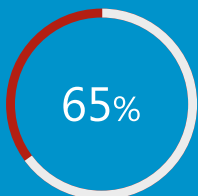
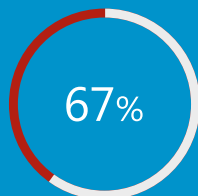


Report of the pilot

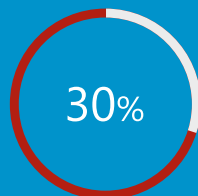
Pilot of Implementing Case Management for Rare/Complex Conditions in Sălaj County Romania



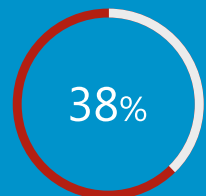
of people living with a rare disease have to visit different health, social and local support services in a short space of time*



of people living with a rare disease and carers say that different services communicate badly between them*



of carers for people living with a rare disease spend more than 6h per day on health-related tasks*



of patients and carers were absent from work due to health-related issues for over 30 days in the last 12 months*

*This survey was conducted via EURORDIS survey initiative, RareBarometer Voices, and in the scope of the INNOV Care project.

*This material was created by the Romanian Prader Willi Association in the project
INNOVCare - Innovative Patient-Centred Approach for Social Care Provision to Complex
Conditions (2015-2018), co-funded by the European Union*



Report

Pilot of Implementing Case Management for Rare/Complex Conditions in Sălaj County Romania

Contents

1. Project presentation	3
1.1. The objectives of the project	3
1.2. Description of WP 6 of INNOVCare project	4
1.3. Brief information about the Pilot.....	5
2. Case management legal framework in Romania.....	6
3. Preparing the Curricula and training of the case managers.....	6
4. Networking.....	8
5. Case management.....	10
5.1. Case management service at NoRo Center	10
5.2. Support to Pilot Evaluation	11
5.3. Work methodology and tools of the case managers	12
6. Intervention areas	13
6.1. Access to diagnosis and health services	13
6.2. Access to social services	13
6.3. Access to education and employment	14
6.4. Empowering patients and their families	14
7. Conclusions	15



1. Project presentation

INNOVCare - Innovative Patient-Centered Approach for Social Care Provision to Complex Conditions was a project co-funded by the European Commission in the Call for Projects "Innovation in social policy to support social reforms" of the Program "Employment and Social Innovation "EASI" - 2014-2020, PROGRESS component".

The project addressed the social challenges faced by people with rare diseases and the gaps in the coordination of medical, social and support services in the European Union (EU) Member States (MS). In most MS, care pathways are not structured and patients have problems accessing the services they need.

The recommendation of the European Commission's Rare Disease (RD) Expert Group (2016) on supporting the inclusion of rare diseases in social services and policies underlines that Member States "will promote measures to facilitate multidisciplinary, holistic, continuous, participatory and person-centered care for people with rare diseases, supporting them to fully accomplish their fundamental rights."

The project developed and tested a holistic, personalized care path that aimed to strengthen the medical, social and educational service partnerships between public, private service providers and the civil society.

1.1. The objectives of the project

The objectives of the project were:

- Assessing the unsatisfied social needs of the persons with RD and of their families;
- Analysis of care patterns in the Member States;
- Exchange of experience/good practices between resource centers;
- Proposal of an optimized care path model:
 - Implementation and assessment of case management within a pilot project in Romania - NoRo Center;

- Assessment of the social, economic and cost-efficiency for RD impact of the care pattern;
 - Analysis of the possibility of transposing the pattern for other diseases in other Member States;
- Strengthening the partnership between service providers from different sectors – public sector, private sector, civil society;

1.2. Description of WP 6 of INNOVCare project

Work Package 6 was a **joint responsibility** of the Romanian Prader Willi Association and Salaj County Council and consisted in the following activities:

- Establishment of an innovative partnership;
- Assessment of the current service provision quality and horizontal organization;
- Implementation of good practices recommended by WP5;
- Training of case handlers;
- Implementation of the pilot and creation of a network between the resource center and the regional care providers;
- Support to Pilot Evaluation.

The pilot study was implemented in Romania at the **NoRo Pilot Reference Center for Rare Diseases (NoRo Center) of the Romanian Prader Willi Association (RPWA/APWR)**, and the socio-economic impact and the cost-benefit ratio was **evaluated by expert teams** from other Member States.

