INNOVCare

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

Bridging the gaps between health and social care: results of the EU-funded project INNOVCare

Raquel Castro - Social Policy Director, EURORDIS-Rare Diseases Europe

www.innovcare.eu **#INNOVCare**

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This project is co-funded by
the European Union

What is a rare disease?

OVER 6000 distinct rare diseases

Rare, **complex**, **chronic**, **disabling**, progressive, degenerative, often life-threatening

Each one affects fewer than **1 IN 2000 PEOPLE**

NO CURE for the vast majority of diseases and few treatments available

All together, an estimated **30 MILLION PEOPLE** are living with a rare disease in Europe

They are **geographically scattered** and often **isolated**

Expertise, **knowledge**, **information** on diseases and their consequences are **scarce and difficult to access**

Few experts, geographically **scattered**

Research is fragmented

What are rare diseases?

Complex conditions

Disabilities

Socio-economic Vulnerabilities

Chronic diseases

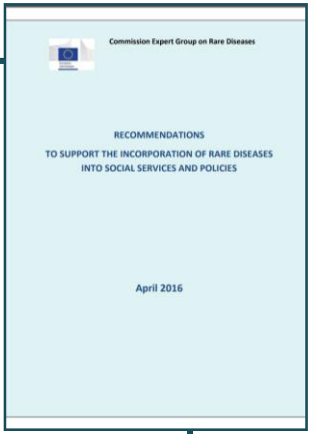
Complex conditions

Disabilities

Innovative care for rare diseases can be up-scaled to improve long-term care & social inclusion of other people with

Socio-economic Vulnerabilities

Chronic diseases



Commission Expert Group on Rare Diseases

RECOMMENDATIONS
TO SUPPORT THE INCORPORATION OF RARE DISEASES
INTO SOCIAL SERVICES AND POLICIES

April 2016

“*The **serious unmet social needs of people with a rare disease** and their families **affect their dignity, autonomy and other fundamental human rights***

Member States should promote measures that facilitate **multidisciplinary, holistic, continuous, person-centred and participative care provision** to people living with rare diseases, supporting them in the **full realisation of their fundamental human rights”**

Commission Expert Group on Rare Diseases Recommendations to Support the Incorporation of Rare Diseases into Social Services & Policies

See all the recommendations here

Juggling care and daily life: The Balancing Act of the Rare Disease Community

First Europe-wide survey on social impact of rare diseases, involving 3000 rare disease patients & carers

Rare Barometer

Juggling care and daily life

The balancing act of the rare disease community

A Rare Barometer survey

EURORDIS INNOVCare

Report with full results

Serious impact on patients' everyday life

More than 70% of people living with a rare disease have difficulties with:

1. Daily activities and tasks — Household chores, Preparing meals

2. Motor/ sensorial functioning — Visual, Hearing

Complex & often invisible

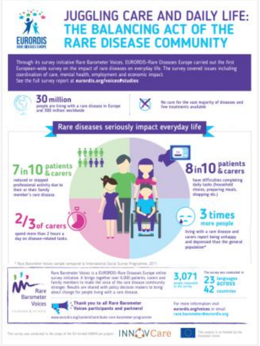
"The difficulty lies in the **impossibility of carrying a routine** (...). The problem arises when **one day you appear completely healthy, the next day you are sick**, and two days later you appear completely normal again. Many people find it difficult to understand the disease and the process, and the absenteeism that entails"

Female, Spain

Symptoms vary & can be invisible in many ways

EURORDIS.ORG

Presentation of key results



JUGGLING CARE AND DAILY LIFE: THE BALANCING ACT OF THE RARE DISEASE COMMUNITY

Through its survey initiative Rare Barometer Voices, EURORDIS-Rare Diseases Europe carried out the first European-wide survey on the impact of rare diseases on everyday life. The survey covered issues including coordination of care, mental health, employment and economic impact. See the full survey report at **eurordis.org/voices#studies**

30 million people are living with a rare disease in Europe and 300 million worldwide

No cure for the vast majority of diseases and few treatments available

Rare diseases seriously impact everyday life

7 in 10 patients & carers reduced or stopped professional activity due to their or their family member's rare disease

8 in 10 patients & carers have difficulties completing daily tasks (household chores, preparing meals, shopping etc.)

2/3 of carers spend more than 2 hours a day on disease-related tasks

3 times more people living with a rare disease and carers report being unhappy and depressed than the general population*

3,071 people responded to the survey

23 languages across 42 countries

Thank you to all Rare Barometer Voices participants and partners!

Infographics with key results

INTEGRATED CARE FOR RARE DISEASES: BRIDGING THE GAP TO IMPROVE THE LIVES OF 30 MILLION PEOPLE IN EUROPE

RARE DISEASES

Rare, complex, chronic, disabling

30 million people affected in Europe

Fewer than 1 in 2000 people affected by each rare disease

No cure for the vast majority and few treatments available

Expertise and knowledge on their consequences are scarce and difficult to access

PEOPLE LIVING WITH A RARE DISEASE AND THEIR CARERS FACE SERIOUS CARE BURDEN

65% have to visit different health, social and local services in a short period of time

67% feel that these services communicate badly between each other

7 in 10 do not feel well informed about their rights

7 in 10 find that organising care is time-consuming; 6 in 10 find it hard to manage

INTEGRATED HEALTH AND SOCIAL CARE IS ESSENTIAL TO ENABLE PEOPLE LIVING WITH A RARE DISEASE TO

- **Overcome their care burden and to secure the services and support that they require**
- Achieve a **quality of life on an equal footing with other citizens**
- **Participate in society and in the job market** to their highest potential
- Fully **realise their fundamental human rights**

SHARE THIS FACTSHEET TO HELP RAISE AWARENESS OF THE NEED FOR INTEGRATED CARE FOR RARE DISEASES #RareDisease | #INNOVCare innovcare.eu

Factsheet on integrated care for rare diseases with survey results

Survey performed via EURORDIS survey initiative
Rare Barometer Voices
and within the EU-funded INNOVCare project

Rare Barometer Voices

A EURORDIS INITIATIVE

Rare diseases have a serious impact on everyday life of both people living with a rare disease and their carers

**Juggling care and daily life: The Balancing Act of the Rare Disease Community*
First Europe-wide survey on social impact of rare diseases,
involving 3000 people living with a rare disease & carers

Rare Barometer

Juggling care and daily life

The balancing act of the rare disease community

A Rare Barometer survey

[Report with full results]

[Presentation of key results]

Serious **impact on Activities of Daily Living**, impairments & **disability**
Symptoms/impact of the disease may vary or be invisible

