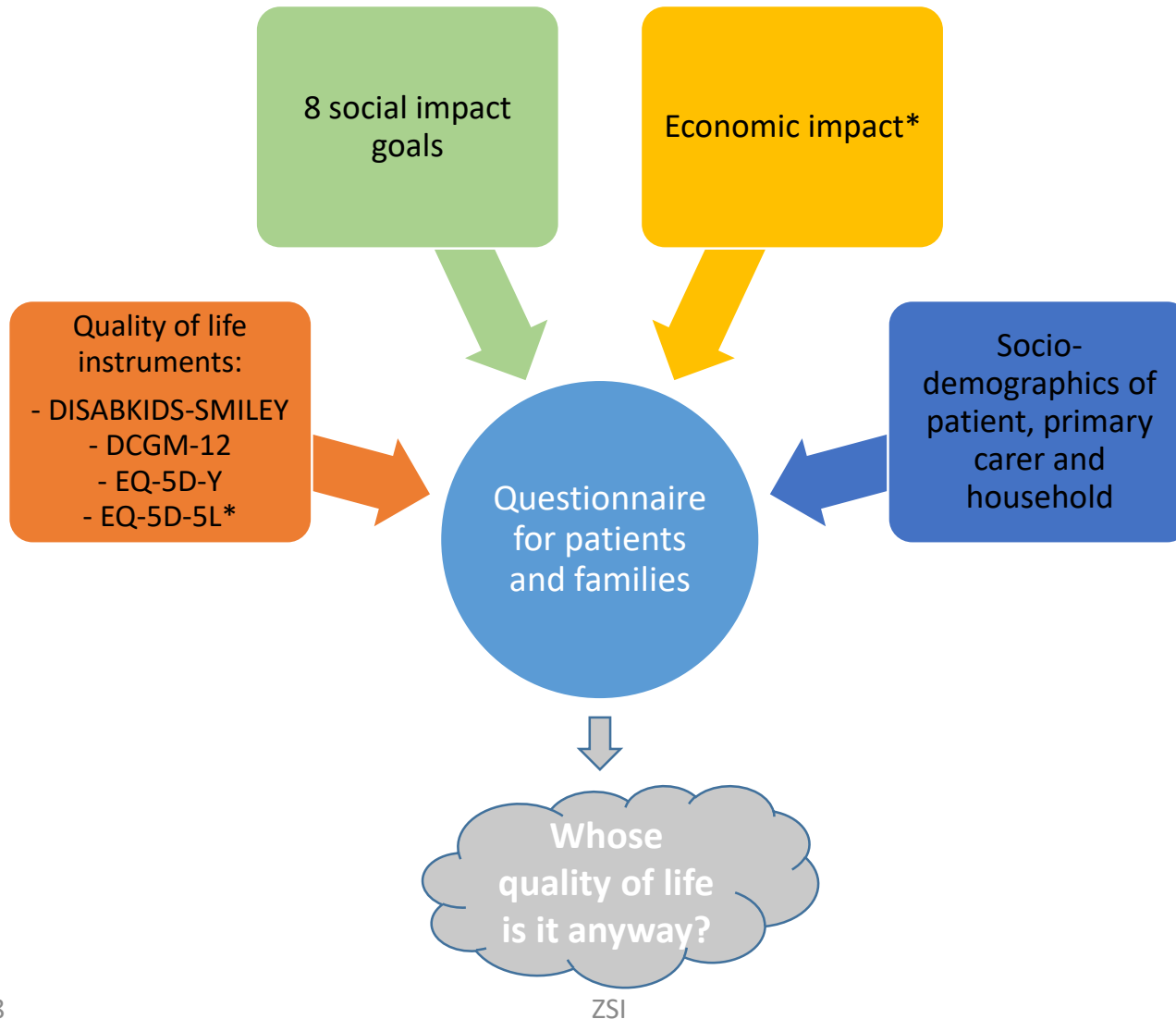
The INNOVCare evaluation design

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

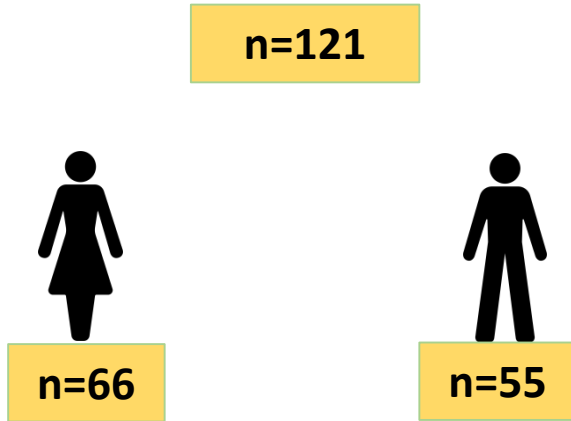


- Experimental design / randomised control trial rather than quasi-experimental designs
