D 9.4: ROADMAPS FOR UP-SCALING

Possible pathways to patient-centred, holistic care for RD Patients and patients with complex needs in Austria, Romania and Spain

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This project is co-funded by the European Union

Call for Proposals VP/2014/008; EaSI PROGRESS, DG Employment, Social Affairs and Inclusion

Introduction

The project INNOVCare aims to bridge the gap in the co-ordination between medical, social and support services in the European Union Member States. It does so by developing and testing holistic care pathways for the social inclusion of EU citizens affected by rare diseases.

The activities of the INNOVCare project encompassed:

1. Assessment of unmet social needs of people living with a rare disease and their families in Europe and analysis of existing care models in a selection of EU Member States;
2. Proposal of an innovative care pathway bringing together national resource centres for rare diseases and regional case managers, in partnership with public bodies:
    - Implementation of a pilot of this pathway in Romania
    - Evaluation of the socio-economic impact and a cost-benefit analysis of the care model;
3. Analysis of opportunities to upscale the model to other Member States and beyond rare diseases;
4. Exchange of good practices between resource centres gathered in a European network of services;
5. Strengthening partnerships between public, private and civil society organisations.

The following report focuses on activity 3, namely the analysis of opportunities to upscale an innovative, holistic, person-centred care pathway to other Member States and beyond rare diseases in Romania, Spain and Austria.

3.1 WHAT IS UP-SCALING?

Up-scaling is not about transferring innovations from one regional context to another. Rather “scaling up refers to identifying opportunities and barriers at broad institutional scales, with the goal of changing the system that created the social problem in the first place” (Westley et. al. 2014, 4). In order to create societal, systemic change it is therefore very important to consider and address “institutional and also cultural and normative environments [in which the social innovations] are embedded” in (Holtgrewe and Millard 2018, 71). Scaling opportunities are determined by the “initial starting conditions, existing competences and resources, obstacles and opportunities” (Westley et.al. 2014, 24) that the social innovation faces.

The following report is one outcome of the up-scaling activities[1] undertaken in WP9 of the INNOVCare project. It discusses possible ways to up-scale elements of integrated, person-centred, and holistic care for people with complex and/or rare conditions to other member states (Austria and Spain) and other regions and also beyond the field of rare diseases in Romania.

Up scaling processes appear to be a "permanent battle" rather than a linear roadmap to follow, as one of the experts interviewed pointed out. This means that up-scaling processes cannot be easily considered as following a linear model linking policy directly to its implementation[2]. Rather, up-scaling can be conceived as a "circular" "adaptive" or "evolutionary" process (Alexander 1985, 1). This consideration has implications for the conceptualization of possible pathways to integrated, patient-centred, and holistic care for rare disease patients and patients with complex needs.

The roadmaps in hand focus on potential priority areas as well as possible next steps that can be taken in the respective countries towards holistic care models, improving the care situation for patients with rare diseases and/or complex needs and also for their families and carers. Rather than suggesting a linear pathway to follow we focus on milestones named by the interview partners and possible ways of how to tackle the obstacles in the different priority areas. As a matter of course the important milestones identified by the experts depend on the environmental context and on the perspective the experts take when speaking about integrated care.

We focused on three priority areas, defined as scalable domains of the INNOVCare project (see D 9.5). These are:

- a stronger collaboration and coordination on the policy level across domains and also between municipal, regional and national policy levels;
- the establishment of multidisciplinary teams and professionalised care coordination on the meso level of care delivery organisations and professions, including case management;

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[1] For a detailed analysis of the three intervention levels (macro, meso, micro), the obstacles and enablers of integrated care, the scaleable domains as well as the methodology of the up-scaling process itself see D 9.5 Scaling Report.

[2] http://expandnet.net/PDFs/WHO_ExpandNet_Practical_Guide_published.pdf

- empowerment of patients and the inclusion of the social context on the micro level, as the main objective of holistic care.

The findings in this report draw from the interviews we conducted with stakeholders in Austria, Romania and Spain as well as from the expert workshops conducted by the project (chapter 4, D.9.5). In those workshops we discussed in which areas measures taken to improve the care situation of people with rare diseases and complex needs are most promising and most realistic to be implemented. We also asked experts which stakeholders need to be involved in the action and what their role/ the role of their institution would be. The input of the experts in these discussions was used to identify possible milestones in the different policy areas and possible next steps that can be taken to enhance the situation for patients with rare diseases in the respective countries.

In the following we first give a short summary of the findings presented in D 9.5, describing obstacles and opportunities identified during the up-scaling process. These findings have also been a resource for the formulation of recommendations on bridging the gaps between health services, social and local services to improve care for people living with rare and complex conditions, presented at the final conference of the INNOVCare project.[3] Second we focus on the country-specific challenges and enabling elements for up-scaling in Austria, Spain and Romania and present potential next milestones towards integrated care for people with rare diseases and complex conditions.

1. Mapping potential ways to integrate care – priority areas

As the pilot model was only developed and implemented during the project and its evaluation conducted in parallel to the up scaling process (due to the time constraints of a three-year project), we decided not to scale up the pilot implemented in Salaj, Romania, per se, but opted for a broader definition of up-scaling. Assessing the scalability of the pilot implemented in Romania we identified three scalable domains: the collaboration and coordination on the political level, multidisciplinary teams and (professionalised) care coordination as well as the empowerment of patients & Inclusion of the social context. For a detailed analysis of these three areas see D.9.5. (Scaling Report).

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[3] https://innovcare.eu/wp-content/uploads/2018/09/INNOVCare-project-Recommendations.pdf

Collaboration and coordination on the policy level

Collaboration and coordination between different ministries is needed, to implement integrated care for people living with rare diseases and other complex chronic conditions/disabilities e.g. the respective ministries of Health, Social Affairs, and Education. Likewise other institutional bodies of the policy fields of health, social affairs and education need to collaborate. Moreover, more coordination is needed between national and regional bodies. In rare diseases, cross-border coordination is also a key priority.

