



WP9: MEMO

**On existing integrated care practices and exploration
of possible application areas for rare disease patients**

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SUMMARY

Rare diseases are not only complex but also frequently unpredictable, requiring stays in hospital, specialist care and access to professional and medical knowledge that is not always available or may not even exist. Hence, rare diseases are likely to benefit considerably from integrated care that bridges professions and knowledge bases. However, they have special requirements which distinguish them from other complex or chronic diseases.

Such requirements are not just practical but institutional as well. Generally, the successful implementation of integrated and innovative care models requires attention to several levels: clear commitments by the policy level, organizational and cross-professional capabilities, structures and processes, and competent provision of care, support and problem-solving to patients and their immediate environment. Due to the rareness of rare diseases, initiatives supporting patients and their families often lack the necessary policy background and connections and are therefore limited in impact and sustainability. Based on this experience and knowledge of the special needs concerning Rare Diseases, INNOVCare draws on the various theoretical and practical concepts and case studies concerning the integration of health and social services (namely case management, care pathways, integrated care and innovative care) to scale-up the pilot implemented in Romania (NoRo) to other countries in the field of Rare Diseases.

The literature review and desk research shows that pilots of integrated and innovative care have been implemented widely all over Europe in the areas of complex diseases, chronic diseases etc.. This report assembles these findings in order to get a clearer picture of common requirements and useful strategies to ensure success and sustainability. In the next step, focus groups with professionals, policy makers and other relevant stakeholder groups will help to gather more in-depth information about necessities and requirements to implement and sustain of pilot projects. With regard to the specific group of people living with rare diseases their limited visibility and the limited knowledge about these conditions needs to be taken into careful consideration when it comes to scaling-up the intervention. At the same time, people living with rare diseases can benefit greatly from innovative and integrated care concepts. The knowledge gathered in this paper, expanded by the focus groups, helps to suggest roadmaps for providing improved services to people living with rare conditions and beyond. Two possible directions of scaling-up emerge and will guide ongoing research:

- Are the needs of patients with rare diseases incorporated into universal strategies to provide integrated and innovative care to those who need it (a kind of “mainstreaming”) ?
- Or do concepts of integrated and innovative care need to be adapted and tailored to the particular needs of this group of patients?

1. INTRODUCTION

INNOVCare develops and tests an innovative care pathway for EU citizens affected by rare diseases and networks expert service providers, regional and national public bodies to do so. The pilot in Romania tests a national-level one-stop-shop service for rare diseases and the introduction of regional case handlers in the form of a social experiment to assess improvements in care delivery, social inclusion and cost effectiveness. The project also explores the possibilities of scaling up the model to other EU member states and areas of social care. WP9 conducted desk research on current innovative, integrated and holistic care delivery models, (pilot) projects and initiatives. This paper explores the landscape of social health and care innovations in the area of integrated and innovative care delivery and draws conclusions on possible scaling options for INNOVCare’s approach.

The field, care delivery to and social inclusion of patients with rare diseases and their families, is situated at the crossroads of the general and the specific: The general aspect of delivery of care and the specific request patients with rare diseases have.

The general aspect of care delivery includes medical and social services, to both patients and their families. It takes place in the contexts of

- patients’ individual needs, living situations and family relationships and obligations,
- the organization of medical and social services in the respective regional and national context,
- the involvement of different professions and bodies of knowledge, and
- welfare states’ balancing of social inclusion, service quality and cost effectiveness.

This is common to all kinds of care that is long-term, involves complex conditions, bridges residential and mobile care and involves both families and multi-professional teams.

The specific aspect is the rareness of rare diseases: by definition they are varied, complex and progressive conditions that may generate multiple disabilities and require access to state-of-the-art specialists’ knowledge and attention at times that are not always predictable – but also a holistic and personalised approach to care that takes the individual case and its context into account.

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Reference to the general and the specific is thus not a trivial observation: modern societies at large move through tension fields of universalism (for example, social inclusion, equal opportunities) and specialisation (of for example, professions, bodies of knowledge, organisations and also interest groups), and, increasingly, optimisation of resources. In the health sector, these modern logics are articulated by people, on their bodies and in their life worlds. From the view of patients and their families, this translates into needs to manage the lived realities, find “good” carers, arrange services, handle bureaucracies, provide and direct information, and so on. However, patients’ and families’ capacities to overcome organizational and specialist logics are limited, especially as health systems are becoming more complex.

