INNOVCare

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

Progress on INNOVCare pilot of case management for rare diseases

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Advancing holistic and innovative care for rare diseases and complex conditions

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Topics to be addressed

1. Why do we need this project?
2. INNOVCare implementation
3. NoRo – a Pilot Reference Center for Rare Diseases
4. Pilot implementation of case management for rare diseases
5. Challenges of the implementation
6. Communication and exchange of good practices
7. Roles of case managers & training outline
8. Empowerment and training of support people and services in community;
9. Up-scaling process

Why do we need this project?

- **At international level:** *the lack of integrated services addressed to those affected by rare diseases, to facilitate the diagnose and to give the power to go forward and look for treatments, therapies, rehabilitation, inclusion in school and community…*

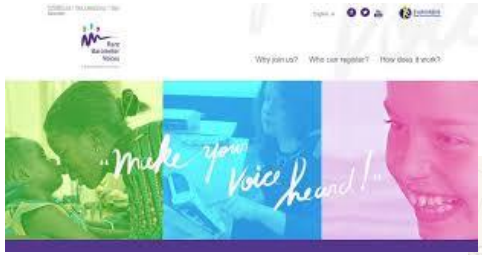
- **Rare Diseases in Romania**: *declared a national priority, too often forgotten, considered to be costly and that the patients have NO real chance for cure…*

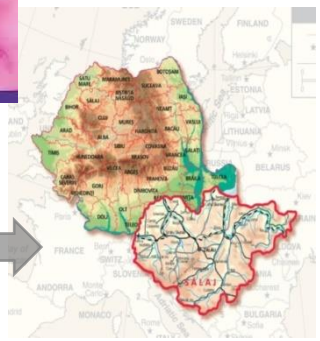
European Reference Networks

INNOVCare implementation

OBJECTVES

- ✓ To **give voice** to the social needs of people living with a rare disease
- ✓ **To test** a holistic, personalized care pathway
- ✓ To implement a **pilot of this pathway** in Romania;
- ✓ **To promote** project activities;





NoRo
Centrul Pilot de Referință pentru Boli Rare

ACTIVITIES WP6

- ✓Training of case managers
- ✓Case selection
- ✓Assessment process and contracting
- ✓Care planning
- ✓Care co-ordination
- ✓Evaluation and up scaling

Where we are?

- ❖ Building on the results: **Partners' Meeting** in Madrid , **Workshop** on Improving Integrated Care for People Living with Rare Diseases and Complex Conditions - **Ågrenska**, Gothenburg, 8-9 September 2016, **workshop in Vienna** "Scaling innovative care delivery - directions and possibilities"and the Mid-way meeting at CREER**, Burgos, 29th-30th of March 2017**

NoRo- a Pilot Reference centre for RDs

- Opened in June 2011 through a project of the RPWA, funded by Norway grants (Frambu center as our partner)

NoRo is:

- **a Resource Centres for Rare Diseases** in Romania
- **recognized as a HCP** to participate in ERN & CoE, part of a national consortium;
- a **one-stop-shop style of service**, specifically designed for people living with a rare disease, **combining medical, social and educational services;**
- creates **a bridge** between patients/families and various professionals and services involved in patient care;
- **involve patients** at local, county and national level in our services;
- participate in the **steering group of the RaResourceNet;**

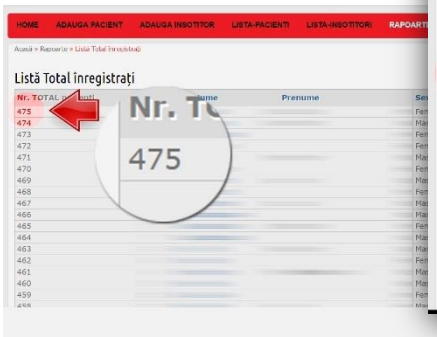
NoRo services: day care & residential care

- ✓ Therapies and therapeutic education
- ✓ Patient groups
- ✓ Interdisciplinary approach
- ✓ Continuity of care and cooperation with other services
- ✓ Summer camps and therapeutic weekends
- ✓ Help Line NoRo
- ✓ Electronic patient registry
- ✓ Research capacity

www.edubolirare.ro

✓Guidelines for emergency services, integrated care, books, leaflets, guide of services, map of services