Challenges:

- RD falls into responsibility of different ministries
- Federalism and regionalism hinder the exchange of knowledge and collaboration between service providers
- Legal frameworks and funding schemes hinder stronger collaboration
- As sustainable structures of collaboration are often not available, the implementation of a new care solution depends on the will of key players.

Opportunities:

- Budgets dedicated to the coordination of political bodies
- Stronger involvement and accountability of local administrations and communities
- Coordinated budgets for health and social care provision
- Learning how to collaborate – building on positive experiences
- Qualified staff responsible for communication and mediation

Benefits for RD and beyond: better collaboration/coordination between communities and with the national policy level fosters:

- The development of an accessible primary care system. This can benefit elderly people in rural areas strongly, as community nursing approaches show.
- Political planning, knowledge and data-exchange and the coordination between services
- The integration of different policy fields

Multidisciplinary teams and professionalised care coordination

Challenges:

- Doctor-centred health care systems: Doctors are not used to collaborate with other health care professionals in a non-hierarchical way
- The need to consult with multiple health and social care professionals and to manage those appointments accordingly may pose a risk for the continuity of care. This is especially true for the transition phase of young patients to adulthood.
- Case Management is a very promising approach to facilitate care coordination. The challenge is how and where (hospital, county level, patient organization) to best implement case management, which duties case managers should fulfil, and to decide on the scope and duration of case management.

Opportunities:

- Case Managers to facilitate the coordination of care and to help patients navigate through the care and social systems and the concomitant bureaucracies
- Use of public procurement to foster collaboration of care professionals (top-down)
- Mutual learning and recognition of the competences of the other health/social professionals by the professionals in the field
- Training for different professionals (teachers, social worker, doctors,..) together with patients
- Intervention plans/protocol of treatments

Benefits for RD and beyond: Professionalized Care Coordination

- helps to orient the patients and to inform them about their diseases and services they can access and are entitled to
- takes the time burden from doctors, providing patients with a first contact point
- takes the time burden in the coordination of care from patients and their main care givers
- allows for better continuity of care and therefore for better health outcomes
- is an important aspect of holistic care models focusing not only on medical care needs but also on the social needs of patients.

Empowerment of patients & inclusion of the social context

Challenges:

- Patients often are too little informed about their diseases
- Professionals often lack confidence in t patients' abilities to organise care

- Time constraints of family carers limit their possibilities to make use of therapies, support and social services
- Lack of psychological support and social services for parents and siblings
- Lack of awareness of and support for teachers, day-care teachers, work colleagues and school mates are a potential barrier to the social inclusion of people with RD
- Limited resources for interest groups

Opportunities:

- Dedicated support for caring family members to take care of their own physical and mental well-being is considered as beneficial and having benefits in preventing crises, burnout, etc. This includes training of relatives on care giving duties as well as counselling, mediation and domestic help.
- Such psychological support and social services for family members must be organized in a way that allows them to make use of it and takes their time and financial constraints into consideration
- Support for siblings – helping them to cope with their situation
- Support for families in daily life activities (domestic work) and mobility
- Guidelines and awareness-raising for teachers, social workers and other social care professionals to inform them on RDs in general and the situation of their specific clients or students and support measures that enable them to play an active role in the social inclusion of people with RD

Recommendations

- Empowerment of patients is not only the job of patient organisations but other institutions need to be involved.

Benefits for RD and beyond:

- For the empowerment of patients it is paramount that they are well-informed on their disease and that they have an active voice in the organization of their care. Holistic care approaches train caregivers to listen to the patients.
- Inclusive services and schooling facilities will support main caregivers of people with RD or complex conditions in organizing everyday life and inclusion in education and employment.
- Inclusive schooling facilities will open access to education and may indirectly raise awareness of society at large.

- The active participation of patients and their relatives in social and economic life supports them in becoming economically independent.

2. Roadmap to integrated care for Spain

MACRO-LEVEL: COLLABORATION AND COORDINATION ON THE POLICY LEVEL

In Spain social and health care are organised by the autonomous communities. Thus, Spain does not have a uniform model neither for the provision nor for the coordination of health services and social services (García-Armesto et.al 2010, 37). Nevertheless, the Ministry of Health, Social Services and Equality is responsible to guarantee the equitable functioning of health services across the country. This includes the definition of the basic benefits basket, the setting of minimum thresholds for services regarding expenditure and quality, and a performance monitoring function. It is coordinating the regional health systems, which are accountable only to the regional parliaments and thus not hierarchically linked to the national level (García-Armesto et.al 2010, 38).

Since social and health care falls primarily into the responsibility of the autonomous communities, the coordination and collaboration across communities and with the national level is challenging. It means that 17 different care systems have to find a common language and the will to communicate with each other

Still, in the context of rare diseases Spain can be regarded as quite advanced since many different initiatives, pilots and innovative care solutions are in place. This plurality can be partly attributed to the fact that the regions are autonomous in designing and implementing health and care solutions. This means that the potential for peer-to-peer learning and for the exchange of best practices among the autonomous regions is very high in Spain. Thus, the realisation of integrated care for patients with rare diseases and complex needs could be facilitated by intensifying the exchange among regions. Learning to exchange ideas and to collaborate on a political level might however require a change in the mind-set of the autonomous regions since health care has always been their domain. Possibly, coordination and cooperation on the political level could be facilitated – more than by additional budget, which is also helpful – by coordinators employed by the respective political bodies that are in charge of supporting the coordination of regions and facilitate knowledge exchange.