This, the tension of specialisation and the integration of varied specialisms into the delivery of good-quality care, is the subject of current social, integrated and innovative care models. Institutional and social innovations are needed to provide support on the level of integrating specialist functions and services: Models of integrated care for example aim to enable patient empowerment, professional and specialised roles, high quality services and cost-effectiveness (cf. SIE 2016) – objectives that are not always coherent. In this paper we address these tensions as key information to develop possible scaling options for INNOVCare approach.

Health care systems offer highly specialized services, but are often highly fragmented and lack direct interaction with systems of care provision. Yet, well-connected and integrated health and care systems are especially important for people with complex and long-term care needs, who may move between various services of institutions and professions and require smooth and effective communication and transfer of knowledge among their care providers. On the other hand, disabling and severe conditions may limit patients’ capacities to direct that knowledge circulation and manage their care themselves. These burdens on patients and their carers may prevent people with complex and long term care needs from participating in society and are exacerbated for people in remote regions, with low incomes or other vulnerabilities. In order to ensure inclusion for people with complex and long term care needs, integration of health and social care systems is essential. Also, families of people with complex and long term care needs live with often inadequate support schemes, which leave the organization and, to varying extents, the actual delivery of care to themselves. Relief that makes a difference requires some innovations in health and social care, which are focused at meeting the specific needs of these groups but also address the generic problem of integrating and co-ordinating functions and services driven by specialisation. At the policy level improved health and social care systems in this sense may

offer various synergies: elimination of double efforts and friction with limited use for patients, cost savings, more satisfaction of both professionals and other carers and care recipients at all levels of the service chain.

2. FRAMEWORKS FOR HEALTH AND SOCIAL CARE PROVISION FOR PEOPLE LIVING WITH A COMPLEX CONDITIONS

The literature review found different theoretical and practical approaches in how to improve and bring together fragmented health and social care services, focusing on different aspects of the health and care process. **Care pathways** emphasize the improvement of service efficiency on the organizational level. **Case management** focuses on the patient`s perspective to make his/her health and social care experience more satisfying. In essence, case management helps the individual and his/her family to navigate through fragmented health and social services through communication with professional roles but does not integrate health and social services per se¹. Insofar, case management acts as an important tool for integrated care, aiming at the minimization/ elimination of frictions and redundancies among fragmented health and social care services. **Integrated care** aims at the integration of health and social care systems and the respective health and social care services in order to improve patient satisfaction and cost-effectiveness². Integrated care therefore brings together the individual (micro) level with the meso (organizational) and inter-organizational level, aiming at a systemic integration which goes beyond case management and care pathways. In the concept of **innovative care** the aim is to form a health and social care triad between

- patients and their families,
- the health and social care organizations
- and the policy level

¹ Allen, D. „From boundary concept to boundary object: the practice and politics of care pathway development.“, Hutt, R., u.a. „Case managing long term conditions.“, Schrijvers, G., u.a. „The Care Pathway Concept: concepts and theories: an introduction.“

² Axelsson, R., und Axelsson, S. B. „Integration and collaboration in public health—a conceptual framework.“, Billings, J. R., und Leichsenring, K. *Integrating health and social care services for older persons. Evidence from nine European countries.*, Kodner, D. L., und Kyriacou, C. K. „Fully integrated care for frail elderly: two American models.“

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to improve health and social care for people with chronic conditions and complex health and care needs. Through the policy level awareness can be raised and health and social care organizations can be changed accordingly³.

Table 1: Frameworks for care provision

Concept	Level	Overall goal	Application contexts
<i>Case management</i>	Individual (micro)	Increasing quality of care and quality of life	Elderly, dementia, chronic conditions, complex conditions, rare diseases
<i>Care pathway</i>	Organization (meso)	Improving service efficiency	Elderly, dementia, mental illnesses, complex conditions
<i>Integrated care</i>	Individual and organization (micro and meso)	achieving improved patient care and cost-effectiveness through better coordination of health and social care services	Elderly, chronic conditions, complex conditions
<i>Innovative Care</i>	Individual, organization and policy (micro, meso and macro)	Active participation of patients and families through a care triad between patients/families, health care teams and community supporters; preventative care	Chronic conditions

Source: author

Thus, the concept of innovative care represents the overall goal of health and social care for people with complex care needs, in which case management, care pathways and integrated care serve to achieve the goal of innovative care for people with complex conditions. In the following, these four

³ World Health Organization, „Innovative Care for Chronic Conditions. Building Blocks for Action: Global Report.“

concepts will be described in detail (conceptual context, overall goals, application areas and case studies).