Significant **time burden**

Strong impact on **work-life balance and economic burden**

Care pathways are complex and hard to manage

Lack of information and **social services are badly prepared**

Serious impact on mental health: 3x more depressed than general population

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EURORDIS.ORG

Survey performed with the INNOVCare project, via
EURORDIS survey initiative Rare Barometer
www.eurordis.org/voices

Rare Barometer Voices
A EURORDIS INITIATIVE

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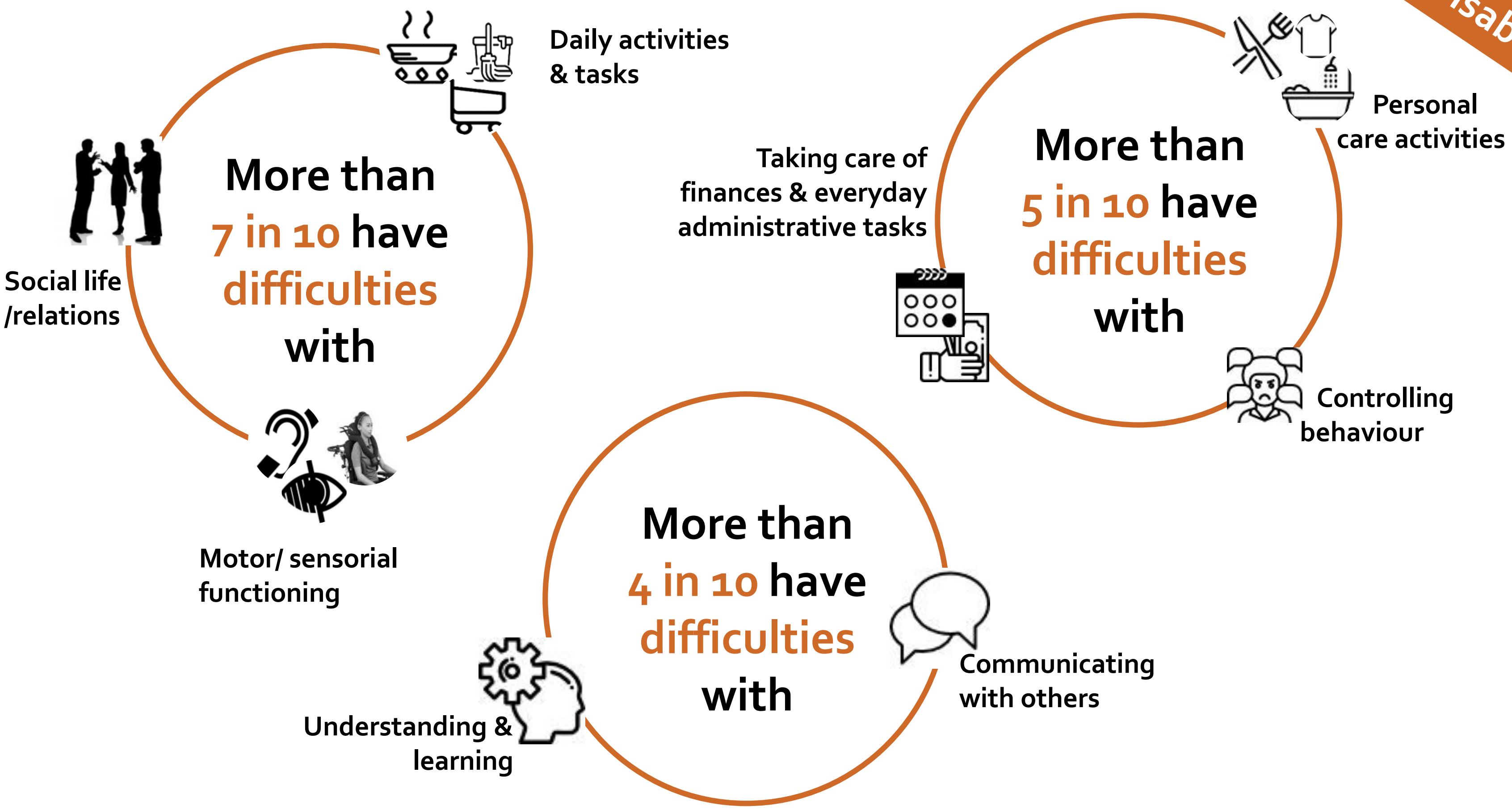
RARE DISEASES EUROPE

People living with a rare disease have difficulties with several Activities of Daily Living

Disability



More than **7 in 10** have **difficulties** with

- Daily activities & tasks
- Social life /relations
- Motor/ sensorial functioning

More than **5 in 10** have **difficulties** with

- Personal care activities
- Taking care of finances & everyday administrative tasks
- Controlling behaviour

More than **4 in 10** have **difficulties** with

- Communicating with others
- Understanding & learning

EURORDIS.ORG

Survey performed with the INNOVCare project, via EURORDIS survey initiative Rare Barometer
www.eurordis.org/voices

Rare Barometer Voices
A EURORDIS INITIATIVE

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RARE DISEASES EUROPE

Rare diseases are complex and often invisible

Discrimination

Symptoms vary & can be invisible in many ways

“**One day you appear completely healthy, the next day you are sick**, and two days later you appear completely normal again” Female, Spain

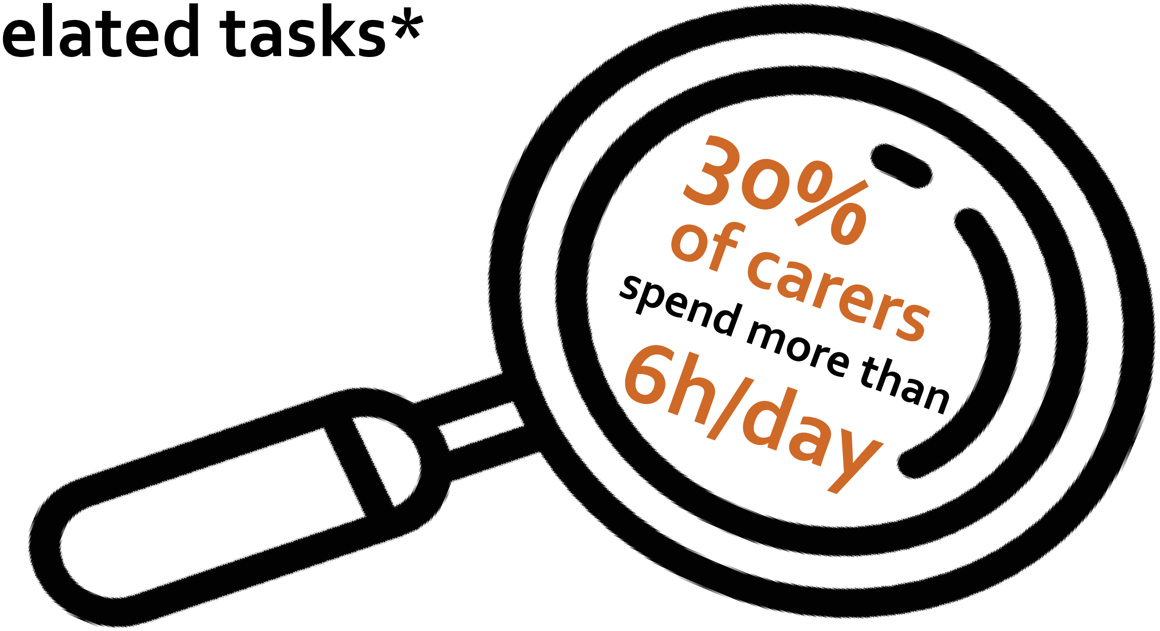
“**I don't look ill but am very ill** with a condition which no one understands or has heard of” Female, United Kingdom