Compared to other European countries the awareness of policy makers of the issues of rare diseases is high in Spain. An indicator for the importance of the issue on the political agenda is that one of the fifteen National Health Strategies that are in place in Spain is on rare diseases. 2013 was declared the Spanish Year of Rare Diseases with the aim of raising awareness for health, social and research-related issues of rare diseases. During this year the National Strategy was discussed and updated by various stakeholders involved with rare diseases. However, the updated version is still pending approval by the CISNS [Committee for Public Health of the Interterritorial Counci l of the National Health System].

The high relevance attributed to rare diseases shows in the fact that out of all the national health strategies in place, the one on rare diseases is the only one that has a dedicated budget for its realisation in the regions. With this budget regional registries on rare diseases are to be implemented that will feed their data into a national registry on rare diseases. The regional registries are set up by the autonomous regions. In Murcia, for example, the registry has been set up together with the regional action plan. It collects data from 42 different sources of information including patient organisations. According to the public administrators interviewed the registry runs completely stable and is very advanced. In Catalonia, for example, a registry was installed on two different levels. The registry on the first level obtains information from traditional health care providers and gives a general idea on the prevalence of rare diseases. On the second level the information from expert centres is collected which gives a clear picture on the concrete diagnoses as well as on the treatment including its cost and time. Within the next ten years the second level will become the main source of information on rare diseases for political planning in Catalonia. The examples show that some regions in Spain are rather advanced when it comes to the implementation of regional and national registries. Nevertheless, two challenges are arising in this regard. First, in order to set up meaningful and informing registries suitable for political planning the right data and its respective providers have to be identified. Second, all the autonomous registries have to agree on what kind of information will be fed into the national registry and how to communicate with the national registry and among each other. So far it has not been possible to exchange the information that the regions feed into the national registry between the autonomous regions. So, for example, if patients are moving from one region to another it has not been established yet how the information on this patient already collected in one region will be shared with the other region.

Important milestones for a stronger collaboration of on the policy level in Spain are:

Agreement on which data is fed into the national registry on rare diseases by the autonomous regions

Finding an agreement and a technical solution how the autonomous regions can share the information they have collected on patients with a rare disease

Support the coordination on policy level by appointing coordinators

Regions engaging in mutual learning dialogue to exchange best practices and lessons learned

MESO-LEVEL: MULTIDISCIPLINARY TEAMS AND PROFESSIONALISED CARE COORDINATION

Rare diseases patients are dependent on the expertise of many different professionals. This is why a close collaboration between all care giving services is needed: firstly, it relieves patients from repeatedly explaining themselves and their situation; secondly, it facilitates continuity of care; and thirdly it reduces the time burden of care coordination. However, the close collaboration of health care and social professionals of different levels (primary, secondary and tertiary care) and of different professions (such as doctors, nurses, nutritionists, physiotherapists, social workers, teachers, speech therapists, and occupational therapists) is challenging. One potential obstacle to a closer collaboration is the power structure between those professions that has evolved over decades. Therefore, the mutual recognition of the health care professionals involved is of utmost importance. Moreover, working together with other professionals can be costly in terms of time and hence requires finding a common platform (such as regular case conferences) and a common language. Hence, trainings on rare diseases in which professional of different domains participate can be of great benefit in this regard.

Some of the experts interviewed regarded the establishment of a network of care that included the different levels of care as well as social care as a key point and a priority in their region. Furthermore, the integration of care providers and care professionals could be facilitated by connecting the designated reference centres to other levels of care. Especially primary care doctors and social workers need to be brought closer to the reference centres so that the different levels of care can engage in a more coordinated manner. In some regions, like in Murcia, the establishment of a closer network of primary care doctors, social care professionals and other non-medical health care professionals with closer ties to the reference centres is expected to be achieved in the short term as regional plans on the development of these networks already exist. This measure will improve the continuity of care in everyday life for people living with rare diseases.

One way to realise integrated care and to improve the coordination of care is case management which can be set up in very different ways. Two contrasting examples included in the sample are Catalonia and Murcia. These two autonomous communities are different from each other and from the approach tested in the framework of the INNOVCare project in Romania. In Murcia case management is installed in public hospitals connecting them the with reference centres. Case managers in the hospitals will also be responsible to coordinate care with family doctors and other services on the primary level. In

Catalonia case management was already piloted in some hospitals. Case managers there had to facilitate the coordination of multidisciplinary teams, focusing on specific rare diseases. Currently Catalonia is introducing a more encompassing model that offers case management at two different, yet complementary levels: an expert care level and a territorial/community level. The case managers on the expert levels are installed in hospitals and coordinate primarily the multiprofessional teams of the clinical units. The territorial case managers facilitate the coordination between primary health care services, social services, educational centres and support equipment services. Both case managers are also supporting the contact of the patient to patient organisations. Moreover, e-health tools and ICT will foster the exchange between all professionals involved.

Given the experience of Spain with case management some important learnings can be drawn based on the interviews conducted in the course of the INNOVCare project. First, when installing case management it is very important to find the right place to do so. It is beneficial to build on existing resources, such as the public hospitals. Yet, not all the health care providers that are asked to install case management by regional guidelines have the same resources. Hence, case management is installed very differently even within a region. Therefore, additional resources for the installation of case management would be helpful. Second, further steps can be taken to professionalise case management. The experts interviewed who have been involved in the implementation of case management emphasise that it is of great importance to define the profile of case managers and agree on the role, function and the necessary competences. They underlined that they do not necessarily favour one profession over the other to recruit case managers from, but that the clear definition of the role should be a priority. Yet, some case managers see a high capacity of nurses to work as case managers. Having a clear profile will help to advance the professionalisation of case management. Moreover, training courses, peer-to-peer-exchange and clinical supervision can help case managers to develop their professional (or trans-professional) identities.