2.1 CASE MANAGEMENT

Concept and aim

Case management creates a specific role, the case manager, to support patients (or clients in the social services) in the planning and coordination of their care (or other social service) needs. The function, and in the US, profession originates in the US health insurance system and there, as part of a managed care paradigm, bundles functions of assessment, planning, facilitation and evaluation.

However, case management lacks a clear definition. One is offered by The American Case Management Association (ACMA): it broadly defines case management as “a collaborative practice model including patients, nurses, social workers, physicians, other practitioners, caregivers and the community. The Case Management process encompasses communication and facilitates care along a continuum through effective resource coordination. The goals of Case Management include the achievement of optimal health, access to care and appropriate utilization of resources, balanced with the patient's right to self-determination.”⁴ Hutt et al (2004) define case management as “the process of planning, co-ordinating and reviewing the care of an individual”⁵. Both definitions reflect the complex and integrative role of case management. Its possible benefit is to draw the attention to the patient's rights and abilities. Yet case management in itself underemphasizes the role of the organizational and institutional context.

Functionally, they are thus boundary-spanning roles (Holtgrewe and Kerst, 2001) between individuals with certain needs and organisations that have standardised ways of delivering their service. Translating between needs and offers, people and systems, everyday life and organisational rules and resources is thus the core of case managers' work. In the health and social system, they also manage relations between organisations and professions, ensuring continuity, handovers and information flows on behalf of patients. They have the paradoxical task of specialising in overcoming the limitations of specialisation. They also have to negotiate conflicts of interest as synergies between quality and

⁴ American Case Management Association ACMA, <http://www.acmaweb.org/section.aspx?SID=4>

⁵ Hutt, R., u. a. „Case managing long term conditions.“

quantity, patients', carers' and professionals' interests are not a given but need to be created in the light of limited resources, frequently unclear priorities, and different agendas and perspectives of all actors involved.

Hence, case managers (like other customer-facing roles in services) have a risky role that is not just dependent on adequate skills and discretion but also on an adequate organisational context that provides sufficient services, support and knowledge to deliver. Ross et. al. (2011) point out that "Case management works best as part of a wider programme of care in which multiple strategies are employed to integrate care. These include good access to primary care services, supporting health promotion and primary prevention, and co-ordinating community-based packages for rehabilitation and re-ablement."

Application context and findings

Hence, case management models are applied in various contexts under very different circumstances. This variation makes it hard to draw general conclusions on its impact and effectiveness. Since for case management changes in existing patterns of care provision are not necessary, it is a very commonly used method to improve patients' satisfaction within fragmented health and social care services, especially for those patient groups that require long-lasting follow-up care, i.e. patients with chronic conditions, frail elderly people, and other people with multiple care needs.

In the application cases reviewed by this memo case managers were mostly either nurses or social workers, and sometimes a combination of both. Evidence from the UK examples shows that case managers should already have previous practical experience working with the target groups, i.e. in long term care. Whether case managers are nurses or social workers does not seem to make any difference in relation to effectiveness and patient satisfaction, but special training for case managers should be provided⁶. Evidence from the case studies and from existing scalability efforts shows that international findings are not always easily transferred to different local contexts due to variation in policy frameworks and differences in original training and professional outlook of the professions involved and the training provided to case managers. The consensus is that for effective case management it is essential to see the patient as a whole within her/his social, psychological and

economic environment and to meet her/ his needs accordingly. So, case management needs to go beyond the condition itself to see the person behind the condition with his/her health and care needs in order to be effective⁷.

Case Studies

Spain

Extean Ondo⁸: Extean Ondo is an approach to person-centered care and case management aimed at older people and people with disabilities and their families operating since around 2011. It was initiated by the Matia Fundazioa-Matia Instituto in cooperation with the Basque government. The overall goal is to enhance quality of health care, of social care and ultimately of life through the combination of case management and individual care plans.