Illustrative photo. This presentation does not necessarily reflect the position of the person in this photo. Source: EURORDIS Photo Contest

Heavy time burden for patients and carers

Time burden

42% of people with a rare disease & carers spend **more than 2h/day** on **illness-related tasks***



30% of carers spend more than **6h/day**

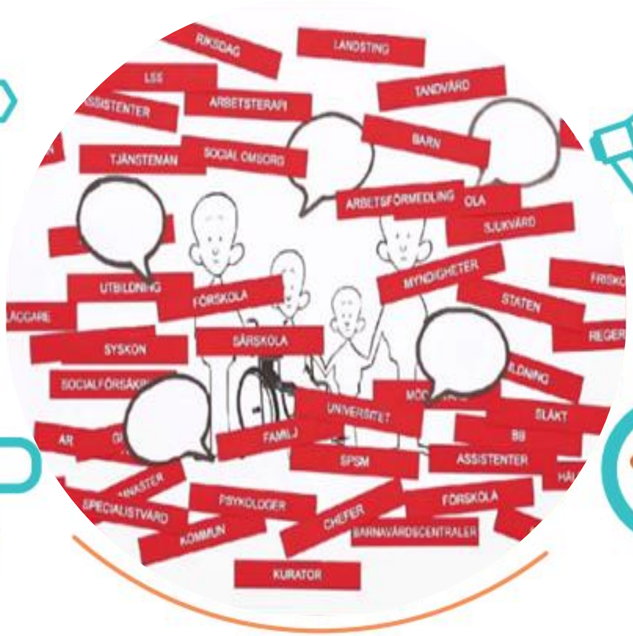
* *Hygiene, administration of treatments, helping with house chores, helping the patient to move*

Care pathway is complex and hard to manage

Integrated care

65%
have to visit different health, social and local services in a short period of time

67%
feel that these services communicate badly between each other



7in10
do not feel well informed about their rights

7in10
find that organising care is time-consuming; 6 in 10 find it hard to manage

Image on care pathway used for illustration purposes.
Source: [Nationella Funktionen Sällsynta Diagnoser](), Sweden

Significant impact on professional life

Employment

7 in 10

People living with a rare disease & carers had to **reduce or stop professional activity** due to the disease

The rare disease led to an **income decrease for 69%**

Survey performed with the INNOVCare project, via EURORDIS survey initiative Rare Barometer
www.eurordis.org/voices

Rare Barometer Voices
A EURORDIS INITIATIVE

Deteriorated mental health

Mental Health

3 times more people living with a rare disease and carers report being unhappy and depressed than the general population*

* Rare Barometer Voices sample compared to International Social Survey Programme, 2011

Building solutions to address the needs of patients and carers

INNOVCare

Mission: Bridging the gaps between health, social and local services to improve care of people living with rare and complex conditions

Total project budget: 1 994 414.72€ (EC co-funding 80%)
Project duration: 3 years, 2015-2018
Consortium: 8 partners, 6 EU countries
EC funding: EaSI programme, Progress axis

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INNOVCare

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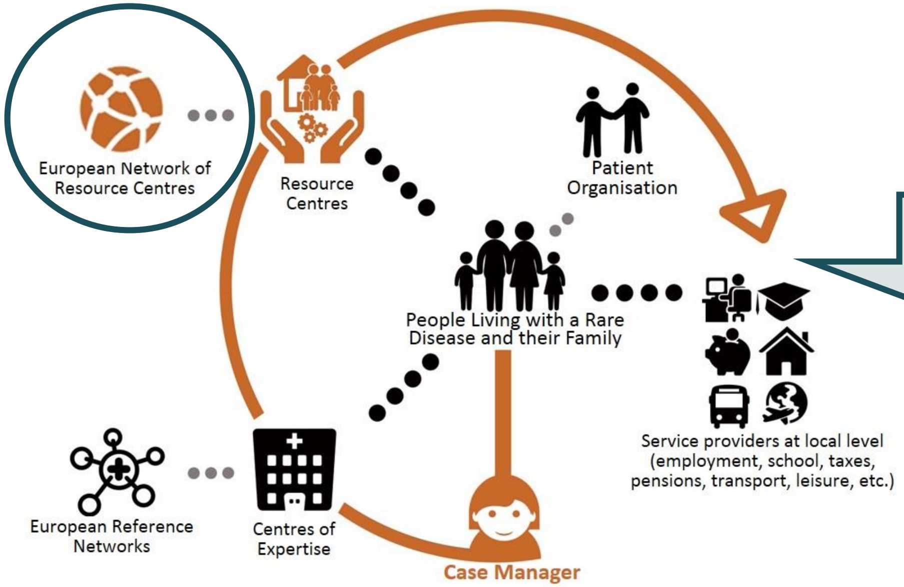
1st Europe-wide survey on the social impact of RD

Unmet needs

European network of resource centres (one-stop-shop)



Pilot of case management for RD

Social Impact

Good practices

Economic Impact & cost-benefit

Multi-stakeholder Workshops & up-scaling research

4 workshops, 100 participants, 24 countries

Advisory Group: including 17 representatives from national/regional competent authorities including Helena Kaariainen

Recommendations

Good practices

Key issues to support up-scaling

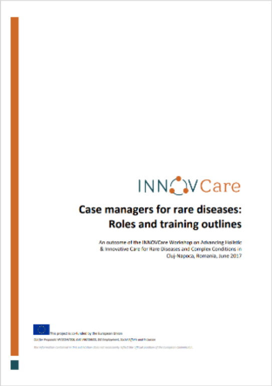
https://innovcare.eu/events/
https://innovcare.eu/resources/