The NoRo Center already had the following social and medical services:

1. **Day care center for recovery of children with rare diseases and from the autistic spectrum** - individualized intervention for children with rare diseases and autistic spectrum disorders;
2. **Recovery and rehabilitation center** – Groups of patients with rare diseases in 5-day residential system;
3. **"Trial for Flight" Independent Life Training Center** - a program for young people with special needs to develop independent life skills;
4. **NoRo Help Line** - Information and Counseling Service;
5. **Special ambulatory** - pediatric psychiatry, medical genetics, pediatrics.



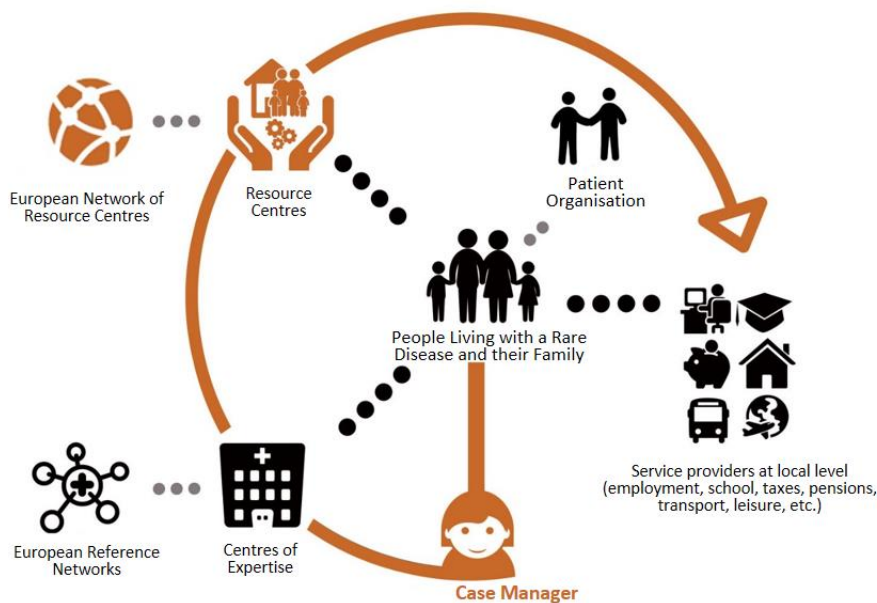
Since the beginning of its work, the NoRo Center highlighted the interdisciplinary nature of addressing people with rare diseases, this being the only possibility for effective intervention to increase the quality of life for people with rare diseases. The interdisciplinarity and collaboration with other community services has a major importance in terms of service continuity.

The importance of the INNOVCare project from the point of view of the NoRo Center, lies precisely in the fact that through the activities carried out within the project, we gained scientific proof of the necessity of this approach and of the effectiveness of coordinated interdisciplinary intervention.

It has been shown that among the **essential needs** of the patient and of his/her family there is also the need of **coordinating the care services**: access to medical, social and educational services.

1.3. Brief information about the Pilot

The time frame for the service provision: 18 months, starting from 03/2017 to 07/2018 (overlapping two groups in November 2017). **The 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 benefited from the service – 30/period. A total number of 146 patients have been contacted, 120 beneficiaries identified and 118 included in the intervention, 3 left and remained 115 until the end of the project. The maximum number of simultaneous “cases” (patient & family) per FTE case manager: 30. We have employed 4 part time case managers with a profile of: 2 social worker, 1 legal advisor and 1 special education teacher.



Besides the implementation of case management, the partners from WP6 had the following activities:

- 1) Assessment of the rare disease patients' needs and of existing care models in Salaj County;
- 2) A Study on care provision for people with rare diseases in the County of Salaj, mapping care providers, payers, patient/disability organizations in Salaj, other community services or community support;
- 3) Creating/ adapting working tools for case managers in their interaction with the patients and their families;
- 4) Exchanging of expertise and good practices between county level and national level;
- 5) Supporting case managers in their communication with the local services and local authorities;
- 6) Support for evaluating patient-centred provision of social care in Salaj - Romania;
- 7) Analysing transfer opportunities of the pilot beyond rare diseases to social care for people with disabilities at large, promoting it and advocating for it at national level;
- 8) Strengthening the partnership between our organization and the local and national authorities;
- 9) Establishing an Advisory Committee and an Ethics Committee.