Sweden

Esther⁹: project start in 2000; patient-centered approach to health and social care for elderly, including case management. Esther (the name of a fictitious patient that was used to model care delivery) was successfully piloted in a particular region in Sweden from which it spread out globally, i.e. using Esther as a best-practice and implementation strategy was worked out in Wales¹⁰.

Action plan in the region Skane: A model enforcing the cooperation between home care, primary care and hospital care for the most ill elderly people. To this purpose regional development leaders serving as focal points of knowledge between home, primary and hospital care are implemented. Considered best-practice, the action plan was implemented in 21 counties in Sweden through the use of quality registers, teaching and monitoring¹¹.

⁷ Gravelle u. a., „Impact of case management (Evercare) on frail elderly patients“; Murphy. „Case management and community matrons for long term conditions“; Bergen. „Case management in the community“; Challis u. a., „Self-care and case management in long-term conditions“; Russell u. a., „Service developments for managing people with long-term conditions using case management approaches, an example from the UK.“

⁸ Extean Ondo: <http://www.matiainstituto.net/es/proyectos/etxean-ondo>

⁹ Esther: <http://plus.rjl.se/infopage.jsf?nodeId=31383>

¹⁰ Davies u. a., „Person Driven Care. A study of The Esther Network in Sweden and the lessons that can be applied to enable NHS Wales to become a patient-centred healthcare system.“

¹¹ Gomez. „European Innovation Partnership on Active and Healthy Ageing.“

UK

Community matrons¹²: Community Matrons act as a central contact point for patients with complex and multiple conditions. Community Matrons were introduced in 2005 following the NHS Improvement Plan to reduce unplanned hospital admissions for people living with long-term conditions. Although the role of Community Matrons is clearly defined, so far there is little evaluation from a patient’s perspective.

2.2 (INTEGRATED) CARE PATHWAY

Concept and aim

Care pathways were originally introduced in hospitals in the US in the 1980s but were quickly adopted in the UK and then transferred the rest of Europe. Although definitions vary widely, the UK National Institute for Health and Care Excellence (NICE) introduced a largely accepted one. It defines a care pathway as follows: “Each pathway includes all relevant NICE guidance, including clinical guidelines, public health guidance, technology appraisals, interventional procedures, medical technology and diagnostics guidance, and quality standards, and accompanying tools produced by NICE to support implementation”¹³. Similar to the NICE definition is the one from the Marie Curie Palliative Care Institute Liverpool (MCPCIL): “a care pathway is a complex intervention for the mutual decision making & organization of care processes for a well-defined group of patients during a well-defined period”¹⁴. Care pathways thus are situated in between “hard” standardization of care and health services and the reliance on the case-specific judgement, both supporting and monitoring professions and organisations. They may be associated with lump sum compensations or other health insurance practices that standardize care delivery. More general they can be seen as institutionalized tools of care management that map actual and anticipated patient needs, organizations and systems that deliver services, and create procedures and guidelines on how to bring them together. They are “care management tools which map out chronologically key activities in a healthcare process”.

¹² <http://www.nuffieldtrust.org.uk/node/463>

Moreover they can be defined as “a workflow system and a record of care”¹⁵. They are thus both a tool of the trade of a case or care manager and a higher-level management tool to align services and standardize their delivery across organizational boundaries. On either level, they do not determine procedures but require interpretation and negotiation with regard to the case/person in question in the light of the adequacy of procedures, steps and data. Indeed, Allen argues that some vagueness can be functional: “The popularity of pathway methodology can be explained by its effectiveness in aligning a range of interests in offering a single solution to shared health service problems”, offering the care pathway as a somewhat underdefined “boundary object” between managers, professionals and end-users around which negotiations and relations of cooperation and conflict can be developed.

Case Studies

UK

Care pathways are in use in various medical and surgical conditions (i.e. asthma, chest pain, stroke...) all over the UK. Initiated by the National Health Service, care pathways are also used in elderly care for several years now (starting in the late 90s, early 2000s), especially for acute admission and depression, but aim to cover all aspects of health and care for the elderly.