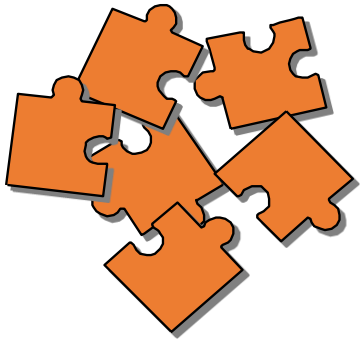
✓2 magazines

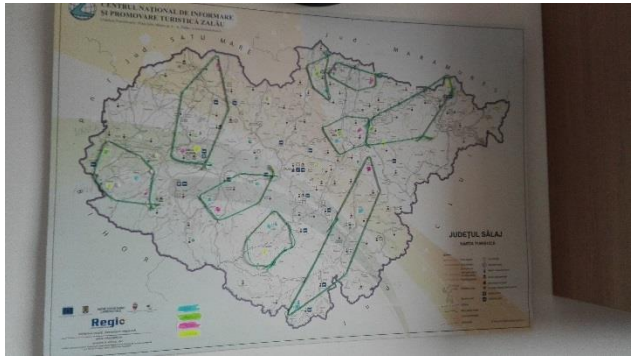


Development of our services

*A continuous updating of our services to the needs of patients, in an efficient way,…**considering the realities of our environment**:*

- ✓ many questions has **no answers yet**
- ✓ most of the patients have **not accessible treatments**
- ✓ we can't talk about social inclusion without **education for all** and **employments opportunities** for patients and families
- ✓ Considering **rarity** of cases but also **resources, services and expertise**





Case management: *coordination of care to develop the link between health, social and local/support services, including employment, school, financial support, housing, transport, leisure, etc. It is important that the case manager does not take roles of other professionals accompanying the patient/family but fills the existing gap.*

WP6: Pilot implementation

NoRo & County Council Salaj
Role in the implementation **(WP6)**

- Pilot Advisory Committee
- **Assessment of current service provision** quality and organisation
- **Training and employment of regional case managers** (pilot)
- **Implementation** of the case management
- **Facilitation of pilot evaluation**
- **Transfer of good practices**

Case management implementation

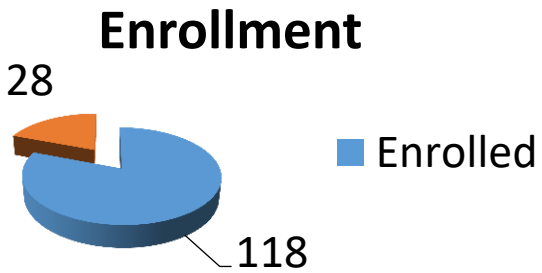
- ✓ **Time frame** for the service provision: 18 months, starting from 03/2017 to 07/2018 (overlap in Nov. 2017)
- ✓ **Target population:**
  - ❖ patients with complex conditions (children and adults) and their families;
  - ❖ both current beneficiaries of NoRo and new ones;
  - ❖ NoRo's current 60 beneficiaries will benefit from the service – 30/period;
  - ❖ Total of 120 beneficiaries identified and **118 included;**
  - ❖ Not included or refuse: **2**

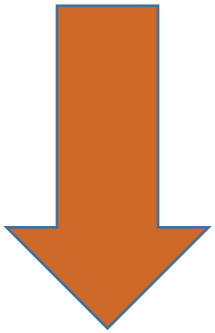


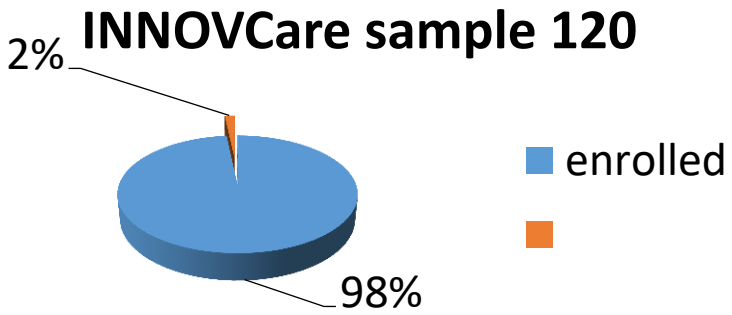

- ✓ Maximum nr. of simultaneous "cases" (patient & family) per case manager: 30 (2x29 & 2x30) ;
- ✓ Number of case managers employed: 4;
- ✓ Profile of case managers: 2 social workers, 1 lawyer and 1 special education teacher;
- ✓ Geographical scope of action: Salaj;

