

POLICY BRIEF 23

How to improve care for people with multimorbidity in Europe?

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Co-funded by
the Health Programme
of the European Union



European
Observatory
on Health Systems and Policies
a partnership hosted by WHO



Keywords:

Chronic Disease

Comorbidity

Patient-Centered Care – methods

Delivery of Health Care, Integrated

Europe



This policy brief is one of a new series to meet the needs of policy-makers and health system managers. The aim is to develop key messages to support evidence-informed policy-making and the editors will continue to strengthen the series by working with authors to improve the consideration given to policy options and implementation.

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What is a Policy Brief?

A policy brief is a short publication specifically designed to provide policy-makers with evidence on a policy question or priority. Policy briefs:

- Bring together existing evidence and present it in an accessible format
- Use systematic methods and make these transparent so that users can have confidence in the material
- Tailor the way evidence is identified and synthesised to reflect the nature of the policy question and the evidence available
- Are underpinned by a formal and rigorous open peer review process to ensure the independence of the evidence presented.

Each brief has a one page key messages section; a two page executive summary giving a succinct overview of the findings; and a 20 page review setting out the evidence. The idea is to provide instant access to key information and additional detail for those involved in drafting, informing or advising on the policy issue.

Policy briefs provide evidence for policy-makers not policy advice. They do not seek to explain or advocate a policy position but to set out clearly what is known about it. They may outline the evidence on different prospective policy options and on implementation issues, but they do not promote a particular option or act as a manual for implementation.

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This report arises from the Innovating care for people with multiple chronic conditions in Europe (ICARE4EU) project, which has received funding from the European Union (EU), in the framework of the Health Programme. The authors wish to thank all country expert organizations and the programmes that participated in the ICARE4EU project. The authors are grateful to the programme managers for sharing information on their programmes.

The authors and editors are also grateful to Jan de Maeseneer (Ghent University, Belgium) and Nick Fahy (independent consultant), for reviewing this publication and contributing their expertise.

What is ICARE4EU?

The Innovating care for people with multiple chronic conditions in Europe (ICARE4EU) project aims to improve care for people with multiple chronic conditions (multimorbidity) in European countries (www.icare4eu.org). An estimated 50 million people in Europe live with multimorbidity. The complex health problems of these people and their need for continuous and multidisciplinary care pose a great challenge to health systems and social services. From a patient perspective, improvements in, for example, the coordination of care and patients' own involvement in the decision-making and the care process are also important. ICARE4EU describes and analyses innovative integrated care

approaches for people with multiple chronic conditions in Europe. By disseminating knowledge about innovative care programmes or practices, the ICARE4EU project aims to contribute to the improved design, wider applicability and more effective implementation of integrated care for people with multimorbidity. Observations from the ICARE4EU project are described in five policy briefs and key elements of multimorbidity care are addressed from the following perspectives: patient-centredness [1], use of e-health technology [2], integration [3] and financing systems [4]. A final policy brief (this one) integrates all lessons learned from the ICARE4EU project on how care in European countries could be improved for their citizens with multiple chronic conditions.

How do Policy Briefs bring the evidence together?

There is no one single way of collecting evidence to inform policy-making. Different approaches are appropriate for different policy issues, so the Observatory briefs draw on a mix of methodologies (see Figure A) and explain transparently the different methods used and how these have been combined. This allows users to understand the nature and limits of the evidence.