In the study by Allen (2009) a care pathway was applied for the management of patients at risk of harming themselves in a psychiatric in-patient facility. Here professionals were shown to carefully leave some of the procedures and assessments somewhat vague in order to retain adequacy to specific situations and space for professional judgement.

Liverpool Care Pathway: Care of the dying

A specifically controversial example is the **Liverpool Care Pathway (LCP)** that is applied to end-of-life care. Patients expected to die within the next hours up to the next 3 days, either at home or in a hospital, were put on the LCP to ensure end of life care. The decisions to put patients on the LCP are to be taken by health professional teams in close communication with patient’s families. The LCP was

¹⁵ Allen, D. „From boundary concept to boundary object: the practice and politics of care pathway development.“, 354

developed by the Royal Liverpool University Hospital and the Marie Curie Hospice in Liverpool, supervised by the Marie Curie Palliative Care Institute Liverpool at the end of the 90s.

The LCP and its use in practice were heavily criticized due to numerous complaints from patient's families, the main concerns being bad care for patients and incentives for health and social care professionals to let patients die fast. A lack of communication and training were two of the main problems that could be identified. Also, financial incentives given to facilities for each patient on the LCP led to misplaced end of life care. In addition, there was strong evidence for age discrimination and a severe lack of dignity and respect given to dying patients. Recommendations were made to phase out the LCP and replace it with individual care plans for dying people, intensify training with respect to care needs and communication with patient's families for health and social care professionals¹⁶. In late 2015, the pathway was replaced by new recommendations by the National Institute for Health and Care Excellence¹⁷.

Application context and findings

While there is some (limited) evidence for the cost-efficiency of care pathways, there is no evidence on the improvement of quality of care for patients. Implementing care pathways does not guarantee consideration for the patient and his/her needs since care pathways per se only aim at the improvement of service efficiency. Delivering good and situationally adequate quality care requires distinct efforts. To avoid unintended (negative) effects ongoing evaluation of care pathways is a must, as well as appropriate training of staff involved, communication and information of patients, families and professionals involved¹⁸. Not least, an emphasis on short-term cost savings and financial incentivisation before quality is assured may undermine this concern.

2.3 INTEGRATED CARE

Concept and aim

Integrated care is a concept aiming at bringing together fragmented health and social care services and has been used in Europe and North America for about 25 years. As with case management, there

¹⁶Neuberger J. "More care, less pathway: a review of the Liverpool care pathway."

¹⁷ <https://www.nice.org.uk/guidance/ng31>

¹⁸ Campbell u. a., „Integrated care pathways.“; Zander, „Integrated care pathways“;

is no common definition for integrated care, and also a lack of a common knowledge base. Several authors and professionals have provided definitions. Ovretveit (1998) defined Integrated Care as “The methods and type of organization that will provide the most cost-effective preventative and caring services to those with the greatest health needs and that will ensure continuity of care coordination between different services.”¹⁹ Leutz (1999) defines Integration as “The search to connect the healthcare system (acute, primary medical and skilled) with other human service systems (e.g., long-term care, education and vocational and housing services) to improve outcomes (clinical, satisfaction and efficiency)”²⁰. A similar definition is provided by Kodner/Spreeuwenberg (2002) speaking of “a coherent set of methods and models on the funding, administrative, organizational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors” with the goal to “enhance quality of care and quality of life, consumer satisfaction and system efficiency for patients with complex problems cutting across multiple services, providers and settings.”²¹

Application context and findings

Integrated care aims at the entire care continuum and health system to ensure continuity of care on a personal and an institutional level. The implementation of case management is one of the techniques that can be used to achieve integrated care. Examples are integrated primary and secondary care, multidisciplinary teams, specialist clinics, use of nurse practitioners, and integrated community outreach²². However, integrated care is differently used in the US and in Europe. While in the US integrated care aims at the integration of functions (i.e. the financing and the delivery system), integrated care in Europe is targeted at the integration of sectors (i.e. the cure and the care sector). The overall goal, improving outcomes for the target population, remains the same though²³. Evidence from the literature shows that especially people with complex and/ or chronic conditions benefit the

¹⁹ Kodner, D. L. „All together now: a conceptual exploration of integrated care.“

²⁰ Leutz, W. „Five laws for integrating medical and social services: lessons from the United States and the United Kingdom.“

²¹ Kodner, D. L., und Spreeuwenberg, C. „Integrated care: meaning, logic, applications, and implications—a discussion paper.“

²² Gemmill, „Research note : Chronic Disease Management in Europe“, 12.