INNOVCare pilot: case management for rare diseases & other complex conditions/disabilities

Regional case managers hired by NoRo resource centre Romania (one-stop-shop service), in partnership with the County of Salaj

Role of the case manager:

- ✓ Main and stable point of contact on care issues
- ✓ Inform, support and empower beneficiaries and professionals
- ✓ Hub of information, knowledge & needs assessment
- ✓ Holistic and person-centred care planning and care co-ordination



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Case managers for rare diseases: Roles and training outlines

An outcome of the INNOVCare Workshop on Advancing Holistic & Innovative Care for Rare Diseases and Complex Conditions in Cluj-Napoca, Romania, June 2017

This project is co-funded by the European Union

[Download here the case manager role & training outlines]()

Objectives of the case management pilot:

- ✓ To improve/increase beneficiaries':
  - Knowledge/information on: their disease, their rights and available services
  - Capacity to manage their own care – self-management
  - Communication skills, to explain their condition and care needs
- ✓ Connection to others with the same condition – peer-support
- ✓ To support the coordination between different health and social services
- ✓ To raise awareness and understanding of the community
- ✓ To prevent avoidable risk situations & optimise use of services

Developed with input from patients and carers

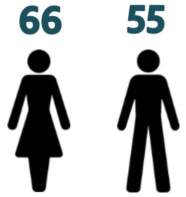
INNOVCare pilot: case management for rare diseases & other complex conditions/disabilities

Pilot framework:

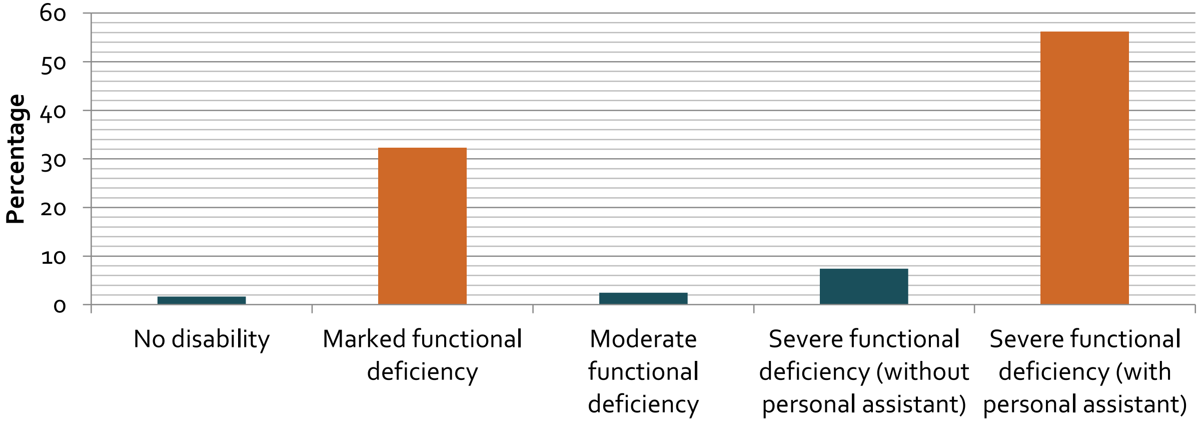
- At NoRo centre: one-stop-shop service delivering therapies, therapeutic education, training, medical, social services
- Time frame: 2017-2018, 9 months for each person/carer
- Target: people/carers with a rare disease/complex condition
- Geographic scope: region of Salaj, Romania
- Nr of case managers employed: 4, but 2 full-time equivalents
- Nr of simultaneous cases per case manager: 30
- Profile of case managers: 2 social workers, 1 legal advisor, 1 special education teacher
- Actions taken to develop the pilot: focus group with beneficiaries, mapping of care providers, gathering of an Advisory Committee and an Ethics Committee

INNOVCare pilot: profile of beneficiaries

n=121

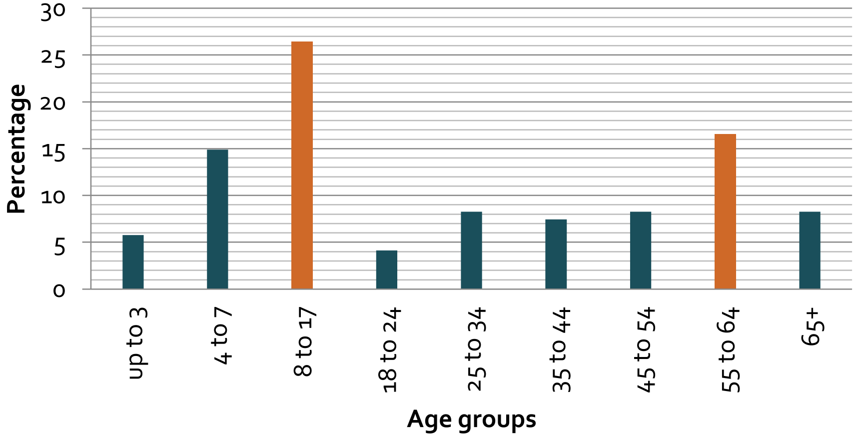


Level of disability:



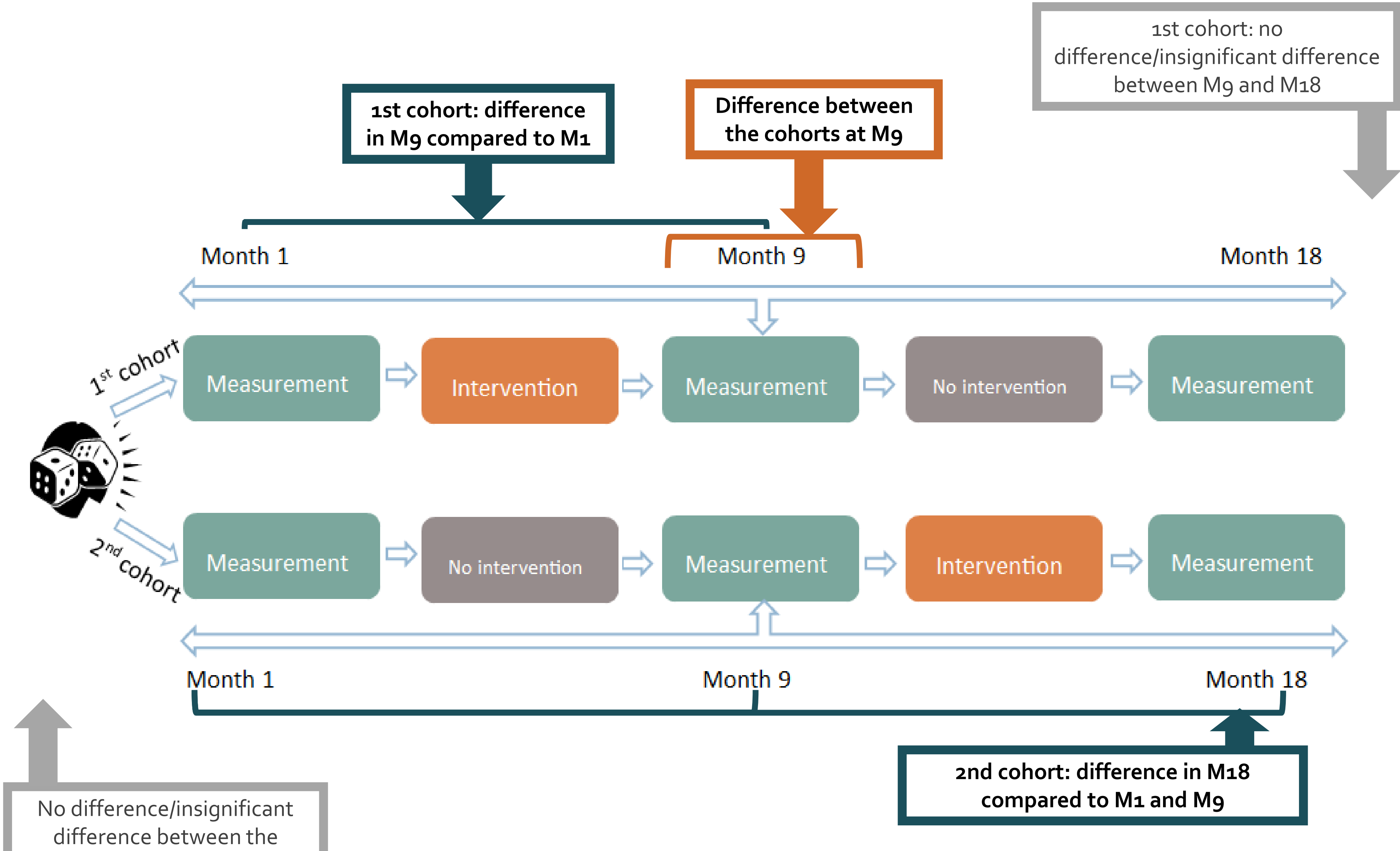
More than 30 rare/complex conditions represented

Age groups:



Type of disease/condition:

INNOVCare pilot: evaluation design & expectations



1st cohort: no difference/insignificant difference between M9 and M18

1st cohort: difference in M9 compared to M1

Difference between the cohorts at M9

Month 1 Month 9 Month 18

1st cohort: Measurement ⇨ Intervention ⇨ Measurement ⇨ No intervention ⇨ Measurement

2nd cohort: Measurement ⇨ No intervention ⇨ Measurement ⇨ Intervention ⇨ Measurement

Month 1 Month 9 Month 18

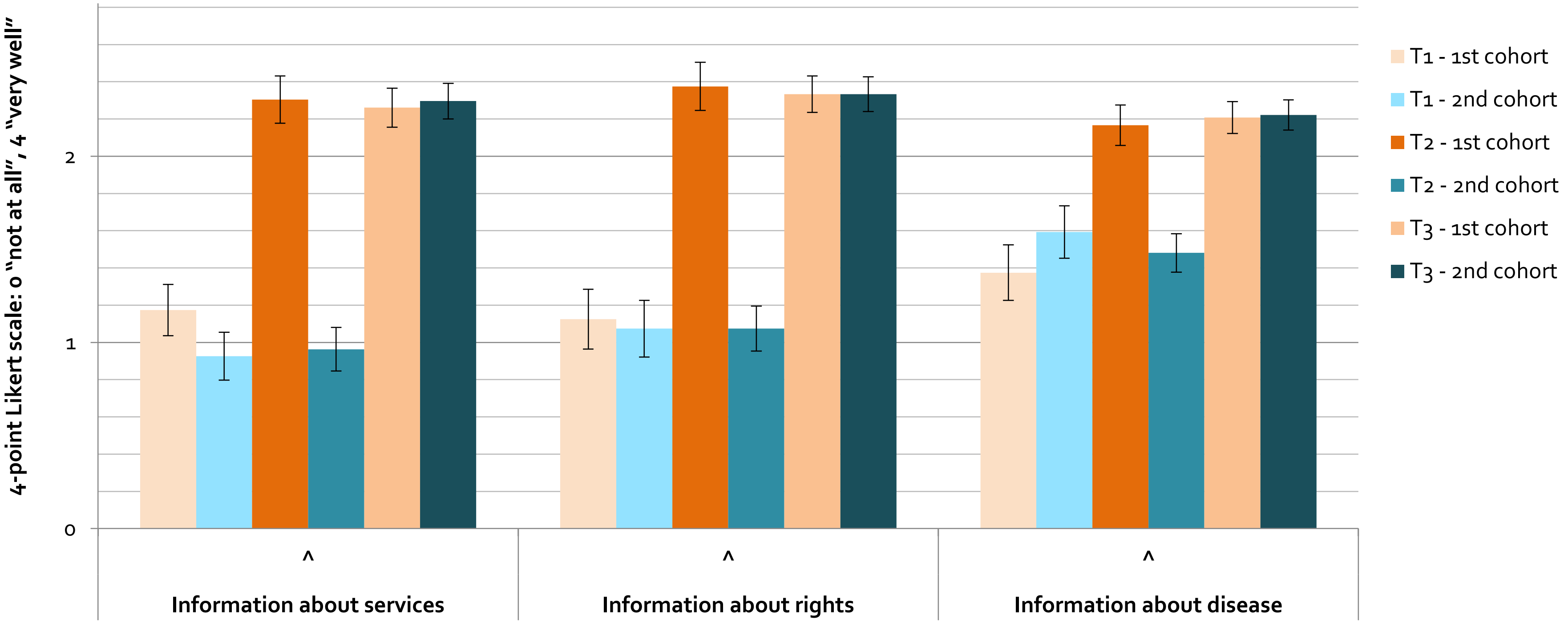
2nd cohort: difference in M18 compared to M1 and M9

No difference/insignificant difference between the cohorts

A basic two-condition repeated-measures design / rotation design
Experimental design /randomised control trial