The current situation:

- ✓Beneficiaries at this moment:
- ✓- Total contacted: 146
- ✓- Total enrolled: 118 (the goal was 120)







80% of the contacted cases accepted to participate

Probably without the study, more people would accept to work with case managers

Numbers

- First set of data

	Needed	Existing internal data	External data
First sampling	120	60 (50+10)	215 anonym → 60 selected by ZSI
Second sampling	25	6	4 requests + the remaining anonym data

- After contacting cases

	Needed	Total enrolled	Enrolled internal	Enrolled external	Total refuses
First sampling	120	95	57	38	25
Second sampling	25	22	6	4+12	3
Total	120	117+1	63(-3)	54+1(+3)	2

- not motivated refuse -11+3, not living in SJ anymore - 5, declare that they can not be helped - 2+3

Ethical challenges to be considered:

- Taking in consideration the ethical issues – some cases shouldn't be refused to receive services if they know about it and ask to participate…

- ✓ Relatives of selected beneficiaries (n=3), former NoRo beneficiaries (n=2), new NoRo beneficiaries (n=6) asked to be part of the project
- ✓ Need to be changed the cohort, because they have now an emergency and we would assist them anyway

Special situations

- Randomized to a case manager that has to be changed though conflict of interests (personal life contacts)
- Person not speaking fluent Romanian had to be moved to a case manager who speaks her mother tongue

✓To be considered in upscaling models… the *possibility of changing the case manager if needed*…

Case management and NoRo Services

- Taking in consideration, that beneficiaries of NoRo services are in continuous change, some cases leave, some cases come in other NoRo Services

- This can be considered as starting or stopping using other support services while being in case management

- ✓ 3 cases stopped using other services at NoRo, but remain in case management
- ✓ new NoRo beneficiaries (n=6) included in case management

Challenges for case managers

- ✓ Distance… - longest route to a case 70 km

- ✓ Availability of some people only after work hours
- ✓ Longer periods beneficiaries are missing from home – being in hospitals, rehabilitation centers, at relatives…
- ✓ No communication and tension in the family
- ✓ Not realistic expectations from the beneficiaries
- ✓ Different "opinion" regarding the intervention plan objectives

- ✓ Initial assessment, contracts and identification of potential actions (**action plans that have to be discussed and agreed with beneficiaries**)

Collaboration between case managers

- There is a need to have regular meetings of the case managers in order to:

✓ Identify cases with the same problem handled by different case managers – solutions that can be addressed together

✓ Information exchange regarding network contacts, resource persons, other resources

✓ Brain storming for special situations

✓ Exchange of good practices

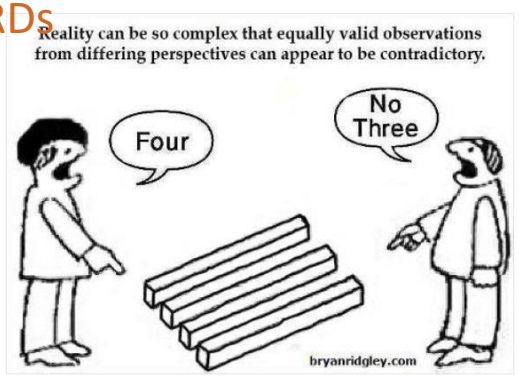
Challenges of our beneficiaries

- PLWRD are isolated, especially those that live in the villages
- Some of them don't know their rights
- Some of them have no treatment and didn't see a doctor for a long time or don't know that there is a treatment for their diseases;