²³ Billings, J. R., und Leichsenring, K. *Integrating health and social care services for older persons. Evidence from nine European countries.*, Glimmerveen, L., und Nies, H. „Integrated community-based dementia care: the Geriant model.“, Goodwin, N., u. a. „Providing integrated care for older people with complex needs: lessons from seven international case studies.“, Valentijn, P., u.a. „Understanding integrated care: a comprehensive conceptual framework based on the integrative functions of primary care.“

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most from integrated care due to their ongoing health and care needs, and the necessity of continuity in follow-up care. Therefore the OECD recommends using integrated care for frail elderly and groups with complex and high-risk conditions in general.

According to Leutz (1999, 2005) to ensure successful and sustainable integrated care 5 types of integration need to be considered²⁴:

Table 2: Levels of care integration

Type of integration	Description	Example
Systemic	Regulatory framework	Policy incentives for coordination
Normative	Shared values, vision across organizations	Common integration goals, clinical relationships
Organizational	Coordination of structures across organizations	Pooled budgets, umbrella organizational structures
Administrative	Budgets and financial systems across integrating units	Shared information systems
Clinical	Coordination of information and services	Inter-professional education, extended clinical roles, shared decision-making

Source: Leutz 1999, 2005

As with care pathways there is always the danger of unintended effects. Evidence shows that especially the use of financial incentives can motivate unintended behavior in the involved professionals, such as gaming, that means, “changes in reporting rather than desired changes in practice” or cherry picking, targeting services at the most “easy” or lucrative cases.²⁵ Also, adequate allocation of resources to all patient groups need to be ensured, and possible inequality to other patient groups must be closely monitored.

²⁴ Leutz, W. „Five laws for integrating medical and social services: lessons from the United States and the United Kingdom.“, Leutz, W. „Reflections on integrating medical and social care: five laws revisited.“

²⁵ Oxman et al 2008, *Integrated Care for People with Chronic Conditions*

Case Studies

UK

Pembrokeshire, Wales: “Community Care Closer to Home” project brings together professionals from health and social care into community resource teams²⁶.

Torbay and Southern Devon Health and Care NHS Trust: Started in 2000 for the provision of health and social care, especially for people recently discharged from the hospital. Teams are multidisciplinary, consisting of health and social care teams and care coordinators. Care coordinators work in geographical zones. Recently a new dimension, proactive case management of at-risk older people and for people with the ongoing need for care and support within the home environment, was added to the project²⁷.

Sweden

Norrtälje: start in 2004; Stockholm County Council and Norrtälje local authority work together to deliver health and social care services for the local population; joint funding model; patients are provided with a case manager who coordinates care from across multiple services and plans individual patient pathways; delivered via TioHundra – digital patient records can be integrated.²⁸

France

MAIA²⁹ (Homes for the Integration and Autonomy for Alzheimer patients): start in 2009; following a National Alzheimer’s plan (2008-2012), MAIA is an approach to integrated care, especially for elderly with complex needs, but not restricted to them. Its overall goal is to improve home care in general. The MAIA project is based on PRISMA, a model successfully tested in Québec, Canada. It uses the six components implemented and tested within PRISMA: 1) Coordination between stakeholders (round tables), 2) case management, 3) single entry point, 4) standardized multidimensional assessment, 5) individualized service plan, 6) shared information system. Breaking with a history of top-down approaches in health and social care services, MAIA uses a two sided model consisting of 2 pilots, a

²⁶ Thiel u. a., „Developing community resource teams in Pembrokeshire , Wales. Integration of health and social care in progress.“

²⁷ Goodwin u. a., „Co-ordinated care for people with complex chronic conditions: Key lessons and markers for success“, 8.

²⁸ Ebd., 14; Bäck und Calltorp, „The Norrtälje model.“

²⁹ MAIA: <http://www.cnsa.fr/parcours-de-vie/maia>

national one working top-down and 17 local ones, operating bottom-up. Within the local pilots the six components were implemented in collaboration with the national project team responsible for the overall management. The national pilot itself is situated at the highest level of governance to avoid conflicts and boundaries of ministries (experience from other health and social care innovation initiatives)³⁰.