2. Case management legal framework in Romania

In Romania there is the legislation on the inclusion of the case management in social and child protection services according to O.G. no. 288/2006 from 06/07/2006, published in the Official Gazette, Part I no. 637 from 24/07/2006 for the approval of the Minimum Mandatory Standards for case management in the field of the protection of children's rights.

During the project we have continued to advocate for the introduction of case management in the National Strategy for community nursing and the Government has approved in 2017 the framework regulations for the organisation and functioning of public social assistance services organised according to the provisions of art. 113 par. (1) of the Social Assistance Law no. 292/2011: <https://legeaz.net/monitorul-oficial-920-2017/hg-797-2017-regualemnte-cadru-organizare-functionare-servicii-asistenta-sociala> (it was approved and the Local Authorities will have to hire: 1 case manager for 50 children for whom a service plan is implemented, 1 case manager for 100 personal assistants, 1 case manager for 50 adults with disabilities with an individual care plan) We have also started to work in partnership with the National Authority for Disabled People to introduce the case manager for disabled persons (including rare disabilities) in the Romanian Code of Occupations in order to be able to train those that will perform this job in the future.

3. Preparing the Curricula and training of the case managers

Preparing the Pilot and the training of case managers we used the information prepared by the partners of INNOVCare project in other work packages or at different events, workshops organized. We also organized focus groups with patients on case management role and expected outcomes.

The skills and the qualifications of the case manager:

The case managers needed to be able to listen, observe and respond. For this they needed specific skills: skills to wait, to specify, to confront, to personalize, to solve problems and to plan actions.

The required **skills** for a case manager: positive approach; effective communication; negotiation skills; knowledge of the functioning of the medical, social and educational system and of rights of patients with rare diseases, of basic notions in accessing services and benefits for people with disabilities, the importance of obtaining informed consent, confidentiality of data and the privacy/autonomy of the beneficiaries; ability to perform patient and family needs assessment; critical thinking and analysis; the ability to plan and organize the activities necessary to achieve the objectives.

Appropriate **qualifications** for case managers: social worker, nurse, psychologist, special education teacher, physical therapist, physician, legal adviser, genetic counselor, pedagogue, etc.

The training curricula was created taking in consideration the recommendations from WP5 and all the partners, in collaboration with the case managers. It has the following contents:

- Introduction - Project presentation, Case studies, Case management;
- Rare diseases - General information, Access to diagnosis, Social Services, Access to education, Employment, Integration into society;
- Communication - Goals and objectives of the case manager communication, Efficient communication, Barriers in communication, Active listening, Nonverbal communication, Assertive communication, Co-operative communication, Conflict resolution, Networking;
- Increase family resilience - Factors that contribute to increase family resilience, Empowering patients and their families, Health literacy, Announcing the diagnosis, Personal development and self-confidence;
- Development and orientation - Independent life abilities, Daily life management, Health management, Money management, Social development, Personal development;
- European & Romania legal framework;
- Personalized intervention procedures / working methodology - Work tools used in case management, Stages of intervention (Initial evaluation, Intervention, Final assessment);
- Bibliography;
- Annexes.

Curricula is accessible on the website of RPWA.

(<http://www.apwromania.ro/CaseManagerTrainingCurricula>)

3 examples of best practices identified at EU level were included in the curricula for case managers:

- “Navigators” project, Rare Diseases Denmark;
- ProRaris – a pilot scheme of the Alliance for Rare Diseases Switzerland;

- Evaluation and management file for the patient with neuromuscular pathology applied by Parent project – Romania.

With the support of our partners from the County Council Salaj, the training curricula has been translated into English as we hope that service providers from other Member States will use this material in their activities and adapt it to their needs (legislation, national recommendations etc.).

4. Networking

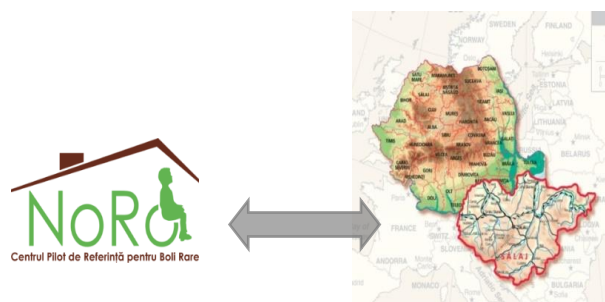
The **network of specialists** from the various services that the case manager's client needs is essential and constantly transforming. The case manager had the task of knowing these services, initiating and keeping in touch with the specialists in these services, both in order to solve the situations with their beneficiaries, as well as to facilitate future communication for the beneficiaries they introduced to these specialists.