Case Management is one of the examples that show that Spain is rather advanced in the realisation of integrated care. It is also one instance where the regions would benefit from a mutual exchange of best practices and lessons learned.

Important milestones to provide a low threshold access to care and for a stronger collaboration of care professionals as well as professionalised care coordination in Spain are:

Connect reference centres with the primary care sector and social workers

Work out a profile for case managers to define their role, function and competences

Stronger mutual recognition of care professional's expertise by providing adequate training. This would allow for a better use of the competences that of non-medical health professionals

Support professionals of different domains in finding a common language and in learning to collaborate (e.g. by facilitating joint trainings)

Support case managers by providing the adequate training and infrastructure

MICRO-LEVEL: EMPOWERMENT OF PATIENTS & INCLUSION OF THE SOCIAL CONTEXT

Many factors contribute to the empowerment of patients. First, they and their families need to be well-informed on their disease and need to have an active voice in the organisation of care. In this regard care settings that do not allow taking time for the patients and care professionals who do not conceive the patients as experts of their own life are obstacles for patient empowerment.

Spanish patients benefit from strong patient organisations that also provide information on the respective disease. Institutions such as CREER offer trainings for patients and their families, sometimes also including care givers and policy makers to enable a mutual learning process. Trainings for family carers have to be compatible with their care duties. Moreover, family members and family carers will benefit strongly from therapy and counselling.

Second, those patient organisations are not only well-connected and strong, but also well included in the policy-making process. They participate in regional and national policy platforms, boards and committees on the formulation of RD strategies, on orphan drugs and other issues related to rare diseases. Nevertheless, potential obstacles for the empowerment of patients also arise in this context. On the one hand it is not always easy for policy makers to find patients and patient organisations that are willing to participate in those boards, especially when they are very technical in nature. One the other hand there is a great demand of patient organisations to participate in some of these boards. However, the number of seats for patient representatives on those boards is restricted. Thus, different patient organisations might “compete” for those seats. It is difficult to organise a rotating system that would allow more patient organisations to be part of the process, because it may be more effective for policy makers to negotiate with only one patient organisation. Some of the regions also had public consultations on initiatives related to rare diseases.

Another important element for the empowerment of patients is their active participation in social and economic life as well as economic independency to the greatest possible extent. However, due to physical and mental stress and little time resources of RD patients, as well as of their caregiving relatives, both often have problems to maintain regular employment. Their situation has worsened due to the economic crisis and the overall rise in unemployment in Spain. The increasingly competitive job market makes it even harder for people with RD and families with care obligations to find employment and to maintain the position due to the burden of everyday care (see EURORDIS 2017).

The active participation in economic and social life of patients and their family members can be further supported by inclusive schooling and day-care facilities. In some Spanish regions, guidelines for inclusive education have been developed that will advance the integration of children with rare diseases.

Important milestones for the empowerment of patients and the inclusion of the social context in Spain are:

Expand trainings for family members that are compatible with their care duties

Involve patients' representative in policy platforms, as has been done so far and define clear and transparent conditions who is participating

Use and adapt existing education guidelines to support inclusive schooling

3. Roadmap to integrated care for Austria

MACRO-LEVEL: COLLABORATION AND COORDINATION ON THE POLICY LEVEL

Collaboration and coordination on the political level are an important precondition for integrated care that includes health and social care. In Austria care competences of both domains are shared between the federal level and the regional level. The Austrian example shows how difficult the fusion on the social and health agenda is: Even though health and social policies have recently been integrated into the political agenda of one ministry, efforts to improve the coordination between the policy fields have not increased considerably so far.

Moreover, competences are divided between regional entities of the social health insurances and across provinces. Furthermore, the medical association has an important voice in deciding how care is organised and how money is spent. As the Austrian experts interviewed and involved in the expert discussions point out, the particular interests of these different stakeholder groups are a considerable obstacle for a stronger coordination on the policy level. Collaboration and coordination on a political level is therefore considered as a very important step towards realising holistic care concepts. Yet, changes in this sector seem to be quite unrealistic. Therefore, the policy level is unlikely to be a priority area for advancing holistic care according to the experts.

Despite these reservations of experts they can name some important milestones and strategies for a better collaboration and coordination of care on the policy level when it comes to rare diseases:

For a better collaboration between the policy levels experts advise to install a delegation system to better negotiate finances between the federal levels. They emphasise that delegates have to learn to overcome particular interests.

Additionally experts suggest pre-financing systems for setting up integrated care and to create overlapping functions in social and health care. A dedicated fund for integrated care and a budget dedicated to facilitate the collaboration between policy makers of different levels would improve cooperation and increase the awareness of policy makers and public administrators of the importance of collaboration.

Experts see a chance for a more holistic view on care systems in the stronger involvement of local administration in the organisation of care, as they are the closest to the patients/families.

When it comes to rare diseases, the foundation of the "National Coordination Office for Rare Diseases", established in 2011 can be seen as an important step. It is a coordinating organisational entity including experts from the health and social field as well as patient organisations. The office was responsible for the formulation of the National Plan for rare diseases and its implementation.

The National Coordination Office for Rare Diseases is also in charge of the designation of ERNs in Austria. The process established involves the health ministry, regions and the social insurances. At present, in November 2018, one healthcare centre in Salzburg, the EB-house and the St. Anna Children Hospital in Vienna have been designated as centres of expertise. Thus, the designation process in Austria has been rather slow so far despite the fact that Austrian physicians and patients would benefit highly from an international exchange of specialised knowledge on rare diseases. Incidentally, the EB-house was installed by patient organisations who received 1 Million Euro from the ministry of health to build the centre. At present, the EB-house is solely funded by donations, as it is not officially connected to the hospital and additional funding is not provided for the ERN's. Patient representatives therefore see the permanent funding of the EB-house as an important step to render its establishment as a reference centre sustainable.