- Main difference: **Randomisation**

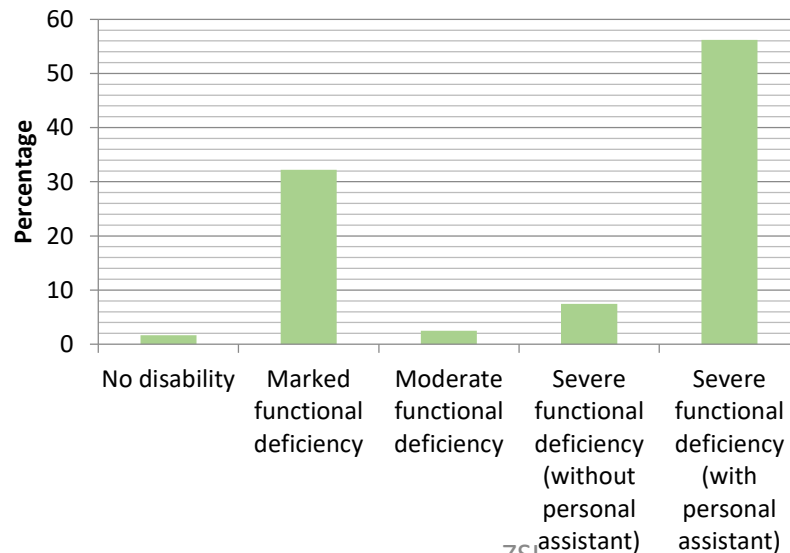
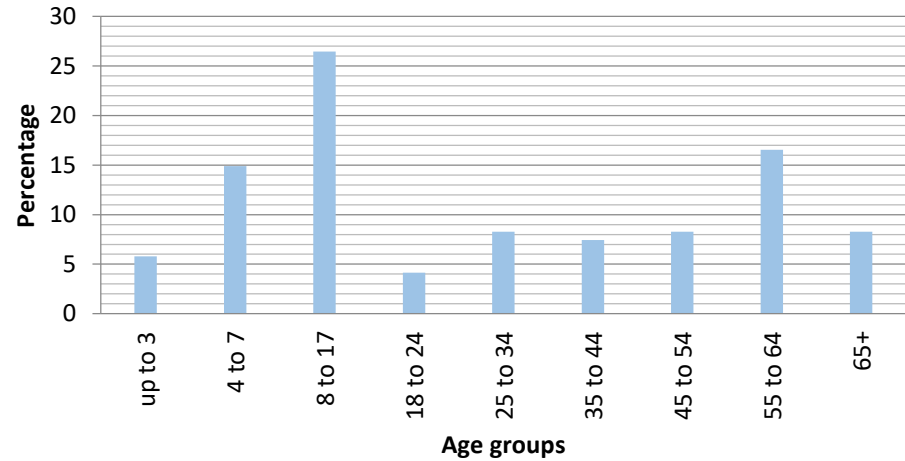
The INNOVCare methodology



The INNOVCare evaluation design: Participants' profile



Age groups:



The INNOVCare evaluation design: Participants' profile

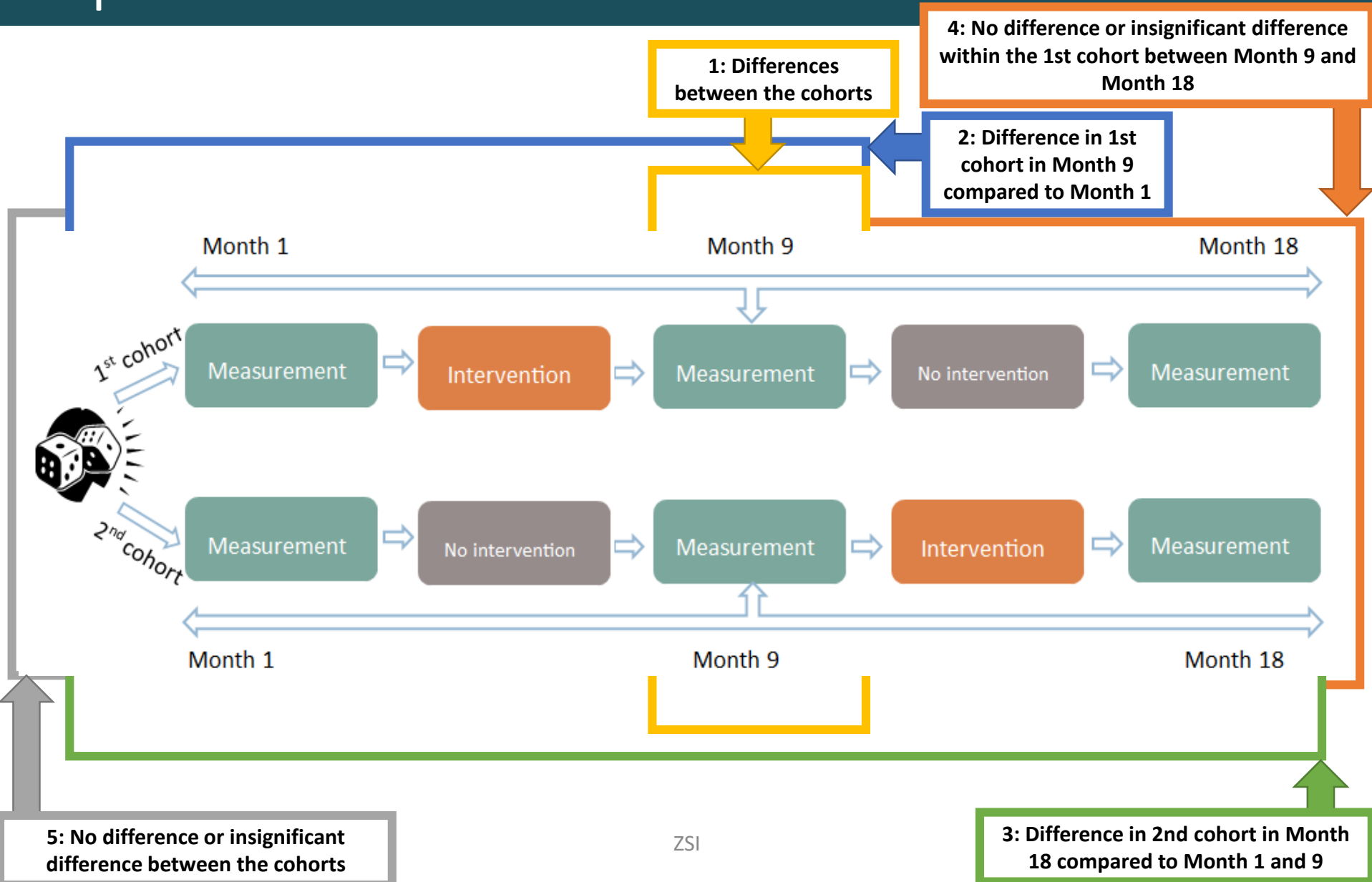


More than 30 rare and complex diseases among the selected patients

Aim of the INNOVCare pilot

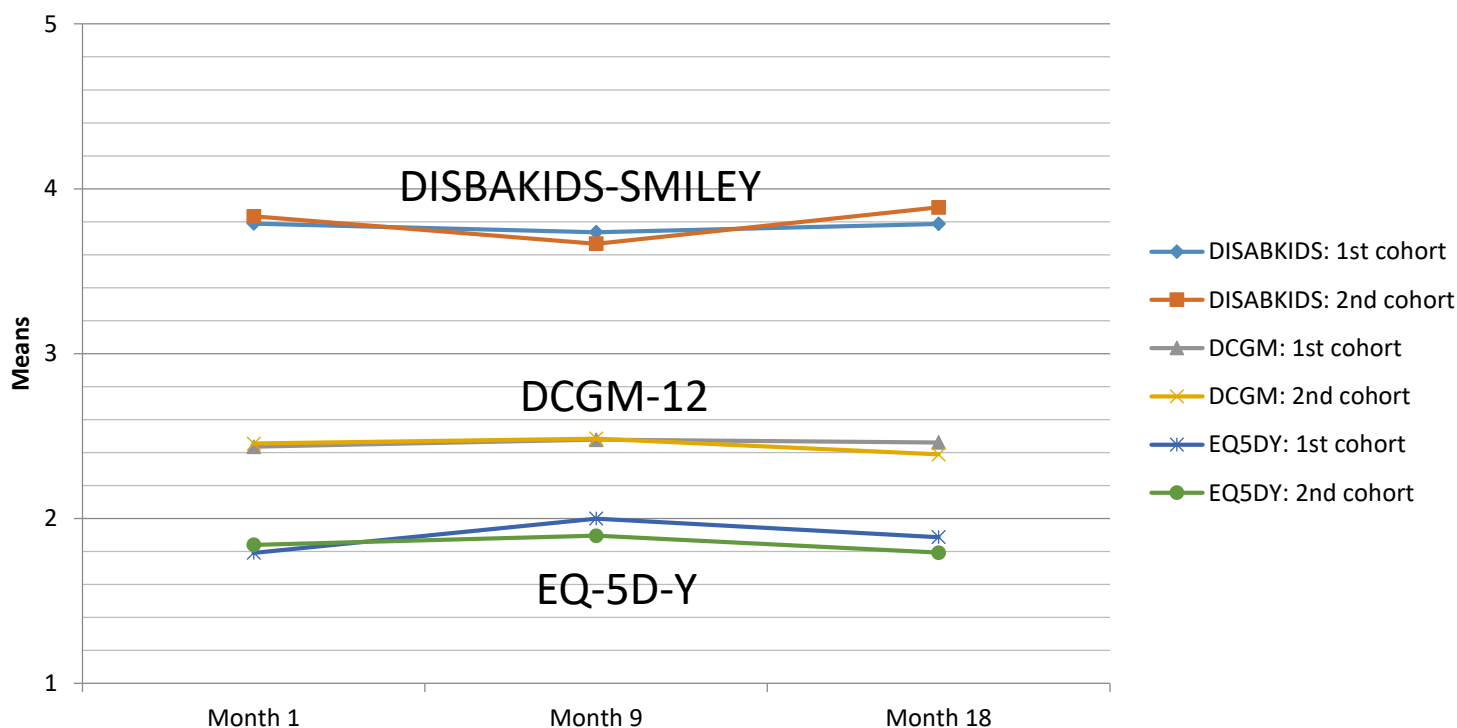
- To improve the **knowledge** of the patients and their families about:
 1. Their disease or condition
 2. Their rights as a patients
 3. The different services available to them
- To increase the ability of the patients and their families to **manage their own care** in the absence of the case manager
- To improve the patient's **communication skills** related to explaining about their condition including symptoms and its development over the years; the treatments and services they've received so far etc.
- To **connect** the patients and their families to other people with the same condition or in a similar condition to be able to not only offer emotional support to each other but also to share their experiences and even tips for coping
- To encourage and support the **coordination** of different services used by the patient and their family
- To raise **awareness** in the community so that people are more accepting and understanding of the patient and their families

Expectations:

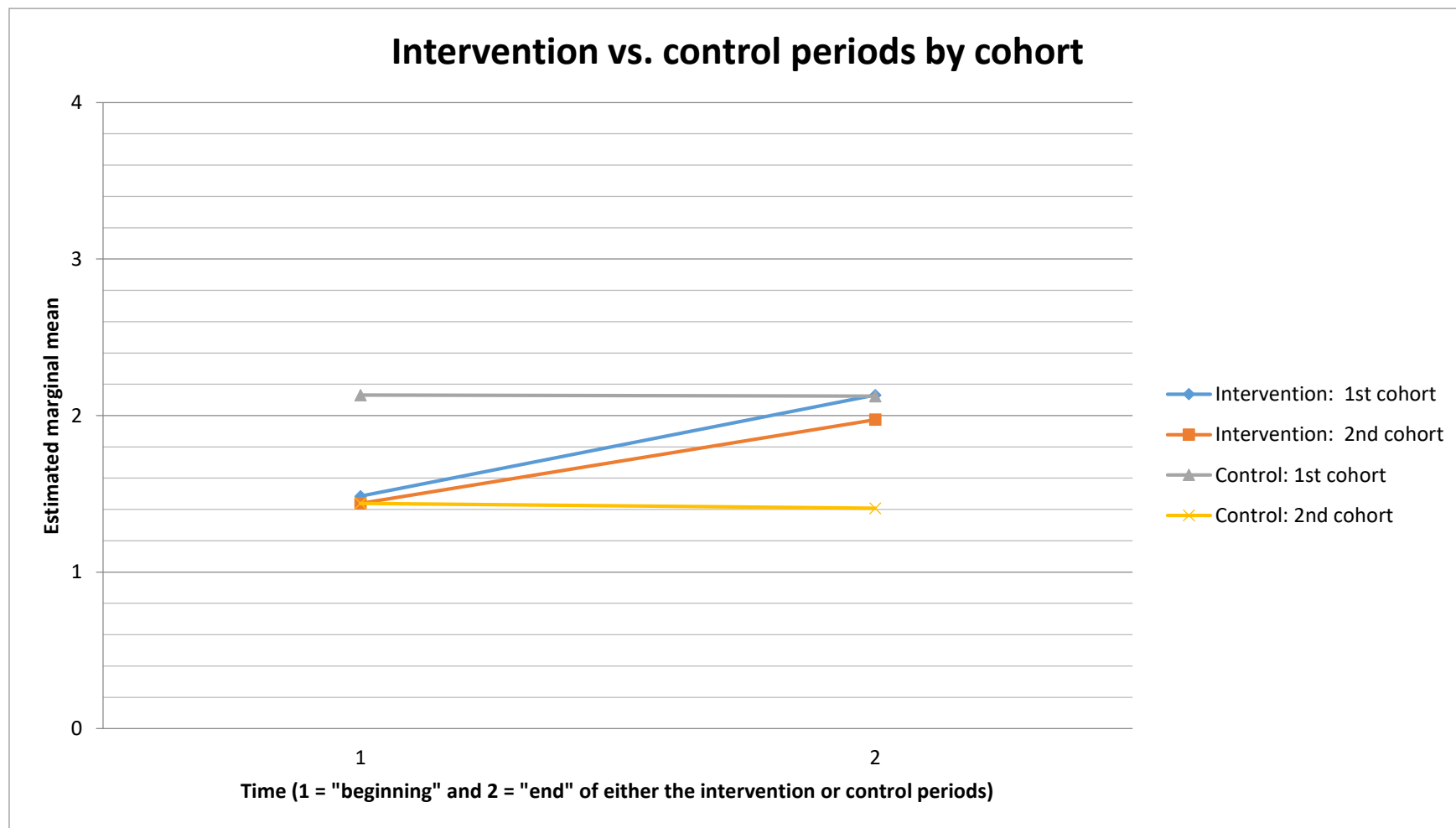


Impact of the INNOVCare pilot on the quality of life of the patients