Collaboration with local, county and national authorities supports the formation of the case manager's resource network.

An important resource for the establishment of the network was the information from the document **State of the art of services provision in Sălaj County**, which was finalized in September 2016 and the document was translated to English in December 2016.

The State of the art – Sălaj County document is due to the necessity of describing the present county level situation in the fields affecting people living with a rare disease and their families. People affected by rare diseases are often persons employed in the category of disability, thus falling into the category of vulnerable people, together with their family members. Because of the need for care and support of the affected person, families often get into financial and psychological difficulties. Case management implementation **reveal the needs of the community** and these needs should be integrated in local strategy and **communicated to local authorities in order to provide/create new services**.

We mapped the existing services in Salaj County, in all the relevant fields for people affected by rare diseases: health, social and educational. This data was used during the implementation of the pilot by all the case managers, when needed by the beneficiaries.



During the first year of the project, all relevant stakeholders were contacted in order to be informed about the project and about the necessity of forming an **Advisory Committee**. The first interaction with them was at the event organized to announce the launch of the INNOVCare project. It took place at the County Council, on 17th of December 2015 and had 16 participants.

In December 2016 we approached again all the stakeholders with a short description of the project and of the role of the Advisory Committee, in order to nominate people from the specific institutions/service providers to attend the working meetings of the Committee. The Committee has been formed officially in the same month, and met for the first time in February 2017. During its functioning, other persons and institutions joined the working process, as diversity of visions and approaches is an essential part of handling complex disorders. The role of the Committee was to have a support in designing and implementing the case management at local level, having the possibility to contact each of the Committee members as often as needed.

Although we initially planned this activity to last for the first 6 months of the project, we considered, that continuous discussions with the stakeholders are essential for the other activities of the project.

We had initiated the Pilot Advisory Committee composed of representatives of our centre and of the local authorities (Social Assistance Directorate of the municipality, General Directorate of Social Assistance and Child Protection, County School Inspectorate, Public Health Directorate, County Council) and decided to also invite members from the Ministry of Social Affairs (National Authority for Disabled People), the Ministry of Health and the National Council for Rare Diseases.

We have chosen organizations, institutions and people that had the expertise or experience in the field according to the needs expressed by our beneficiaries. We have also tried to create links to those who could support our network in the future. With the support of the Romanian National Alliance for Rare Diseases and the County Council Salaj we were able to send our messages to the right institutions at national level in order to extend our impact and to coordinate our advocacy at national level. Also, we were better understood by local authorities in order to communicate with the patients included in our intervention, to create and organize meetings with the community support networks, patients and their families.

Our main activities have been concentrated for minimizing fragmentation in the care provision, using evidence-based guidelines in practice, navigating transition of care, expanding the interdisciplinary team in planning care for individuals and improving patient safety.

In order to implement an efficient activity, the case managers with the support of our partners and Pilot Advisory Committee created community support networks and contacts in order to coordinate the care for their beneficiaries. We have organized community support network meetings and workshops in order to better communicate with all the stakeholders involved and train them. All the contacts that the case managers have established to support their beneficiaries, depended on patients' expressed needs and the intervention plan that they have designed together with the patient and their family. They had a wide variety of contacts as patients' needs were very diverse, from re-evaluation of the degree of disability, appointments to different professionals, looking for a job, access to supportive equipment for disabled people reimbursed by Health Insurance or access to treatment. We had a balanced approach to public and private services, but mainly our case managers approached the institutions that potentially had the solution or seemed to be more open to answer to their requests (patient organizations, professionals in contact with our organizations, social and medical services connected with NoRo Centre, or those in contact with County Council, Advisory Committee members and our partners in the project).

Our networking activity was helped by our actions for **promoting the project** and the need for case management. We have promoted the kick-off meeting of the project that has

been organized by the County Council Salaj and we promoted the project in all our events like: Europlan Conference, closing conference of the project “NoRo – Frambu, partnership for the future”, RDD Conference 2017, other NGOs conferences, Radio NoRo - the voice of patients, Transilvania Events organized by French Embassy in Romania and bilateral project meetings in Angers and Imagine; Case management workshop organized in PAL Awards project in June 2018; The up-scaling case management workshop organized in Cluj Napoca (118 participants, including 4 of our partners from the project). We have dedicated a section of our website to the INNOVCare project and Pilot implementation and have promoted our events on Facebook and in mass media. One of the most important article was published in The Medical Life journal for doctors (http://www.viata-medicala.ro/Manager-de-caz-in-bolile-rare.html*articleID_14724-dArt.html) and our organization has received the Innovation in health award (<http://innovationinhealth.ro/winners-2016/>).