Another important issue addressed in the National Action plan is the establishment of nationwide database on rare diseases which enables evidence-based planning. A centralised mapping of rare diseases is a project already stated by the National Coordination Centre for RDs and Orphanet. (RD Action 2017, 2).

In general experts agree, that in Austria, awareness raising for the needs of rare disease patients and their families is an important issue to make rare diseases and integrated care a political issue to deal with. For now, successes have been somewhat disease-specific and have concentrated on the medical side. They point out that it is especially important to make previous achievements visible in order to convince policymakers to invest in rare diseases. Patient organisations reported that they are trying to establish contact to key policy makers in order to keep the topic of rare diseases on the political agenda.

Important milestones for a stronger collaboration of on the policy level in Austria are:

- Monitoring of the designation process of ERNs as well as a fast implementation and a permanent funding for the ERNs already designated
- Establishment of an encompassing database on rare diseases to enable evidence based policy planning
- Enable collaboration of the health and social sector by setting up pre-financing systems for integrated care and creating overlapping functions
- Awareness raising: Get key policy makers involved
- Install a delegation system to facilitate negotiations between the federal levels
- Stronger involvement of local administration in the organisation of care, as they are the closest to the patients/families

MESO-LEVEL: PROVIDE A LOW THRESHOLD ACCESS TO CARE, FOSTER THE COLLABORATION OF CARE PROFESSIONALS AND PROFESSIONALISED CARE COORDINATION

A stronger collaboration of social and health care professionals and of professionals within the medical field is considered an aim that can be reached in the medium term by the stakeholders involved. One obstacle in this regard is that the Austrian care system is highly doctor centred (for a detailed discussion of this issue see the D.9.4 pp45ff). Although Austria is well equipped with hospitals of a very high quality, people with rare diseases sometimes encounter difficulties in accessing the closest hospitals to them. The problem occurs due to smaller hospitals in rural areas fearing the cost of providing care for chronically ill patients with special needs. Complex cases are considered time-consuming, but are not remunerated adequately. Hence, smaller hospitals and primary care doctors have incentives to prefer less complex cases to deal with. Hospital therefore might ask patients to use bigger hospitals. Experts therefore recommend a financing system which enables smaller units to care for people with chronic diseases. Another problem that occurs in this context is that different social insurance funds[4] do not guarantee the same standards regarding reimbursement, sometimes leaving patients and their families with higher costs. Thus, experts suggest a homogenisation of the services and medical expenses borne by the social insurance funds.

In order to provide patients with rare diseases with adequate care, additional training on rare diseases especially for family doctors is needed. A potential obstacle is that patient organisations and the medical association in charge for providing trainings to doctors could not find a solution on how to cooperate on this issue. Another important step towards a better dissemination of knowledge on rare diseases addressed by the experts is to rework existing treatment guidelines on rare diseases. They stress that the existing guidelines are far too complex and therefore not a practical tool for family doctors.

As an opportunity for a stronger collaboration between care professionals and care services experts name a stronger recognition of care professionals. This is a long-term issue in the doctor-centred health

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[4] Health insurance in Austria is divided by employment status with separate insurances for the self-employed, civil servants, farmers, railway employees etc. Health insurance for the employed is divided by federal states.

systems of Continental Europe and is not restricted to rare diseases. This can be reached in various ways:

According to the experts in the discussion group an important step has been taken with the development of the curriculum for the Bachelor of Science in Health Studies, offered by the University for Applied Sciences in Carinthia. Experts hope that the professionalisation and academisation of care will allow for more delegation of tasks from doctors to upskilled nurses and other care professionals. This could lead to a change in the way care is organised, to a stronger recognition of communication and care management skills and a stronger focus on health prevention. Another possibility for a stronger focus on communication skills is to provide communication trainings for doctors. This is a step that has already been taken in Austria and which could be promoted more strongly. Better communication skills of care professionals (including doctors) can improve interaction between care professionals and patients and have an impact on both the quality and efficacy of healthcare they receive and on their competences to organise care themselves. Experts hope that it will also foster the coordination of care, as care professionals might be able to develop a more holistic view of care than doctors. The higher recognition of the expertise on non-medical care professionals could also be supported by the adaption of legal frameworks, providing them with more formal competences.

Experts also agree that case management is a good way to ensure networking between professionals and services. To ensure networking case managers have a dedicated interface position and therefore play an important role bridging professional and organisational boundaries.

Experts also advise establishing health advisory services as a first point of contact, where not doctors, but nurses and social workers could work and initial service could also be accessed remotely via the phone or the web. This would help patients navigate the health system and take some of the burden from ambulances and family doctors. More generic health services then could handle those cases that need primarily health counselling and routine treatments and could specialise in prevention work, leaving primary care doctors more time to deal with the patients' concerns. It would also support a low-threshold access to health care. First steps in this direction are health hotlines, which have been piloted in Vienna, Lower Austria and Vorarlberg. As the experts pointed out innovative concepts for primary care, including health advisory services, are already well developed in Austria. However, so far very few steps have been taken towards their realisation. One of the reasons behind this is the power structures between the medical professions and especially the interest of the medical association in Austria.

The concept of family care nurses has also been tested in Austria, in the province of Carinthia. In a pilot project a person-centred holistic care model was developed that builds on the crucial role of the family and community nurse who supports the care organisation of elderly people and their families. These Family Nurses also took the role of case managers, organising care for elderly people at home. Similar concepts can also be beneficial for people with a rare disease (cf. the case of Romania). For the implementation of community nursing a change in legislation would not be necessary.