INNOVCare pilot: results

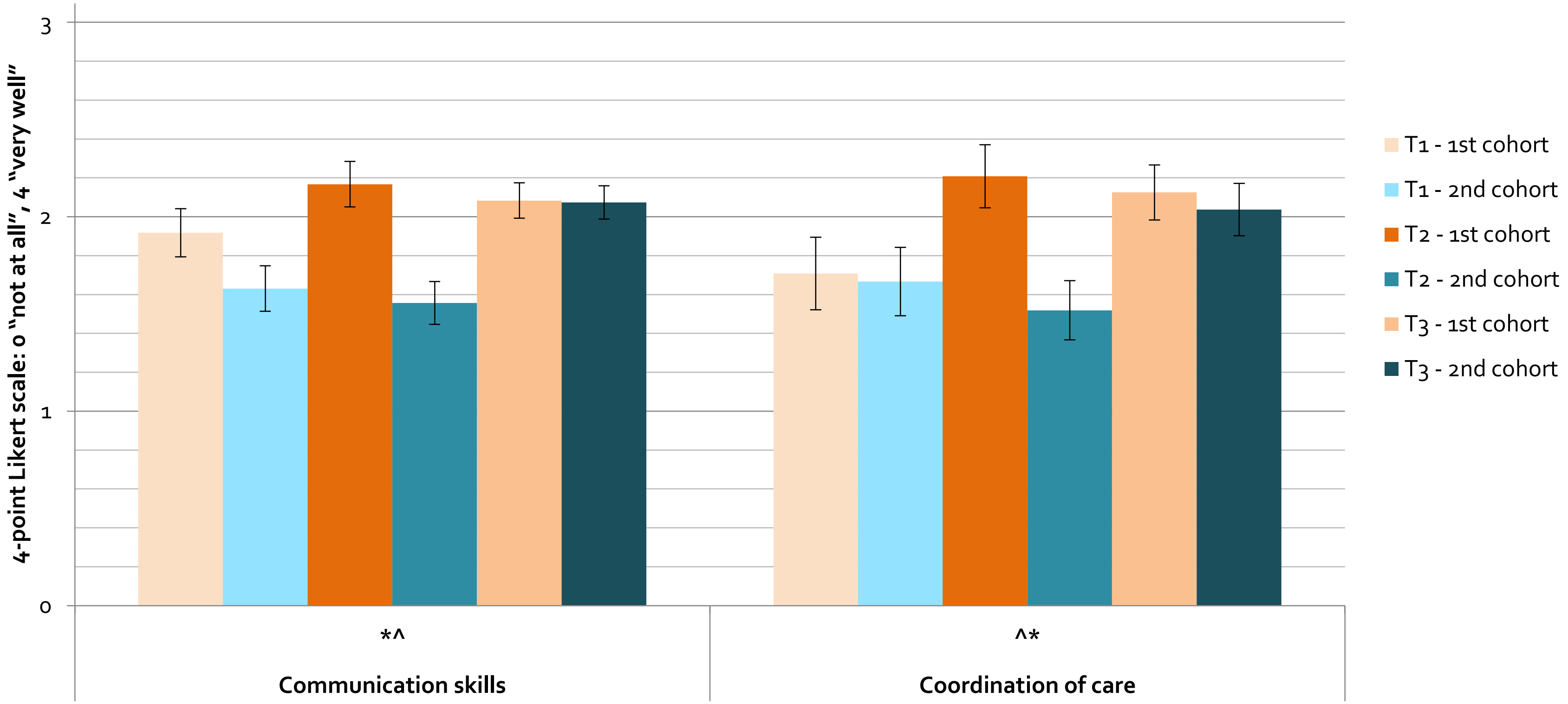
Case management improved beneficiaries' level of information



^ = Significant difference between cohorts at T2 & significant differences within cohorts over time

INNOVCare pilot: results

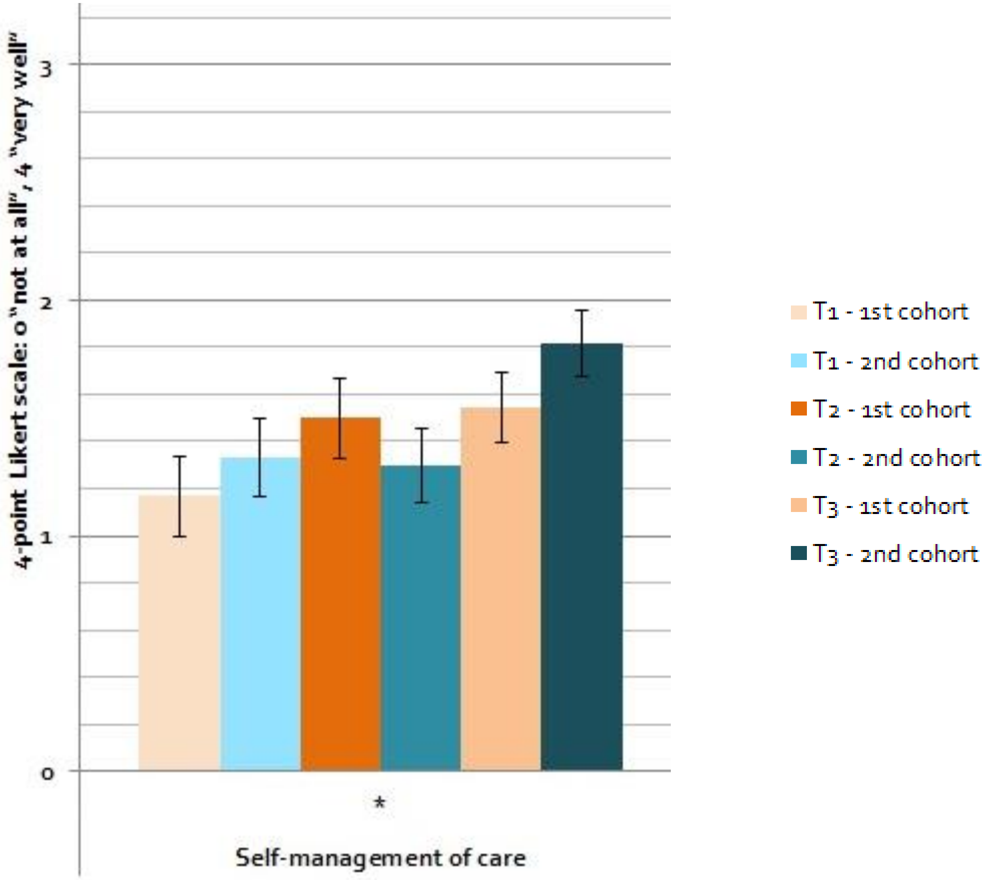
Case management increased beneficiaries’ communication skills & improved coordination of care