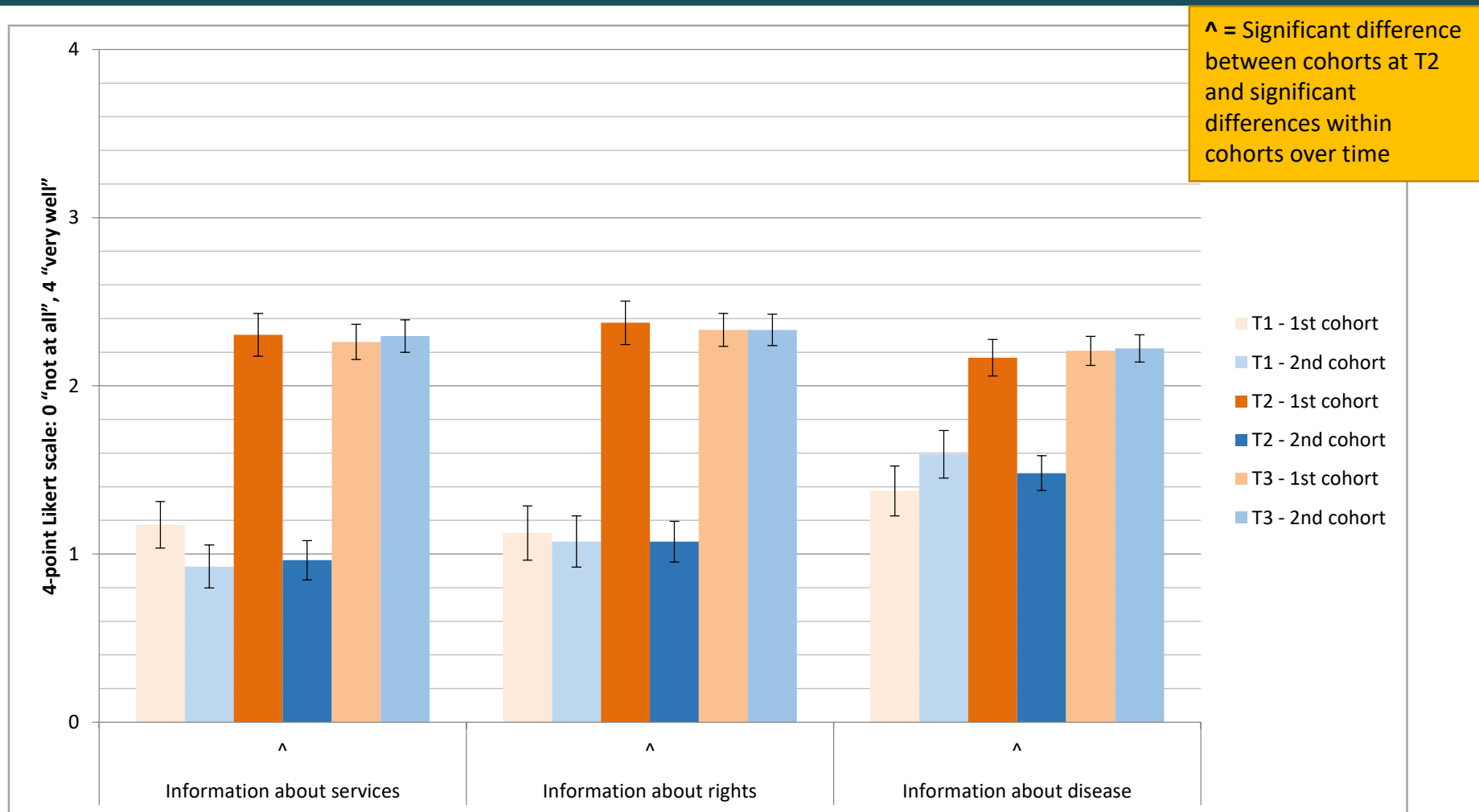
- Quality of life: The intervention seems to have had no significant impact on the quality of life per se