When it comes to specialised services for rare diseases first steps for the establishment of multidisciplinary teams have been taken. Centres of expertise are obliged to have multidisciplinary teams in order to be designated as centres of expertise. Yet, by now only two centres of expertise have been designated. Patient organisations therefore are concerned that Austria cannot catch up with international expertise and that the health system at large loses access to RD-specific knowledge and the international state of the art if the process of designation takes too long.

Important milestones to provide a low threshold access to care and for a stronger collaboration of care professionals as well as professionalised care coordination in Austria are:

Strong involvement in international networks – especially the context of ERNs

Stronger recognition of care professional's expertise by providing adequate training. This would allow for a better use of the competences that of non-medical health professionals

Establish health consulting services as a first contact point for patients; these service can provide information and support a stronger focus on health prevention

Implement community nursing on lasting basis

Rework guidelines for family doctors on RD and provide them with understandable information

Faster and better diagnoses for patients by improving the knowledgebase on RD by a stronger integration into professional networks on a European level (ERN)

Training and e-learning curricula for medical care professionals to learn more about rare diseases.

Communication training for doctors

Case management is a way to professionalise care coordination; Case managers can facilitate the inclusion of the social context of patients

MICRO-LEVEL: EMPOWERMENT OF PATIENTS & INCLUSION OF THE SOCIAL CONTEXT

Empowerment of patients with complex conditions and better support of their families concern all aspects of life. A more empowered logic of organising everyday life asks for:

- more possibilities and support of care giving relatives and patients to actively participate in the labour market. This could be achieved by lessening the burden in organizing care, by providing adequate services.
- for inclusive schools as well as support and knowledge transfer on rare diseases to teachers. Inclusive education is required in the National Action Plan for People with Disabilities.
- for psychological support and (peer-to-peer) training for patients and their family members.
- for a patient-centred health service, informing patients and their relatives on the pathway of treatments and enabling them to decide on the services they need. Patients need clear and understandable information on the potential development of their diseases. Experts suggest a care plan that doctors, patients and their relatives decide on together.

According to the experts, empowerment of patients and adequate support for their relatives is a permanent struggle. Yet, this also means that important steps in the direction of empowerment and a stronger inclusion of the social context of patients have already been taken. Therefore experts argue that a stronger inclusion of patients and their relatives is an aim that can be reached in a short time period in Austria.

They stress that awareness raising is most important in order to keep rare diseases on the political agenda and to have professionals and policy makers of the health sector, the educational sector and the social sector sensitised for the needs of patients with complex conditions, for the needs of their relatives and for the benefits of holistic care approaches. Experts emphasise that the inclusion of people with special needs has to be pushed forward politically, and the responsibility of individual stakeholders (policy makers, service providers, schools,...) must be clearly emphasized.

They highlight in this context that a variety of support services funded by the public hand are available in Austria and that legal frameworks already support inclusive schools and the integration of disabled people in the labour market.

Still, patients and their families often have difficulties to ask for help. One reason is that they cannot cope with the bureaucracy. Patients' abilities to organize everyday life (including services) are closely related to their immediate social environment. The social status and social capital of their families, their networks and educational background influence their opportunities. Patients and their families in general have a higher risk of poverty in Austria, as their possibilities to participate in the labour market are, despite existing legislations, restricted. To ensure that the existing legal frameworks benefit patients and their families, awareness raising among potential employers is an important task.

Moreover, patients and their relatives need to be encouraged to ask for help. Often parents also wish to care for their children themselves and consider care as their responsibility. This especially concerns mothers, who often hesitate to ask for help as patient representatives report. However, taking on too much of a burden renders families vulnerable to crises or burnout of primary carers. This is a problem that can be prevented by the establishment of case management that informs and connects patients with existing services and can assure carers that it is no weakness to make use of them. They would be beneficial, as the experts agree to reduce the burdens of organizing care not only for patients but also for doctors. Despite these potentials of case management some health care providers argue that case management only makes sense if it used temporarily. Case management should be adapted to the life phase and, if the needs are met, suspended.

Experts stress that in Austria especially the situation of siblings of children with complex needs needs more focus. They often have a difficult position in the family as "shadow children" as parents struggle to assure care for their brother or sister with a rare condition. To improve the situation of siblings of children with rare conditions, thereby reducing the stress for families, experts advise to organize workshops for siblings and emotional, psychological support. In Austria this is done occasionally and partly informally by patient organisations.

Empowerment of patients also includes the support of self-help-groups as experts stress. They provide important resources for patients and their families, including social and health care (EB-house) and training. A stronger cooperation of self-help-groups of patients, including self-help-groups of disabled people could strengthen their political position. Patient representatives report that a stronger coordination of self-help groups has encountered structural difficulties, as public funding is limited and self-help-groups compete for these limited resources.

Important milestones for the <u>empowerment of patients and the inclusion of the social context</u> in Austria are:

Existing legal frameworks support inclusive schools and the integration of disabled people in the labour market need to be implemented to the benefits of patients

Awareness raising amongst policy makers and the lay public

self-help groups need sufficient funding which supports networking between them

Organize workshops for siblings of children with rare conditions and provide relatives with emotional and psychological support.

Case management can help to reduce care burdens of families and encourage patients and their families to use existing services

Case management can help to reduce care burdens
to use existing services

Care plan that doctors, patients and their relatives decide on together

4. Roadmap to integrated care for Romania

In the following chapter we introduce milestones and possible next steps for holistic care solution for people with complex needs in Romania. Different to the roadmaps for Austria and Spain we'll focus stronger on the impact of the pilot in Salaj and the advantages it created to further develop integrated, person-centered care solutions in Romania.