5. Case management

5.1. Case management service at NoRo Center

Description of **case management services provided by the NoRo Center** within the INNOVCare project:

a) all beneficiaries were informed in their contract that the services were provided within the INNOVCare project, in the framework of a research on the efficiency of case management services and of holistic approach for people with rare/chronic diseases. The beneficiaries accepted the provision of the services under this contract, and they also accepted the provision of data (to be transmitted anonymously to the project partners) for this study.

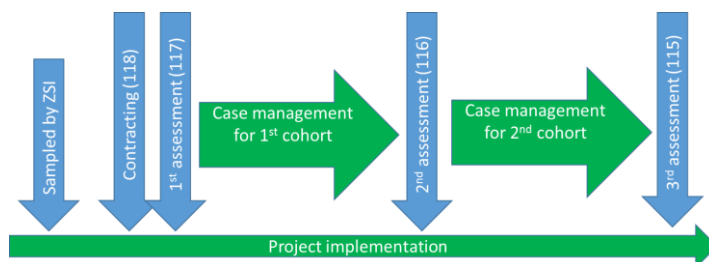
b) with the support of our partners we designated a case manager for each selected beneficiary;

c) the case manager’s task was supporting the beneficiary and his/her family in identifying their needs, elaborating the action plan and implementing it;

d) at least 5 individual interactions and at least 2 group activities were planned and organized for each beneficiary;

e) intervention with a total duration of 9 months, during which 2 questionnaires were applied - 1 at the beginning of the intervention period and 1 at the end of the intervention period. A third questionnaire was applied 9 months before or 9 months after the intervention – depending if the beneficiary was in the first or in the second cohort;

f) the case manager guided the beneficiary to the services he/she needed, established contacts with these services, provided information about services, rights, advised and instructed the beneficiary and the family to better manage the challenges caused by the disease;



Vision: The case managers are recognized as experts and key actors in rare disease co-ordination teams for access to quality and efficient care, and for empowering the patient and his/her family.

Definition: The case management is a participatory process of collaboration, evaluation, planning, counseling and information on care options that meet the conditions for fulfilling the patients' and of their families' needs by communicating and accessing the resources.

The role of the case manager from the patients' perspective:

- ❖ to have someone to ask for advice when they need it;
- ❖ information and finding experts;
- ❖ information on treatment funding and access to care, treatment and education;
- ❖ identification of jobs to ensure their independence.

Case management objectives:

1. Holistic approach to the medical, psychosocial, behavioral and spiritual needs of patients and their families;
2. Intensification of patient involvement in decision-making;
3. Extension of the interdisciplinary team of case managers to include community support persons;
4. Collaboration with service providers and facilitation of patient communication with service providers;
5. Improvement of patient safety.

The basic premise of case management is that when a person reaches the optimal level of well-being and functional capacity, everyone benefits: patients because they have an improved quality of life; support services, health care systems and health insurance systems. Case management serves as a means of achieving the well-being of the beneficiaries and their autonomy through advocacy, communication, education, identification of service resources and facilitation of access to these.

5.2. Support to Pilot Evaluation

As INNOVCare was a research project in which the socio-economical impact of the pilot had to be scientifically evaluated, we had to support the pilot evaluation by sending data about our work (for the Logic Model) and anonimised data about the beneficiaries (for randomized selection) and their situation and views (for the evaluation of the pilot) to representatives of the work packages responsible for the evaluation.

County Council has in it's subordination the General Directorate for Child Protection and Social Protection, which has the database of all the people with disabilities from the County. They provided the anonymized data for the randomized selection of the 60 external beneficiaries of the project. The data about the existing 60 NoRo Center beneficiaries was also anonymized to be sent to WP7 to be able to make the randomization of the others.

Possible beneficiaries of the Pilot were identified and the data was available for randomized selection by March 2016.

As the questionnaires for evaluating the intervention were prepared by WP7 and 9, we translated and tested them. In the specific periods – baseline March 2017, mid-way November 2017, final July 2018 – we applied the questionnaires and uploaded the result to the online platform given by WP7.