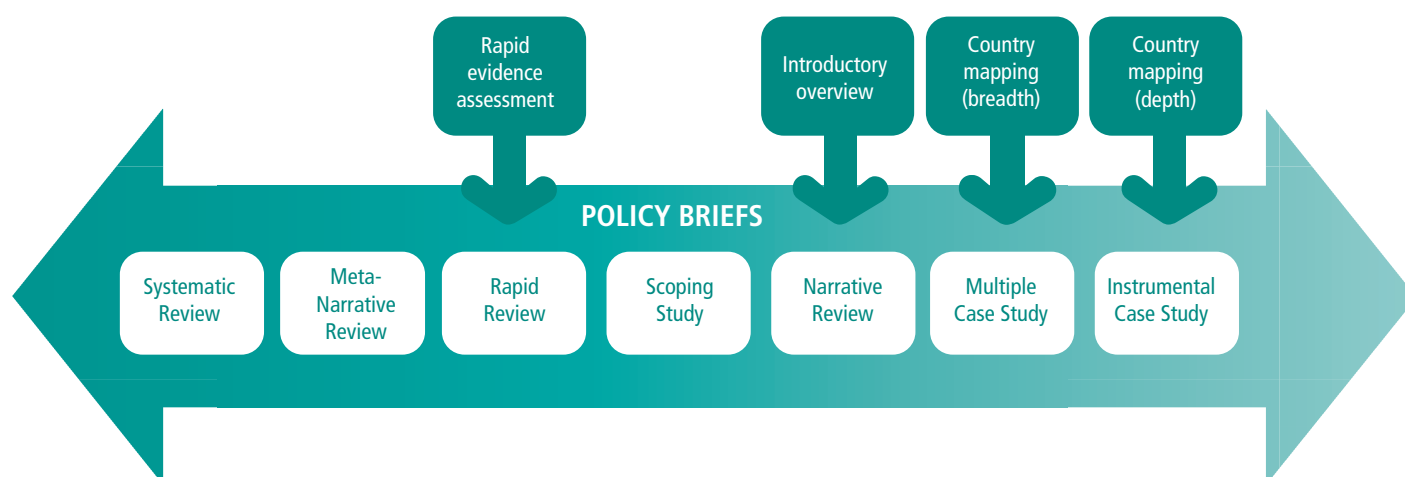
There are two main 'categories' of briefs that can be distinguished by method and further 'sub-sets' of briefs that can be mapped along a spectrum:

- **A rapid evidence assessment:** This is a targeted review of the available literature and requires authors to define key terms, set out explicit search strategies and be clear about what is excluded.

- **Comparative country mapping:** These use a case study approach and combine document reviews and consultation with appropriate technical and country experts. These fall into two groups depending on whether they prioritize depth or breadth.
- **Introductory overview:** These briefs have a different objective to the rapid evidence assessments but use a similar methodological approach. Literature is targeted and reviewed with the aim of explaining a subject to 'beginners'.

Most briefs, however, will draw upon a mix of methods and it is for this reason that a 'methods' box is included in the introduction to each brief, signalling transparently that methods are explicit, robust and replicable and showing how they are appropriate to the policy question.

Figure A: The policy brief spectrum



Source: Erica Richardson

Acronyms

EU	European Union
GP	General Practitioner
ICARE4EU	Innovating care for people with multiple chronic conditions in Europe
ICT	Information and Communications Technology
INCA	Integrated Care
POTKU	Potilas kuljettajan paikalle (Putting the Patient in the Driver’s Seat)
WHO	World Health Organization

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Key terms

- **Multimorbidity** means having multiple chronic conditions at the same time and (typically) complex needs that require the involvement of several care providers. It is a significant and growing challenge to Europe's health systems, with some 50 million people already affected.
- **Integrated care** is when care organizations and staff work together across professional and institutional boundaries to provide seamless care. It often involves the joint development of flexible and continuous care processes and care pathways.
- **Patient-centredness** is an approach to health care that consciously works around patients' needs, responding to individual preferences and trying to ensure that patient values guide clinical decisions.