MACRO-LEVEL: COLLABORATION AND COORDINATION ON THE POLICY LEVEL

The National Action Plan on rare diseases was an important step in Romania to improve coordination on a policy level. It initiated a regulatory, political framework fruitful for the generation of a more integrated system of health and social services and brought rare diseases on the political agenda. The National action plan on rare diseases was in included in the National Public Health Strategy for 2014-2020 ("Prosperity of Health") which is the most important planning tool in the health sector (Vlădescu et. al. 2008, 23). This way, rare diseases policies also build the ground for the formulation of new legislations, which are suitable to enhance the care situation of people with rare and complex conditions also in rural areas. There the care situation is especially complex to organise as social and health care services are often not available and transport possibilities are limited.

A new path breaking legislation was implemented in May 2017 with laws on social assistance and community nursing as well as a new regulation on case management, which will be provided for people with disabilities. Case management also became part of the official classification of occupations (COR) in Romania. This is a legal act which defines the six digit codes assigned to each job position, with job positions clustered by occupational sectors.[5] This is an important recognition of the new position of case management and gives case managers the opportunity to be trained and certified.

The legislation also provides for training of case managers specifically for rare disease patients to be hired by the municipalities. The work of the Romanian project team of INNOVCare at NoRo has clearly contributed to these legal changes. Their work was also recognised by the prize for innovation in health,

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[5] http://eurofast.eu/romania-changes-classification-of-occupations/

which they were granted in 2016, contributing to keeping the topic of rare diseases on the political agenda.

Another important issue addressed in the National Action Plan is the designation of reference centers. This process has already been started and experts set high hopes in it for the further improvement of the situation of patients with rare conditions in Romania. The integration into the European reference networks allows Romanian experts to be involved in knowledge exchange on the European level, building knowledge on rare diseases. Experts hope that this will especially improve the situation of undiagnosed patients. By 2018 twelve centers have already been established.

Due to these new regulations rare diseases have become a political topic of priority in the last years, despite changing ministers. What is more, policy makers of the ministry of social affairs and the health ministry gathered experience in collaborating in the process of the implementation of the National Action Plan and on the regulations for the assessment of care needs for disabled people. Yet, rare diseases are still more in the focus of health policies than that of social policy. Moreover, the educational sector has so far not been involved in joint policy platforms. It would also be an important step to include patient representatives and experts for rare diseases in the expert commission for the evaluation of disabilities, as rare diseases often develop differently from other disabilities and may, for example, be degenerative.

Because of these achievements Romanian experts argue that a stronger collaboration on the political level, especially in the field of rare diseases, is a short time goal to be achieved. Collaboration on the political level remains a challenge as different responsibilities, funding schemes and accreditations pose a barrier to a stronger collaboration. Furthermore, the restricted financial situation in Romania makes the collaboration even harder. An important next step would be to involve the the ministry of education in joint policy platforms. A stronger inclusion of the regional level and coordination with them, taking the different regional situation and the financial situation of regions into account, would also be important as national level policies on health and social care are sometimes not well adjusted to local specificities, as experts argue.

On the regional level the INNOVCare pilot implemented in Salaj provides evidence that existing social services and initiatives can foster the stronger collaboration on the regional policy level as well. In the frame of the INNOVCare project a sustainable partnership between patient representatives, the resource centre NORO and the municipality has been build. Their experiences show how important the collaboration on the local and regional level is to enable integrated care approaches. The experience is a resource other regions in Romania can build on.[6]

An important tool for a better cooperation on the regional level built by NORO in cooperation with the community was a registry on available services and on patients with rare diseases. It allows for evidence–based political planning. Still, further databases supporting the development of regional strategies will be needed, also integrating registries of different centers of expertise. It would be an important step in the future to find a way of integrating these databases nationwide.

While Romania has taken many steps in developing legal provisions and rare diseases are clearly in the political focus, actual implementation across the country is likely to be challenging. The Romanian health sector is resource-poor, and struggles with regional disparities, overall patchy infrastructure, and often staff shortages due to emigration of qualified staff. It is all the more important to make the best possible use of health professionals' skills and capabilities, which provides one good reason for integrated care initiatives. The innovations in healthcare presented here have required hard work by regional “powerhouse” organisations such as NoRo that combine provision of services, patient representation and political networking and lobbying. In Romania INNOVCare has indeed begun to upscale itself. It remains to be seen how its legal and institutional impact develops into a functioning system of integrated care provision in a difficult context.

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[6] https://www.apwromania.ro/workshopCMCluj

Important milestones for a stronger collaboration of on the policy level in Romania are:

Provide adequate funding for the implementation of inclusive services and community nurses on the regional level

Create databases, supporting the development of regional strategies and the work of community nurses

Set up nationwide databases on rare diseases, integrating the information gathered by the centres of expertise

Stronger collaboration between the national and the regional level

Make collaboration between services and across domains a precondition in legislations and provide special funds.

Improve collaborations between specialised social services and communities

PROVIDE A LOW THRESHOLD ACCESS TO CARE, FOSTER THE COLLABORATION OF CARE PROFESSIONALS AND PROFESSIONALISED CARE COORDINATION

The experts interviewed in Romania think that care provision for people with rare diseases has improved in Romania in the last few years. An Indicator for the improvement is, for example, the new legislation on community nursing, which includes a paragraph on case management and rare diseases. Without neglecting the shortage of doctors and qualified medical staff in Romania as well as the limited resources Romanian health and social services have, experts therefore argue, that a more integrated care provision for people with complex needs can be achieved out in a medium -term time range.

Care professionals and care services in Romania can build on the experiences of the INNOVCare pilot. The evaluation of the INNOVCare project provides evidence that case management, offered by a one-stop-shop, improves care coordination and the knowledge base on rare conditions of patients and care providers (see findings of WP7). It proved to be a fitting tool to minimise the fragmentation in care provision and to navigate patients through the care system, improving also continuity of care. Case managers are the core element of interdisciplinary teams. Experts therefore suggest establishing case management not only on the local level, but also in hospitals (cf. the Spanish example), to improve collaboration between hospital and primary care professionals and continuity of care.