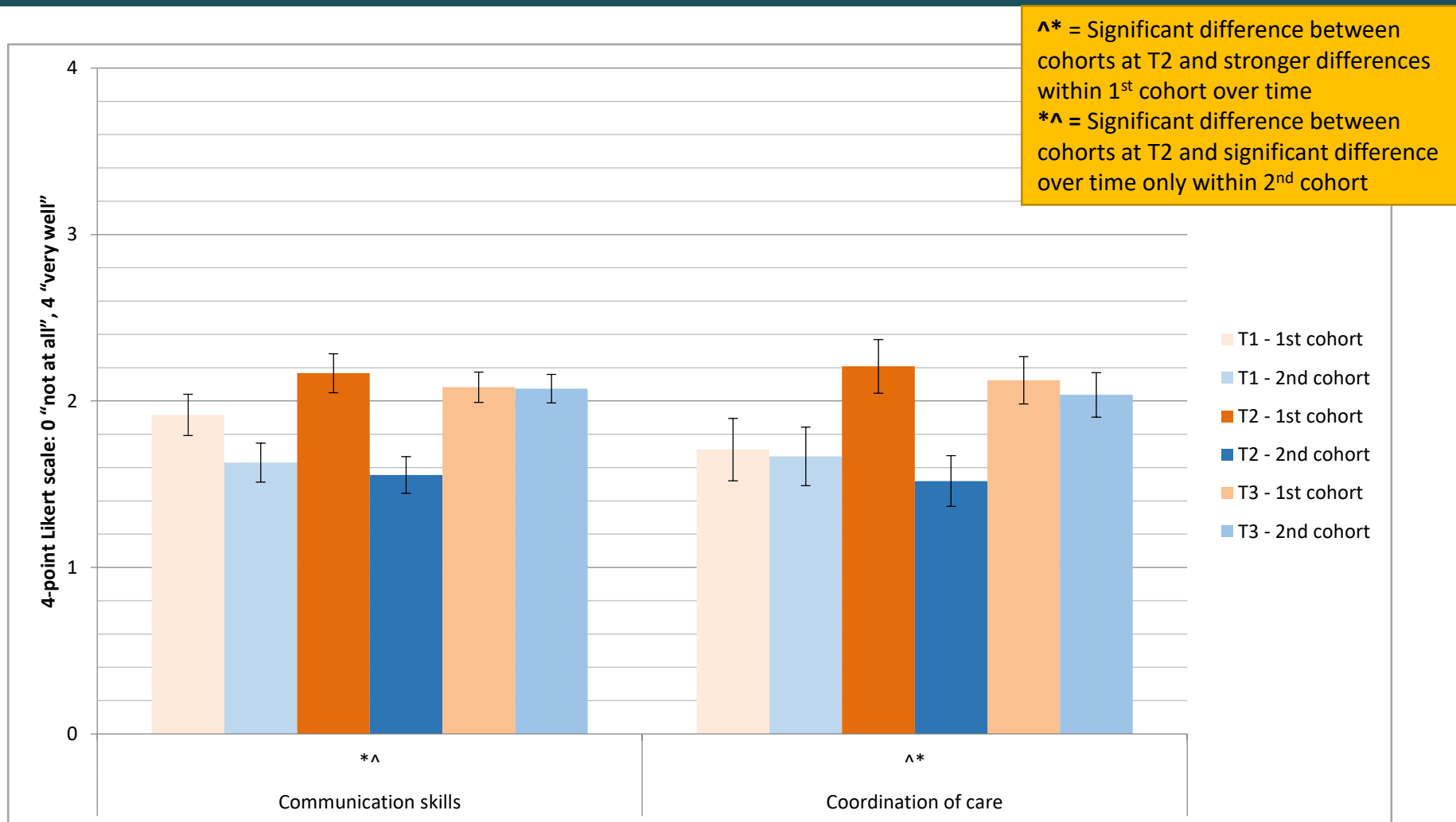
Efficacy of the INNOVCare pilot in general based on an index of the goals of the intervention



The social impact of the INNOVCare pilot: Information about services, rights & disease