Even if the questionnaires were perceived as being too long by our beneficiaries, they were appreciated as they can offer the whole picture of the family status (health, social and economic).

5.3. Work methodology and tools of the case managers

Case management of persons with rare diseases is the set of techniques, procedures and working tools that provide advice to beneficiaries in order to improve their quality of life. This was done through 3 well-defined stages: the initial assessment, the intervention and the final assessment stage.

In the **initial evaluation stage**, the case managers used a **Record Sheet** and attached copies of the beneficiary's relevant documents (medical letters from the specialists, documents proving the diagnosis, disability degree certificate and identity documents of the beneficiaries and if needed other family members/legal representatives). When completing the record sheet, the written consent for processing personal data was required.

The **Contract for the provision of social services** was filled out for a determined period of 9 months and was signed by the beneficiary/representative of the beneficiary and the President of RPWA.



The image shows a contract form titled "CONTRACT PENTRU ACORDAREA DE SERVICII SOCIALE". At the top left is the logo for "ASOCIATIA PRADER WILLI DIN ROMANIA" and at the top right is the "INNOVCare" logo. Below the logos, there is a line for the number "Nr. / /". The main body of the form contains the following text:

Părțile contractante:

1. *Asociația Prader Willi din România - APWR*, denumit în continuare *furnizor de servicii sociale*, cu sediul în Zalău, Str. S. Bărnoșu, nr. 97, bl. SIB 88, ap.14, Sălat, codul de înregistrare fiscală: 15425573, contul nr. RO23 RNCB 0214 0281 3882 0001, deschis la BCR, certificatul de acreditare seria AF nr. 000789, reprezentat de doamna *Dan Dorica*, în calitate de: *președinte*;

și

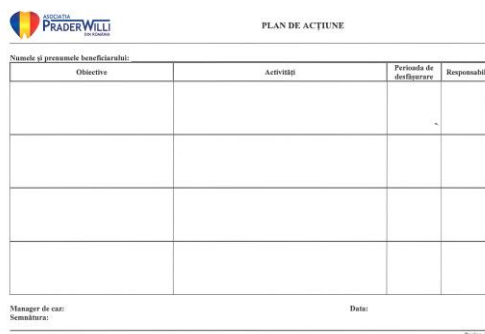
2. _____ (numele beneficiarului de servicii sociale) denumit în continuare *beneficiar*, domiciliat în localitatea: _____ str. _____ județul: _____ CNP: _____ posesor al B.I./C.I./C.N. seria: _____ nr. _____ eliberat de _____ în data de _____

reprezentat de d-l/ d-na _____ domiciliat în localitatea _____ str. _____ județul: _____ posesor B.I./C.I. seria: _____ nr. _____ eliberat de _____ în data de _____ conform (se va menționa actul care atestă calitatea de reprezentant) _____ nr. _____ data: _____

The role of the case manager is to evaluate and identify the needs of the beneficiary and the family. This is done based on the **Social Investigation** that was performed at the beneficiary's home or within the NoRo Center, based on the discussions with him/her/them.

In the **intervention stage** the case manager together with the person with a rare disease / his/her legal representative developed **the action plan**, using the information obtained during the initial assessment stage. In some cases, the action plan had to be reviewed during case management implementation. Every action or interaction through which the case managers tried to apply the action plan was recorded in **meeting reports/action reports**. Meeting reports were completed whenever a case manager met with

the client, and action reports were completed by the case manager whenever he/she took an action in the client's interest (made an appointment for a consultation, looked for a procedure for access to a particular type of service, communicated to the client the results obtained by telephone or vice versa).



PLAN DE ACTIUNE

Numele si prenumele beneficiarului:

Obiective	Activitati	Perioada de desfasurare	Responsabilit

Manager de caz: _____ Data: _____
 Semnatura: _____

Pagina 11

In the **final assessment stage** the case managers used the **Case Closing Sheet**, where they recorded the manner and cause of the case closing, and the case status at that time.

6. Intervention areas

6.1. Access to diagnosis and health services

The first and most difficult obstacle that patients and their families have to overcome is getting a diagnosis: it is often the most desperate struggle. This struggle is repeated with every new stage of a rare evolutionary or degenerative disease. Lack of knowledge about their rare disease often puts the lives of patients at risk and also involves inappropriate, even harmful medication and treatment prescription.

During the implementation of the pilot the case managers experienced that in some cases the diagnosis was established a long time ago and needed to be reconfirmed with new technologies or had to be changed. In some cases the diagnosis was only symptomatologic and had to establish the cause of the symptoms.