*^ = Significant difference between cohorts at T2 and significant difference over time only within 2nd cohort
^* = Significant difference between cohorts at T2 and stronger differences within 1st cohort over time

INNOVCare pilot: results

Case management increased beneficiaries' capacity to manage their own care

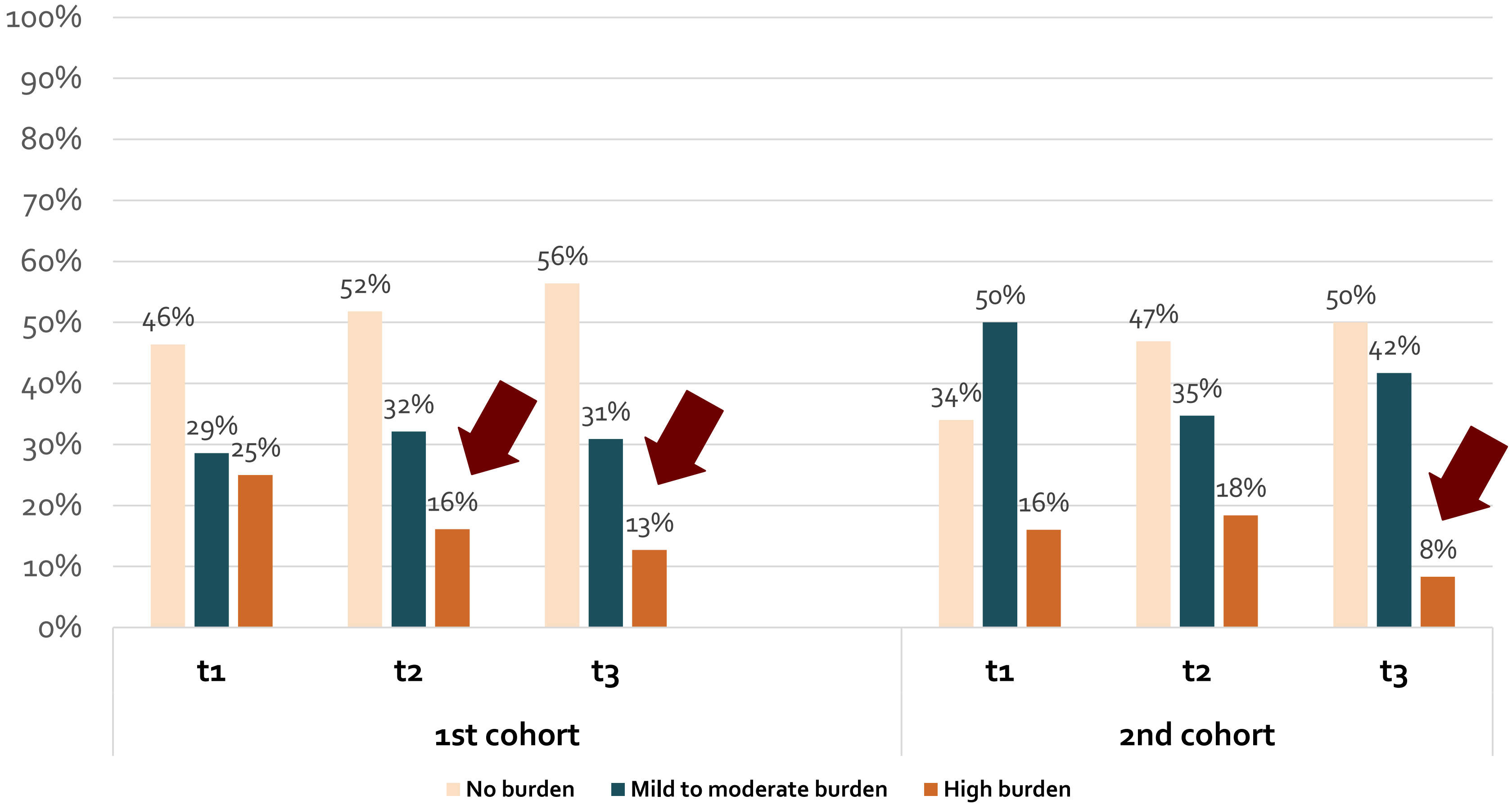


* = Insignificant difference between cohorts at T2 but significant difference within cohorts over time

INNOVCare pilot: results

Case management decreased the burden of care givers

Measured by Zarit Caregiver Burden



INNOVCare pilot: results

● Services/support obtained due to the support of the case manager

Employment

Peer support

Rehabilitation

> "It was great to have someone to take care of me and find for me the right services"
>
> Young beneficiary

Personal assistant

Wheel chair

> "It is a terrible feeling of being so lonely and not understood. My case manager answered to my needs and helped me to get my family back and to become more responsible for my care"
>
> Beneficiary with disability

The pilot of INNOVCare also had a direct impact to shape the Romanian national policies and implementation of case management services and community nursing

INNOVCare pilot evaluation: summary & lessons learnt

- **Case management works!** Beneficiaries are more informed/empowered & coordination of care improved;
- **Improvements on the 1st cohort were sustained** in the 9 months after the intervention;
- There was less use of emergency hospital services and less hospitalisations;

To measure the board social-economic impact of the intervention, it is necessary to:

- ✓ **Conduct long-term implementation and impact evaluation;**
- ✓ **Use tailored QoL and intervention measurement instruments;**
- ✓ **Build the capacity of services to self-monitor their impact.**

INNOVCare outcome: European Network of Resource Centres for rare diseases

> *Advancing holistic high quality care and services for people living with rare diseases across Europe*

- ✓ **Complementary to health care and social services**
- ✓ **Resource hub**

7 members, 7 European countries and growing

Objectives:

- **Networking and mutual learning**
- **Knowledge, expertise and good practices**
- **Training** for care providers, patients, carers
- Contribute to the elaboration of service accreditation **quality criteria**
- Support the elaboration of **impact indicators**
- Promote **innovation** in social services in all aspects and areas
- Promote **cooperation** between all stakeholders involved in care provision

Why up-scaling INNOVCare?

- **Achieving better health and social outcomes;**
- **Relieving and empowering beneficiaries/carers, consequently increasing the their social and economic participation**;
- **Elevating the care system** to best address unmet needs;
- **Creating gains for the care system - increasing efficiency** across health and social welfare systems, reducing duplication of services, increasing prevention;
- Bring about a **wider societal change: leaving no one behind**

Up-scaling INNOVCare and integrated health-social care

Key areas identified:

- **Coordination between public bodies**
- **Multidisciplinary teams** and **care coordination**
- **Empowerment of beneficiaries**

Outcomes of interviews with 32 experts from Austria, Romania, Spain and Sweden as well as from the project multi-stakeholder workshops (100 participants, 24 countries). These included national/regional policy makers and public servants, service providers and representatives of people living with a rare disease. The goal of the interviews was to identify the opportunities and barriers to up-scale integrated care for people living with a rare disease/complex conditions.