Yet, the project also provided evidence that case management on the local level is only one element of a more integrated care system. Case managers need networks and resources they can build on. They work best if they facilitate and become part of interinstitutional collaborations.

In the frame of the pilot action important resources for the further implementation of case management were also built. In cooperation with the county council NORO set up a regional database on available services for RD patients and curriculum for case managers. The tools will support the collaboration between the services in Salaj in the future and the up-scaling of the case management approach in Romania. Especially the training programme for case managers developed by NORO can serve as an important tool for up-scaling the case management approach tested in Salaj to other regions in Romania. It will contribute to professionalised care coordination. Training and supervision for case managers can also be enabled by peer-to peer-networks. An important add on to the training would be improved cooperation between genetic counsellors and case managers. This will allow case managers to set up care plans together with the patients that are adapted to the genetic aspects of diseases.

Patient organisations argue that the patchy social services infrastructure is an obstacle that needs to be overcome for a sustainable development of the care sector. At the moment there are not enough social services to provide patients with the support needed, and funds and staff to set up new services are not available. This means that case managers have to adapt to existing structures which may restrict their capacity to provide solutions. Policy makers on the other hand see the main challenge in connecting existing services working under different legislations (such as social and health care services).

Important milestones to provide a low threshold access to care and for a stronger collaboration of care professionals as well as professionalised care coordination in Romania are:

Build on the experiences of the INNOVCare project including networks built

Provide training to case managers and community nurses newly established by the legal framework on community services

Build resources for case managers to work properly, including networks and a sufficient number of social services.

Establish the profession of case managers and an interface profession with case managers having an interdisciplinary background

Improve the cooperation between genetic counsellors and case managers to provide information on the specific needs of RD patients.

Enable peer to peer learning processes of case managers and community nurses

EMPOWERMENT OF PATIENTS & INCLUSION OF THE SOCIAL CONTEXT

The empowerment of patients is an ongoing challenge in Romania. To advocate for the rights of people affected by rare diseases and complex needs is mainly the responsibility of patients' initiatives that are working on a voluntary basis and have little financial as well as time resources. One of the most influential players in this regard is the Romanian Prader Willi Association, which runs the social resource centre NORO. This resource centre has started several projects to foster the empowerment of patients with rare diseases. They organise support groups as well as trainings for patients on the local and on the national level. Furthermore as an organisation that is lobbying for patients' rights NORO and the Prada Willi Association have facilitated meetings between patients and local authorities and have been a vocal advocate for patients' rights on the national level. In this regard, the case management approach that was tested in Romania also yielded a positive benefit for the empowerment of patients. Especially a tool developed by NORO that allows patients to self-report their health status has challenged the traditional system that was quite paternalistic, as one expert emphasised. Against the background of this example experts see high regional differences in the capabilities of patients and their families to engage in interest groups and to ask for their rights. As patients' organisations are important actors also for the provision of services, this contributes to the inequalities between regions. For a stronger voice of the patients' organisations they see potential in a stronger collaboration with organisations of disabled people.

On a more general level in Romania the empowerment of patients is mainly understood as inclusion into the labour market and/or the education system – and experts observe some deficits in inclusion.. A more encompassing perspective on social inclusion and participation is not commonly shared in Romania. According to the experts interviewed in the project, general awareness raising for the needs of people with complex conditions and resources for self-help-groups and local authorities are needed to improve the situation of patients with complex needs.

Still, integration into the labour market is one important element in the empowerment of people living with a rare disease since it enables patients to be economically more independent. In Romania the work integration of disabled people is guaranteed by law and discrimination against people with disabilities on the labour market is illegal. However, finding employment is still a challenge for people with a rare or a complex condition. Even for better educated people with a disability is hard to find employment due to the lack of accessible workplaces.

Moreover, Romania faces a similar challenge when it comes to the integration of children with rare or complex conditions into the education system. Despite the existence of legislation on integration classes and special schools integration is hindered by a lack of funding for special education teachers and home teachers. Likewise, the scarce infrastructure of adequate transport for children with rare and complex conditions or other disabilities furthers impedes their participation in the educational system. For this reason children with complex needs may not attend school at all and be deprived of education. To increase the participation of children with rare and complex conditions and subsequently foster their empowerment it is highly important that policy makers see this as public issue that calls for solutions on the political and on the structural level. Too often the absence of children with special needs from school is interpreted as a result of the low level of education and irresponsibility of parents and not as a consequence of the lack of infrastructure and possibilities.

However, in this context it has to be underlined that Romania provides financial benefits and tax reductions for the family of children with rare and complex conditions. While the introduction of these payments has been a great step forward the money the families receive does not always cover the costs of the need of the child and does not make up for the lack of infrastructure and inclusive services. One important measure to further improve the empowerment of patients and the inclusion of the social context is to increase the financial support of families with children with rare and complex conditions. Nevertheless, important social services for patients as well as for their family members and informal carers are unequally distributed and still few in number in Romania. The proliferation on a national level of these services is named as a key challenge in Romania by the experts involved in the up-scaling process. Since this development requires the awareness of key decision-makers on the national level and the establishment of new infrastructure and services this aim is deemed as a long-term objective by the experts involved. They see the main responsibility with the Ministry of work to establish the framework conditions and local service providers and patient organisation to create new services.

Important milestones for the empowerment of patients and the inclusion of the social context are:

Increase the accountability of policy makers for implementing inclusive schooling facilities

Increase the financial support for families with children with rare and complex conditions

Expand the social services for patients and their families. Responsible ministries should establish framework conditions

Further raise awareness for Rare Diseases among the public and policy makers

More resources for self-help groups

Increase the awareness of potential employers and increase the chances for labour market integration for people living with rare disease

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