Due to a diagnosis gotten a long time ago, which at that time did not have a treatment, some beneficiaries did not see a specialist for years, they did not know that in the meantime some new possibilities of treatment were discovered and available in Romania.

6.2. Access to social services

Since most rare diseases involve a disability, this must be accepted by the person concerned and recognized by obtaining a degree of disability certificate, as this is the way they get access to social services provided/financed by the authorities.

Even though in the legislation in force things seem fairly simple to achieve, in reality, due to lack of staff and services, many people who would be entitled to access social services are left out. The recovery plans are completed with very little information. Our case managers had a role in orienting beneficiaries to the right and accessible services, to inform them what kind of services they can access in the community or elsewhere.

They had to involve in their network all the social service providers that can be involved in the management of their clients.

Patients also had problems accessing their rights and accessing information. Case managers were a real source of information in any field the beneficiaries needed to get better knowledge.

6.3. Access to education and employment

Although the right to education of the persons with disabilities is regulated by law and there are educational alternatives for children with disabilities, the reduced number of educational services and their geographical distribution limits their access to education.

According to the legislation, for the evaluation, psycho-educational assistance, school orientation and for professional orientation of the children and young people with special educational needs, a School and Professional Orientation and Evaluation Service was created in each county in a Resource and Educational Assistance Center (CJRAE).

The case managers needed to assist some beneficiaries to receive a school orientation certificate accompanied by a Personalized Intervention Plan, which may include the need for a support teacher, an adapted curriculum, or orientation towards special education and occupational classes.

In Romania, only 12% of the people with disabilities who have the age and ability to work have a job (compared with a 20% occupancy rate in Poland or 50% in Finland, Denmark, Luxembourg). Only a small percentage of our beneficiaries were employed and only a few cases expressed their need to be hired. Unfortunately, none of these cases had as a result the employment of the beneficiary, although the case managers have shown efforts in this directions aswell.

6.4. Empowering patients and their families

The case managerers supported patients by:

- encouraging the active participation of patients and their carers in choosing management options to improve the quality of life;
- guiding the patient in seeking and obtaining the necessary information on treatment options so that the patient can actively participate in the choice of treatment (to guide him/her towards specialists and services);
- making them understand that they can be active participants and not passive receptors in the care process and should also be well informed about all aspects of their state of health and the stage of the disease, in order to achieve the maximum benefit in the context of their social actions.

Health literacy was also a key aspect of empowering the patient. Empowerment is more than becoming an educated/informed patient. Accurate information and resources are fundamental tools for empowering the patient. The case managers played an important role in this - they helped the patients find the answers to the questions they had and helped them find the correct information.

7. Conclusions

Patients thoughts...

It was great to have someone to take care of me and find for me the right services. It is a terrible feeling of being so lonely and not understood and these case management answered to my needs....

My case manager helped me to get my family back and to become more responsible for my care.

We have so much to share with each other but there is not enough time and people simply don't understand...Being part of this project changed my perspective and my understanding, too.

Case managers' impressions...

This project helped me to develop my communication skills, my abilities to listen and understand and I feel now more prepared to act on behalf of patients and families.

*I feel that I have a contributed to **increase the resilience of families** and that the **participants in this project are more empowered** and better equipped to fight with the disease.*

*It was also a **great opportunity to engage with other service providers as well as great experts in the field of RDs.***

*It was great to have personal contact with families and patients but also with different stakeholders. **I had the tools to help get their voices heard and solve their problems.***

Main difficulties encounter on the Pilot implementation were:

1. Beneficiaries were not used to be supported and offered free services and it took some time to build trust. Some of them received diagnose a long time ago and they never returned to the doctor or they were not even aware that there is a treatment approved for their disease.
2. The socio economic and political instability had an impact on the overall aspects of the community. Continuous political and economic challenges, associated changes in the practice and delivery of health and social care have led professionals to recognize the importance and links between problem solving and decision-making skills, community needs and development strategies initiated at local level.
3. Distance between beneficiaries and the bad road infrastructure create even more difficulties in accessing the services patients need and create more barriers.