- ✓ *both husband and wife have the same RD and just the wife have been selected*
- ✓ *The biggest problem we faced was to gain the trust of our beneficiaries, to open to us and discuss their problems and offering them the perspective of finding solutions together.*
- ✓ *worries that case managers might cut their benefits*
- ✓ *happy to have someone to speak and share their problems*
- ✓ *too long questionnaires and too many documents*
- ✓ *one of the beneficiaries said that she is 10 years younger because of this visits;*

Challenges for case managers

- ✓ To explain what means our services, that our services are free, that we will try to find solutions their needs together and that we will help them to create links to the services they need
- ✓ The biggest problem we faced was to gain the trust of our beneficiaries, to open to us and discuss their problems and offering them the perspective of finding solutions together
- ✓ The Collaboration with local authorities is very good and welcomed because they were open to support us, obviously because our partner involvement the County Council
- ✓ Families that have several members with the same RDs
- ✓ Finding the best ways of communication
- ✓ Understanding the main priorities of beneficiaries



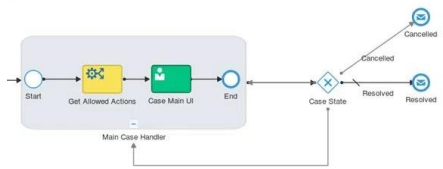
Ativities: NoRo and SJ County/ WP6:

- ✓ Performed a Study on care provision for people with rare diseases in the County of Salaj
  - ❖ Mapping care providers, payers, patient and disability organizations in Salaj, other community services or community support - who does what
- ✓ Shared information about NoRo's current activities
  - ❖ focus groups with patients on case management role and expected outcomes , site visit from ZSI and meeting with stakeholders, shared opinions on what case managers will do and what these interventions would change in patient lives;
- ✓ Establishing the Advisory Committee and an Ethics Committee;
  - ❖ Support on contacting the potential beneficiaries, coordination and intervention of the case management;
  - ❖ Focus groups with patients on case management role and expected outcomes (September);
  - ❖ Ethics certificate issued;
- ✓ Preparing curricula with and for case managers training
- ✓ Case management implementation(over 98% enrolment)
- ✓ Up scaling considerations and debate

Care pathways in rare diseases

- The innovative care pathway involves linking health services with the social and support services that people living with a rare disease use on a daily basis, ensuring the transfer of information and expertise between service providers.

- Centralises the coordination of care through NoRo Center and the case managers with the support of the County Council in an effort to relieve the burden of care management for patients and families.



✓ An optimised care model

more efficiency !!!

Training curricula

1. Introduction

- ✓ Project presentation
- ✓ Vision, Definition of case management
- ✓ Skills, qualification and ablities for case managers
- ✓ Case studies – other national experiences: case management project on MDD, patients navigator in cancer;

2. Rare diseases - general information

- ✓ Access to diagnosis in RD
- ✓ Assessment of the degree of disability
- ✓ Access to education
- ✓ Employment
- ✓ Social inclusion

3. Case management and communication

- ✓ Communication
- ✓ Efficient communication
- ✓ Developing communication skills
- ✓ Conflict solving & Networking

4. Resilience

- ✓ General information on family resilience
- ✓ Empowering patients and families
- ✓ The announcement of diagnosis and it's impact on the family
- ✓ Personal development and self-esteem

5. Development and coordination

- ✓ Description, definition and possibilities
- ✓ Legislation - rights and obligations
- ✓ Finding the right information and accessible
- ✓ Available Services

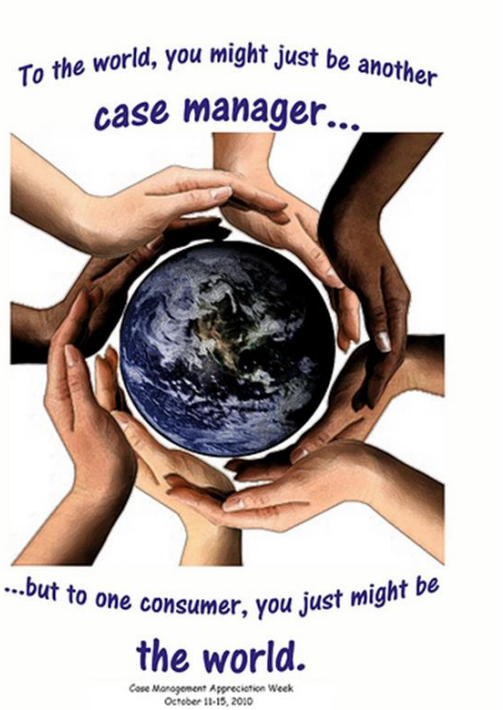
6. Work methodology

- ✓ Methodology of case management for people with rare diseases and their families
- ✓ Working Tools used in case management of people affected by rare diseases and their families