Recommendations for integrated care for rare diseases

Creating a supportive political environment at national level

- Inter-Ministerial working groups;
- Dedicated coordinated/shared budget between public bodies from the social and the health sector;
- Top-down and bottom-up approaches: stronger involvement and accountability of local administration and civil society;
- Including integrated health-social care for complex conditions within national policies.

Recommendations for integrated care for rare diseases

Implementing mechanisms that support integrated care and the empowerment of beneficiaries at national level

- Allocating **financial and structural support to national platforms/networks** that gather and share of **knowledge/good practices**;
- **Pilot projects supported** (allowing long term implementation/evaluation), as generators of good practice and innovative services;
- **Training care providers** (teachers, social worker, doctors, case managers) on key care aspects and on communication with care providers and beneficiaries;
- Requiring **coordination between care providers in public tenders**;
- Putting in place **multidisciplinary care plans**;
- **Implementing services that facilitate care coordination** e.g. Resource Centres and case management (identifying the most suitable point for case management e.g. community nurses, municipalities, social services, primary care, hospitals);
- **Engaging beneficiaries in the design and implementation of services;**
- **Ensuring a smart combination of professional and peer-to-peer support**.

Recommendations for integrated care for rare diseases

Making full use of EU instruments to develop integrated care at European and national level

- Multi-annual Financial Framework to **support to EU-wide platforms and innovative pilot projects** that develop and transfer good practice and evidence;
- European Structural Funds **to support** MS to **up-scale** promising pilots into mainstream services;
- European Semester **as a vehicle to implement integrated care at national level**;
- **European Pillar of Social Rights** as guiding framework to build the future.

Recommendations for integrated care for rare diseases

INNOVCare

Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions ***www.innovcare.eu #INNOVCare***

Based on the INNOVCare project's outcomes,
the project partners RECOMMEND that:

1. The **EU, its Member States and other European countries continue to implement the Commission Expert Group on Rare Diseases Recommendations to Support the Incorporation of Rare Diseases into Social Services and Policies**.
   - The report on the **State of the Art of Rare Disease Activities in Europe**, previously issued by the European Joint-Action on Rare Diseases (RD-Action) **should be continued and used as a monitoring mechanism to assess the implementation of the recommendations** and the sharing of good practices across countries;
2. **The Work-life Balance Directive takes into account the specific needs of persons with rare diseases and their carers as well as of those with other complex chronic conditions and disabilities**;
3. **National and European bodies must allocate financial and structural support to ensure the continuity and the sustainability of Europe-wide platforms that are essential for the development and sharing of good practices** on integrated care for rare diseases and other complex conditions/disabilities.
   - These include **the European Reference Networks, the European Network of Resource Centres for Rare Diseases and other multi-stakeholder platforms that can further discuss and develop these topics** following the secession of the Commission Expert Group on Rare Diseases and the conclusion of the European Joint-Action on Rare Diseases;
   - The **European Commission Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable diseases must embrace and respond to the challenges of people with rare diseases and their carers**.
4. **National Strategies and Plans for Rare Diseases include the provision of integrated care and services for people living with a rare disease**, in coordination between specialised and mainstream services;
5. **Specific integrated care measures are implemented at national level** such as:
   - **Inter-Ministerial working groups and shared budgets**;
   - **Training of service providers**, including case management training;
   - Support to the **implementation of services and of expert networks** that support person-centred care coordination such as **Resource Centres** and **case management** for rare diseases and other complex conditions/disabilities;
6. **Patient/person-engagement in the design and implementation of services and patient empowerment become a requisite for health and social care provision,** in order to guarantee person-centred, participative care;
7. **Pilot projects continue to be supported, as generators of good practice and innovative services,** and that **due time is allowed for their design, implementation and long-term impact assessment.** Systematic and long-term evaluation is necessary to gather quality evidence on the direct and societal impact of the service.
8. **Sustainability mechanisms are put in place and accessible to public bodies, civil society organisations and service providers** involved in the implementation of integrated care services:
   - The new **Multi-annual Financial Framework** must continue to bring **support to EU-wide platforms and innovative projects** that allow Member States to develop and transfer good practice and evidence;
   - The **European Structural Funds must act as an accessible and adequate mechanism to support** Member States to **up-scale** innovative pilots into mainstream services;
   - **The European Semester must be used as a vehicle to implement integrated care** for people living with a rare disease and other complex conditions **at national level**.

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This project is co-funded by the European Union

EU-wide and national measures to guarantee integrated care for rare diseases is implemented and sustainable across Europe. Linking to:

- ✓ EU-level recommendations
- ✓ Work-life Balance Directive
- ✓ European Reference Networks
- ✓ National policies for rare diseases
- ✓ Specific integrated care measures
- ✓ Beneficiary/civil society engagement
- ✓ Support and funding mechanisms

https://innovcare.eu/recommendations/

Recommendations for up-scaling

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    - The new **Multi-annual Financial Framework** must continue to bring **support to EU-wide platforms and innovative projects** that allow Member States to develop and transfer good practice and evidence;
    - The **European Structural Funds must act as an accessible and adequate mechanism to support** Member States to **up-scale** innovative pilots into mainstream services;
    - **The European Semester must be used as a vehicle to implement integrated care** for people living with a rare disease and other complex conditions **at national level**.

www.creenfermedadesraras.es | www.apwromania.ro | www.cjsj.ro | www.eurordis.org | www.finovatis.com | www.ier.si | www.ki.se | www.zsi.at

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EU-wide and national measures to guarantee integrated care for rare diseases is implemented and sustainable across Europe. Linking to:

✓ EU-level recommendations

✓ Work-life Balance Directive

✓ European Reference Networks

✓ National policies for rare diseases

✓ Specific integrated care measures

✓ Beneficiary/civil society engagement

✓ Support and funding mechanisms

https://innovcare.eu/recommendations/

Good practices and resources from INNOVCare

- Role of case manager for rare diseases (adaptable)
- Training of case managers: general outline & specific training contents
- Results of the pilot of case management and lessons learnt
- Identification of the potential role of ERNs in supporting integrated care
- European network of resource centres for rare diseases
- Identification of key elements/tools to support integrated care

https://innovcare.eu/events/
https://innovcare.eu/resources/

Thank you

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