4. Patients were not used to fill out questionnaires and they felt tired to do this. We have explained them that filling the questionnaire will bring to light the needs of people living with a rare disease and of their families in terms of daily life, social care, coordination of care and employment. We explained that we're constantly asked for more data on these issues when discussing with policy makers about treatments and reimbursement, so that this information will be a huge asset for us to advocate for better care and support for people living with a rare disease and their families.
5. Some beneficiaries' health status was too bad to be able to answer the questions, some of them are too young (even for "Smiley" questionnaires). Many of our beneficiaries were severely affected by their rare and chronic condition and in many cases, their disease was progressive, debilitating, not allowing them to fill the questionnaires. In case of the children, they were not able to recognize emotions or faces.
6. The **limit of intervention** was given by services infrastructure which was not the best in rural areas of Salaj County. Our case managers tried to connect patients to the closest services they needed, but sometimes, the services didn't exist in some rural areas and made their intervention quite difficult. Even the 2018 **ESPN Thematic Report for Romanian on inequalities in access to health care** mentioned that *"although Romania has achieved progress in improving its health system, poverty and social exclusion remain among the highest in the EU, with major inequalities in healthcare coverage, the vulnerable population being the most affected. Improving access to healthcare services for the rural population in general, and especially in poor and under-served communities, remains a challenge. The ongoing healthcare reforms in Romania have so far delivered very little. However, the latest health reform measures are promising. The latter include: (a) regional health service master plans, aimed at shifting service delivery to outpatient settings and concentrating expensive inpatient care in the planned regional hospitals, alongside investment in preventive healthcare; (b) early detection of the most prevalent communicable and non-communicable diseases; (c) a significant salary increase for medical doctors; and (d) removal of mandatory health insurance contributions on pensions lower than EUR 430 (RON 2,000). Yet, an assessment of improvements in healthcare coverage and health outcomes will not be possible for some years, as implementation is either in an early stage or delayed. Despite the continuing reform process, the systemic challenges that contribute directly to inequalities in access to healthcare remain the same, as set out below."*
7. Family *mentality*, beliefs are also a **barrier in the intervention in some cases**. We had some situations when families believed that they have to hide that their child has a health problem even from the other family members. In other situations they didn't have the necessary resources to travel to the specialists or did not know where to address for support.

The **Rare Barometer** study "*Juggling care and daily life*" proved that the burden and the social impact of rare diseases on Romanian families' daily life is huge.

38% of the Romanian participants in Rare Barometer study reported that the time allocated to disease management is very high, more than 6 hours/day. 33% would need respiro periods and 51% would need therapeutic respite or adapted holidays. 36% consider that organizing the care is difficult to manage.

Conclusions of the pilot implementation of case management:

Interinstitutional collaboration is essential.

The care of patients with rare diseases is associated with many challenges, in particular those associated with high coordination complexity. Causes for coordination problems have been identified at all levels. Our experience demonstrated the need for creating innovative health-care structures, community networks and collaboration at all levels. Potential solutions range from the initiation of interdisciplinary working groups, cross-sectoral disease management guidelines and interdisciplinary teams of professionals in Centers of Expertise.

Community support networks are needed.

A **case managers' exchange platform** would be a useful resource. Our case managers had the opportunity to work together and to share information and best practices all the time. Solutions in one case had worked for other cases too. Caring for patients and managing rare disease studies require a holistic approach, focused on reducing the patient's and the families' burden.

Promotion and recognition of the case management as a specialized social service has to be the next step. We have advocated to promote case management for people with disabilities and it was introduced in the legislation, as mentioned in the report. We have also initiated the introduction of case managers in the National Code of Occupations in order to be able to train and qualify future case managers, to motivate people to be involved in working with people with disabilities produced by rare diseases.

Continuous monitoring of the beneficiaries is needed in some cases. Some of our cases are severely disabled and need a continuous monitoring and intervention.

Face to face meetings might be completed with **virtual monitoring**. People with rare diseases are living isolated and some times case managers have to travel long distances. The community resource networks would be very useful if they would be completed with virtual case management tools (IT infrastructure is very good while the road infrastructure is quite bad).

The **limit of intervention** is given by services infrastructure in the region.

Case management implementation **reveals the needs of the community**. These needs should be integrated in local strategy and **communicated to local authorities in order to provide/create new services**.

Exchange of best practices and **trainings for all stakeholders** raise the quality of services.

A **multidisciplinary approach** in providing care for people living with rare diseases is critical!

Due to the under-researched nature of their diseases, rare disease patients are very often experts on their disorder and participating in support groups, conferences, workshops, trainings, which provide them with the opportunity to develop new and useful knowledge to manage the rare disease.