Case management implementation

Process of Case Management

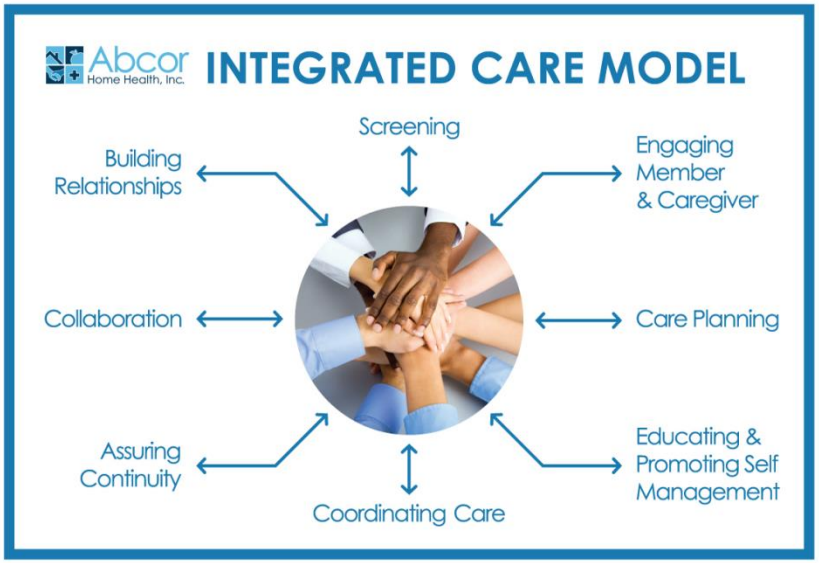
- Needs Assessment
  - Assess/collect data
  - Conducts case screening
  - Identifies client's support systems and care providers
  - Review history and determines current health care needs obtains approvals for contracts
- Plan Development
  - Identifies services and funding options
  - Reviews plan for consensus
  - Advocates for client as needed
  - Develop plan of care as indicated
- Implementation & Coordination
  - Communicates regularly w/client and support system
  - Coordinates treatment plan
  - Promotes coordinated and efficient care
  - Identifies needs for additional services
- Outcomes Monitoring and evaluation
  - Assess benefit value to cost & value to quality of life
  - Review plan for continuity of care
  - Evaluates client satisfaction and compliance w/treatment plan
- Documentation
  - Records services and outcomes
  - Submits report & other documentation as needed



Empowerment and training (needs)

- ✓ Patients need a place to meet and talk to each other.
- ✓ A place to belong to
- ✓ To improve family resilience
- ✓ To learn how to adapt to the situation
- ✓ To train **supportive people** in the community *(family doctors, nurses, community nurses, social workers, teacher, etc.)*

Advocate for integrated care!



Up scaling process- on going activities

- County Council and Advisory Committee involvement
- Training program developed
- Results of Rare Barometer
- Initiated new national and EU collaborations
- Steering committee of **RareResourceNet**
- Training other stakeholders
- Recognized as a HCP, CoE, and became member in ERN ITHACA (+ePAG)
  - ✓ Cooperation with Professionals;

- Finding **the right institution to hire the case managers**
- Creating **networks of support in community**
- **Promote** the model in other counties
- involvement in ***elaboration of national policies***
- cooperation with other social, medical and educational service

Top-down: policy; ongoing interview
Bottom up: Pilot implementation

Next steps

- Action plans and interventions ongoing
- Thematic group meetings at local level with specialists to build the network in the community
- Meeting with the Advisory Committee for planning the up scaling at national level