Spain

MECASS, Health Plan for Catalonia 2011-2015: coordination, collaboration and continuity of care; collaboration between health and social care for chronic disease patients; Implementation of an integrated care pathway for people with chronic diseases, integrated, patient-centered care model³¹.

2.4 INNOVATIVE CARE (POLICY FRAMEWORK)

Concept and aim

Innovative care for people with chronic conditions means the formation of a care triad between patients and their families, health care teams and community supporters.

³⁰ Somme und de Stampa, „Ten years of integrated care for the older in France.“

³¹ Gomez, „European Innovation Partnership on Active and Healthy Ageing.“

Innovative Care for Chronic Conditions Framework



Source: World Health Organization. „Innovative care for chronic conditions: Building blocks for action : global report.“, S. 45

This triad is embedded in the overall health care organization, the policy environment and the broader community. The goal hereby is that patients and families are actively participating in caring, supported by the community and health care team. Innovative care therefore works at 3 levels: The micro level (individual and family), the meso level (healthcare organization and community) and the macro level (policy). At the core of innovative care is the integration of health and social care to minimize fragmentation³². Guiding principles of innovative care are evidence based decision making, a focus on the whole population, a strong focus on quality of health and care delivery, a focus on prevention and the integration of fragmented health and care services. The overall goal is to create more flexible health and social care systems that can easily be adopted to changing needs and future challenges.

³² World Health Organization, „Innovative Care for Chronic Conditions. Building Blocks for Action: Global Report.“

Application context and outcomes

The innovative care model is aimed at individuals with chronic conditions, the model has not yet been evaluated.

Case Studies

NHS and Social Care – House of Care (UK)³³

With the “House of Care” the NHS started a whole system approach for long term conditions, operating since 2005. The House of Care works as a general framework that can be used at the personal level (professionals), local/community level and on the national level. Key factors are a systematic approach linking health and social care, patients and carers; identifying everyone with LTC needs, community matrons providing case management, multi-disciplinary teams, local ways to support self-care and self-management programs and the use of available tools and techniques to make impact ³⁴.

3. LESSONS FOR SCALING-UP FROM THE CASE STUDIES?

From the desk research and literature review on various case studies in different application contexts ranging from elderly care to long term care for people with chronic diseases to mental illnesses there are several common conclusions that can be drawn for successful and sustainable implementation of a pilot project. These aspects address different levels of the intervention and can be subsumed under recommendations for the micro, meso and macro level.

The guiding principle at the micro level is the individual, his/her needs and his/her family’s needs. Lessons from the case studies and pilot projects show that these needs are met best if people with complex and chronic conditions receive individual care plans and continuity of care is ensured. Also, the establishment of a well-functioning communication basis between professionals and care recipients respectively their families must be ensured at all times. In addition, a personal relationship

³³ House of Care: <https://www.england.nhs.uk/house-of-care/>

³⁴ Ham, „Improving Care For People With Long-Term Conditions. A review of UK and international framework.“

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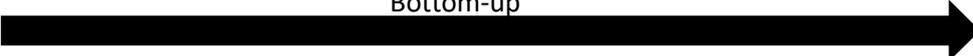
between one specifically assigned case manager and the care recipient as well as his/her family improves patient satisfaction and the meeting of diverse and complex care needs.

Building on these insights at the micro level, some common lessons for the meso level, the health and social care organizations, can be concluded: At the organizational level a holistic care assessment must be ensured as well as the establishment of a well-connected provider network in order to ensure continuity of care. Also, case management and a single point of entry need to be established at the organizational level. For continuity of care, multi-functional teams are also a necessity. Evidence from the case studies strongly suggests that within these multifunctional teams roles must be well-defined and the work basis should be one built on partnership rather than hierarchies between and within professions. Divisions of functions and of labour should be transparent to patients.