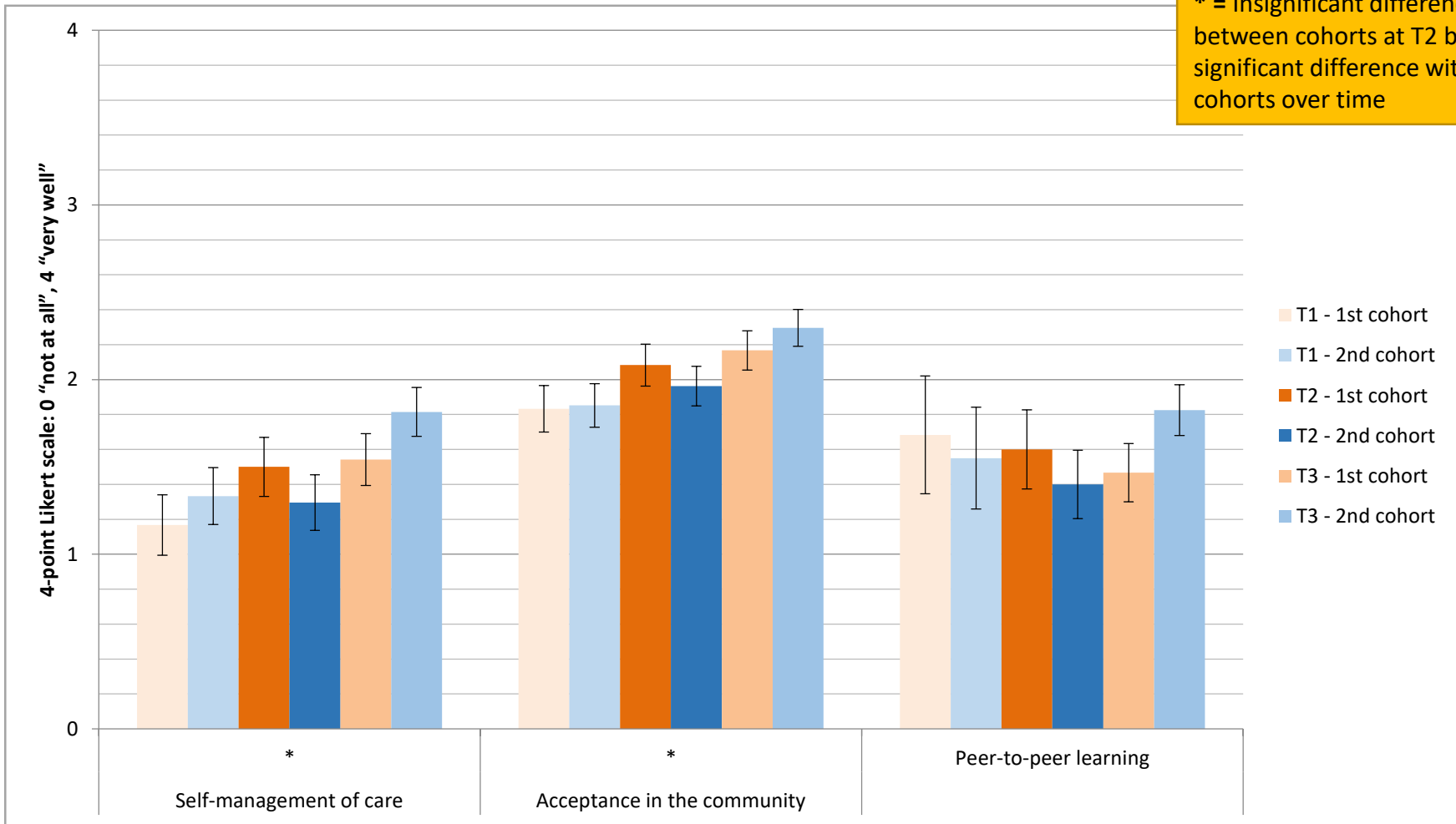


The social impact of the INNOVCare pilot: Communication skills and coordination of care among service providers



The social impact of the INNOVCare pilot: Fitness to manage own care, acceptance in the community and peer-to-peer learning

* = Insignificant difference between cohorts at T2 but significant difference within cohorts over time



In summary...

- No measurable effects regarding the overarching goal of the intervention: improving the general quality of life of the patients
- 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
 - existing quality of life instruments may not sensitive enough

In summary...

- **HOWEVER: Significant improvement** in 7 of the 8 dimensions covered by the intervention. The intervention can therefore be considered successful in terms of its social impact e.g. patients are more empowered and informed, have higher self-confidence to communicate about their condition and manage their own care.
- Furthermore, these improvements have mostly been sustained by the 1st cohort over the period when the 2nd cohort was being treated (up to 9 months after the intervention).
- Learning effect of the case managers was indicated especially in two cases:
 - The participants of the 2nd cohort were significantly more fit to manage their own care at the end of the intervention than those in the 1st.
 - Understanding and acceptance of the patients in the community significantly increased in the second phase of the intervention. Other than this learning effect of the case managers, this could also be influenced by the Rare ResourceNet created in the framework of the project.
- 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.

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Thank you

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