



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

Pilot of integrated & personalised care for rare diseases: case management

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Case management for RD

Case management - *the coordination of services on behalf of a person & accompanying the patient/family and filling the existing gaps;*

- ✓ **NoRo** - a Resource Centre for Rare Diseases in Romania in partnership with **Salaj County**;
- ✓ **one-stop-shop style of service**, combining medical, social and educational services;
- ✓ **tested** a holistic, personalized pilot care pathway including beneficiaries from NoRo Centre and new beneficiaries from county of Salaj;
- ✓ created a **bridge** between patients/families and professionals & care services



Role of the case manager

1. Single and stable point of contact;
2. Listen, inform, support and empower patients and families;
3. Assessment/monitoring of needs (observatory);
4. Holistic, patient-centered care planning and care co-ordination:



- ✓ *Hub of information and knowledge*
- ✓ *Inform, support and empower care professionals*
- ✓ *Facilitate coordination between services/networks of services*
- ✓ *Help to prevent risks & to limit use of health services when not needed*
- ✓ *Develop working methods that support patient/families empowerment*



Target beneficiaries:

- ✓ People living with rare diseases and other complex conditions (including undiagnosed conditions);
- ✓ 146 were contacted, 120 targeted and 118 included in the pilot in 2 cohorts of 60 and 58 respectively; there were 3 dropouts and the final number of beneficiaries was of 115 (60 in 1st cohort and 55 in the 2nd);



- ✓ Number of case managers: 4 professionals part-time, in an actual total of 2 full-time equivalents (FTE); maximum nr. of simultaneous cases per FTE: 30;
- ✓ Profile of case managers: 2 social workers, 1 legal adviser and 1 special education teacher.

Activities: NoRo and SJ County/ WP6:

■ Shared information:

- ✓ Focus groups with patients on case management role and expected outcomes;
- ✓ Site visits, workshops and meeting with stakeholders and partners;
- ✓ Implementation of case management;
- ✓ Advocacy at national level;

■ Study on care provision for people with rare diseases:

- ❖ *Mapped the care providers, payers, patient and organizations in Salaj, other community services or community support - who does what;*
- ❖ *Created a community support network;*

■ Established the Advisory Committee and an Ethics Committee;

■ Prepared curricula for case managers' training;

■ Up scaling involvement;

□ Participate in the European Network of Resource Centres for Rare Diseases (**RareResourceNet**)

INNOVCare Pilot implementation – NoRo Center & Salaj County

Case management pilot implementation

“One stop shop” type of service

Why

- NoRo is combining therapies, therapeutic education, training, medical and social services;

How?

Integrated & holistic health and social care

Medical services
(Ambulatory): paediatric psychiatry & genetics

Social services
1. Day care centre
2. Trial for flight
3. RD Patient groups +
case management

Training for:
Patients
Parents
Professionals

Training and advocacy

Strategy - NPRD
Integration into
National Policies &
Strategies

COR – Code of
occupation for CM
- Partnership with
NADP

Training
Case managers +
community
support network

Communication
Workshops, trainings,
conferences,
publications,
Radio NoRo

Recognition
The prize for
Innovation in
Health

Conclusions:

Impact

INNOVCare
115 people

4 case
managers (1/2
FTE each, 30
cases/pers)

National Law
and Strategy
changed

Case
managers:
1/50 persons
with disability

Training - COR

Sustainability
CM to be hired
by Local
Authorities

Patient story 1

- A young person with a rare disease. With the support of the case manager, the person could access:
 - ✓ Rehabilitation services: the patient entered the waiting list for rehabilitation;
 - ✓ Peer support: the patient organisation contacted invited the person to meet others with the same disease;
 - ✓ Employment: the CM facilitated meeting with a project consultant to help the person start a small business;
- **Feedback from the patient:** *"It was great to have someone to take care of me and find for me the right services"*

Patient story (2)

- Patient with a rare disease and disability without personal assistant and without family in the region. With the support of the case manager (CM), the person could access:
 - ✓ Personal assistant: patient's case was re-evaluated to obtain a personal assistant; The case manager convinced his niece then returned from abroad to take on the role of his personal assistant which also meant that he got more family support;
 - ✓ Wheelchair: National Health Insurance approved the patient's access to a wheelchair.
- **Feedback from the patient:**
 - ✓ *"It is a terrible feeling of being so lonely and not understood and this case management answered to my needs";*
 - ✓ *"My case manager helped me to get my family back and to become more responsible for my care".*

Difficulties:

- ✓ Beneficiaries become suspicious when asked too many questions;



- ✓ They prefer face-to-face discussions, where they feel more in control;



- ✓ Distance and lack of infrastructure or access to services;

- ✓ Some beneficiaries' health status was too bad to be able to answer the questions, some of them are too young (even for "Smiley" questions)



WP6 Project legacy:

- Trained case managers and a community network created and active;
- Training curricula available;
- Reinforced collaboration with local and national authorities;
- RareResourceNet established and ready to “fly”;
- Updated LAWs (for social assistance and community nursing):
<https://legeaz.net/monitorul-oficial-920-2017/hg-797-2017-regualemnte-cadru-organizare-functionare-servicii-asistenta-sociala>
- Introduction of Case Management in the Romanian Code of Occupation – ongoing;
 - ✓ *Innovation in health award in 2016;*
 - ✓ *New projects opportunities;*



Lessons learned:

- ✓ **Interinstitutional collaboration** is essential
- ✓ **Community support networks**
- ✓ **Case managers exchange platform**
- ✓ **Promotion and recognition of the case management** as a specialized social service
- ✓ **Continuous monitoring** of the case
- ✓ F2F meetings might be completed with **virtual monitoring**
- ✓ **tools for case managers**
- ✓ the **intervention is limited** by services' infrastructure
- ✓ family mentality, beliefs could also be a **barrier in the intervention**
- ✓ case management implementation **reveal the needs of the community** & these needs should be integrated in local strategy and **communicate to local authorities in order to create /provide new services**
- ✓ There is a need for exchange of best practices and **training for all!**



INNOCare project implementation:

And all the good things, including INNOCare are coming to an end...

*Thank
you* 