At the policy level, the macro level, the evidence from the case studies gives recommendations on two aspects – the initiation of the policy innovation and the sustainability of the policy innovation. In order to start a policy innovation, a general recognition of the importance of integrating health and social care systems needs to be established and appropriate funding must be secured. To ensure sustainability of pilots, it is crucial to be able to rely on political leadership over a longer period of time, at best at a high level of governance in order to circumvent pre-existing conflicts between fragmented health and social care organizations. Through political leadership (successful) pilots can be integrated into existing health and social care systems and the organizations can further evolve around them. Another important aspect at the policy level common to all case studies and crucial for the sustainability of pilots is the establishment of round tables between all relevant stake holders. These round tables need to come together on a regular basis and need to be situated at all levels of the organizational and political level. Table 3 summarizes the main conclusions and recommendations drawn from the case studies that are crucial for scaling-up innovative pilots³⁵.

³⁵ Goodwin u. a., „Co-ordinated care for people with complex chronic conditions: Key lessons and markers for success“; Nolte, Knai, und McKee, *Managing chronic conditions*; Gemmill, „Research note : Chronic Disease Management in Europe“; Humphries und Curry, „Integrating health and social care.“; Hutt, Rosen, und McCauley, „Case managing long term conditions“; Somme und de Stampa, „Ten years of integrated care for the older in France.“; Thiel u. a., „Developing community resource teams in Pembrokeshire , Wales. Integration of health and social care in progress.“

Table 3: Recommendations for scaling-up

Micro: Individual needs	Meso: Health and social care organisations	Macro: Policy
Individual care plan	Holistic care assessment	Provision of funding for innovative pilots and integration of pilots into existing health and social care systems
Continuity of care	Well-connected provider network	Recognition of the importance of integrating health and social care systems
Personal relationship between case manager and recipients/ families	Case management and a single point of entry	Implementation of roundtables between stakeholders at all levels
Communication between professionals and care recipients/ families	Multifunctional teams with well-defined roles (based on partnership)	Political leadership (preferably at a high level of governance)
 Bottom-up		

4. CONCLUSIONS AND DIRECTIONS FOR SCALING-UP

As the desk research and literature review on health and social care systems has shown, due to their high degree and need for specialization, health and social systems are often very fragmented and not at all in interaction with each other. This fragmentation concerns every level of the health and social systems: At the individual level, fragmentation for example means the lack of an individual care plan for patients living with long-term conditions. At the organizational level unclear or poorly communicated professional roles or the absence of multi-disciplinary teams may lead to fragmentation and increase burdens on patients and their families to coordinate care and treatment. At the policy

level fragmentation is often the result of a specific distribution of tasks between different ministries or policy levels (regional, local, national).

Putting the individual (the person living with the long-term condition) into the centre of attention and concern these inter- and overlapping levels of fragmentation often lead to a frustrating health and social care experience which often means that individuals are deprived from the best possible care. As elaborated, these experiences then again mean that individuals as well as their families (who are often left to provide care and social support on their own) are excluded or limited in their possibilities to participate in various spheres of society.

These experiences are not specific to people living with Rare Diseases. As shown in the previous sections of this paper also people living with well-known and quite common diseases are affected by the fragmentation of services and professions. What is specific for people living with Rare Diseases is that there is no common approach in how to provide health and social care for those individuals, since Rare Diseases in itself are very fragmented, serving as an umbrella term for all kinds of different conditions. So when talking about Rare Diseases or more accurately about people living with them, integration of services and also knowledge is all the more important, not only within but beyond national contexts. Only then will it be possible to provide people living with Rare Diseases and their environment with the best possible care.

Nonetheless, there are synergies from the concepts and case studies presented above that can and should be used when scaling-up the intervention designed at the INNOVCare project. The crucial prerequisites as well as the unintended effects of various modes of integrated and innovative care delivery can serve as examples and are likely to apply to care delivery in the case of Rare Diseases. They thus provide orientation in scaling-up the intervention for people with Rare Diseases while at the same time expanding and transferring practices and experiences to other contexts. Bringing together existing practical interventions and research will be of benefit for scaling-up the intervention.

Putting the individual's needs into the center and with regard to the experiences from case studies applied in other contexts, close attention must be given to unintended effects on the concerned individuals but also on other groups not at the center of attention. Only then can integration of fragmented health and social services be of benefit for everybody and contribute to the social inclusion of vulnerable groups.

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Memo on existing integrated care practices and exploration of possible application areas for rare disease patients

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