Key messages

- European health systems do not meet the needs of patients with multimorbidity because they are “disease oriented” and organized around single medical specialties which fragments care.
- Fragmented care is associated with contradictory medical advice, over-prescribing, over-hospitalization and poor patient satisfaction.
- Policy-makers can improve care for people with multimorbidity by better integration.
- Making care patient-centred is another way of approaching the fragmentation of care and of increasing patient satisfaction. It requires a clear strategic (and ideally shared) vision.
- Policy-makers can foster both integrated and patient-centred care by:
 - Aligning policy, regulatory and financial environments so that they are supportive of integrated care and help make effective care for people with multimorbidity sustainable;
 - Developing multidisciplinary guidelines;
 - Developing new professional roles (e.g. care coordinator) or functions and assigning explicit responsibility for coordination and links between sectors;
 - Implementing individualized care planning (supported by integrated electronic health records);
 - Putting in place electronic decision support systems that enable patient-centred care and integrating them with information systems and eHealth applications;
 - Adapting privacy and data protection legislation to allow sharing of patient information;
 - Investing in training and tools that help care professionals adopt patient-centred approaches (including training in patient-centred communication and multiprofessional and intersectoral teamwork);
 - Developing the knowledge and skills of patients and their informal carers and encouraging active participation in decision-making and self-management;
 - Promoting collaboration between health care, social care, patient organizations and carers;
 - Including patient-relevant outcomes as performance indicators, as well as clinical outcomes, so that providing integrated care becomes part of quality measurement;
 - Putting in place payment mechanisms to incentivize patient-centred integrated care.
- The continuous evaluation of innovative practices is needed over the long term to identify effective elements and further strengthen patient-centred integrated care.

Executive summary

What is the problem?

Almost all European countries are coping with an increasing prevalence of multimorbidity as medical technology advances and people live longer. Having multiple chronic diseases is associated with poor quality of life as well as increasing mortality and disability rates. The increasing number of people living with multimorbidity constitutes a challenge for health care in European countries. Care systems in Europe are currently highly fragmented and organized around single diseases. This way of organizing care delivery is not responsive to the needs of patients with multimorbidity because their multiple conditions require care from multiple care professionals. Furthermore, disease-specific treatment guidelines may not apply to those with multiple chronic conditions as they may be mutually incompatible. Providing patient-centred integrated care to patients with multimorbidity is a potential solution, but how to do this in practice remains poorly understood.

How is it addressed? Findings from the ICARE4EU project

In the ICARE4EU project, country experts in 31 European countries identified 101 integrated care programmes that were directed at improving care for patients with multiple chronic conditions. In these programmes a variety of interventions have been applied to improve the delivery of patient-centred integrated care at the level of care for individual patients, for example, by introducing comprehensive needs assessments and individual care planning, and by supporting patients and informal carers in decision-making and self-management.

Improving care coordination and multidisciplinary collaboration were the main objectives of most programmes. Collaborations were most often established within the health care sector, and mainly within primary care; collaborations between primary and secondary care and with other sectors (e.g. social care) and informal carers remain limited. Electronic health records are used in most programmes, but sharing electronic health records with other care professionals and patients themselves is not yet common practice. Furthermore, for most of the identified integrated care programmes, no specific payment methods to support integration were used. Current innovative approaches to provide patient-centred integrated care to patients with multimorbidity are mainly initiated bottom-up, in spite of, not due to national regulations.

Improving care for people with multimorbidity in European countries

At the level of care organizations:

- The first step in providing integrated patient-centred care is the development of a conceptual and strategic vision (within and across care organizations) shared by both the

management and care professionals. Care organizations may also need to invest in the development of care professionals' knowledge and competences to provide patient-centred integrated care (including training in patient-centred communication, multiprofessional and intersectoral teamwork, and working with eHealth applications).

- Linking same-level professionals of different departments or different care organizations to enhance coordination and collaboration could be considered. Additionally, digital communication systems that make it easier for providers to organize meetings may help. The development of care pathways for patients with multimorbidity can also support collaboration between care professionals and the coordination of care.
- The implementation of individualized care planning, integrated in electronic health records and based on a goal-oriented approach including periodic comprehensive needs assessments, can improve the responsiveness of care to the medical needs, personal goals, resources and care preferences of patients.
- Supporting patients and their informal carers by improving their knowledge and skills and encouraging active participation in decision-making and self-management are also important to improve care for people with multimorbidity.

At the level of national or regional health systems in Europe:

- Developing a conceptual and strategic vision of patient-centredness with all national or regional health and social care stakeholders would be a first step in improving care for patients with multimorbidity at system level. This vision can be disseminated by supporting local, regional or national initiatives directed at enhancing patient-centred and integrated care for multimorbidity patients.
- Adaptations in training for health professionals and social workers, directed at improving knowledge and skills related to multimorbidity care and multidisciplinary collaboration are required. The development of new professional roles (e.g. care coordinator) or functions may also be needed, alongside appropriate training programmes.
- For current care professionals, the development of multidisciplinary guidelines for multimorbidity patients, as well as the development of electronic decision support systems to support patient-centred care for people with multimorbidity are needed. Decision support systems need to be integrated into information systems to be used by multiple care professionals in order to enhance collaboration and care coordination. To enhance collaboration between care professionals, privacy and data protection legislation may need to be adapted, to allow sharing of patient information.

- Research to support the standardization of valid measuring instruments for health care needs assessment and patient group segmentation is needed. In addition to clinical outcomes patient-relevant outcomes need to be included as performance indicators. Alongside this, the development of interventions that allow systematic and continuous evaluation over the long term to add to the evidence base around the effectiveness of programmes is also required.

What to consider when implementing patient-centred integrated care for people with multimorbidity?

Multimorbidity affects European countries in different ways and to a varying extent: prevalence and patterns of multimorbidity differ, which relates to differences in population

characteristics, socioeconomic factors and cultural values. Policies to improve care for people with multimorbidity therefore need to be geographically specific, taking into account a country or a region's population, its health and social care system(s), including legislation, financing, workforce and cultural values. As the prevalence and patterns of multimorbidity relate to social inequalities, policy-makers also need to pay attention to inequity in access to health and social care as well as in access to and use of eHealth solutions, when developing policies to improve care for people with multimorbidity.

In addition, continuous monitoring and evaluation over the long term to generate conclusions about the (cost-)effectiveness of various integrated care approaches for people with multimorbidity that have been, or will be implemented, in European countries and regions is also needed.

Policy brief

Introduction

The challenge of caring for people with multimorbidity

European countries are facing a rapid increase in the number of people living with chronic illness and this puts pressure on their health systems [5, 6]. Recently, awareness has grown that multimorbidity may be an even greater challenge for health care in Europe. Multimorbidity can be defined as the occurrence of two or more chronic diseases within the same person [7]. Data show that the number of people with multimorbidity is increasing at a greater rate in some countries than is the already rapidly increasing number of people with one chronic condition [8]. Caring for people with multimorbidity is also even more complicated than caring for people with one chronic condition.

In many European countries, chronic disease management programmes have been implemented to provide proactive, evidence-based multidisciplinary care for patients with specific chronic diseases, such as diabetes mellitus or chronic obstructive pulmonary disease (COPD) [9, 10]. However, because of their disease-specific approach, such programmes cannot adequately respond to the health care needs of people with multimorbidity, resulting in both gaps and overlaps in the care provided. Apart from this single chronic disease management approach, health care in European countries is almost always organized around medical specialties focusing on specific organ systems, which risks losing sight of the patient as a whole person. In countries where people register with a general (primary care) practice and the primary care physician functions as care coordinator, patients with multimorbidity may be better served, although they will still experience fragmentation when using specialized or hospital care. These so-called vertical silos are an important reason why care for people with multimorbidity is suboptimal.

Another reason for this is that there is a lack of evidence about the effectiveness and safety of medical interventions for patients with multimorbidity [11-13], due to exclusion of people with co-morbid conditions from clinical trials that test the effectiveness and safety of medical treatments. Moreover, people with multiple chronic conditions may have comprehensive needs for care and support that are beyond the realm of health care. The complex health needs may impact on their social relationships, participation in society, income and living situation as well. It is obvious that problems in other domains of life require the involvement of other types of care and support, such as home help, social care or community services. Also, the involvement of informal carers is of the utmost importance for many people with multimorbidity, to prevent institutionalization and maintain quality of life. At the same time, it has become clear that not all people with multiple chronic conditions should be considered patients with "high" or comprehensive needs. Large differences exist in the extent to which people with multimorbidity experience various health-related problems [14],

and greater need for care not only relates to disease patterns, but also to physical and mental functioning, personal characteristics and social situation [5].

The care models predominating in European countries are not appropriate for responding to the diverse and comprehensive needs of people with multimorbidity in a customized way. Reforms are needed to provide patient-centred, integrated care, while using innovative methods and technologies to support patients, informal carers and care professionals in the care process. This provision is needed to produce better outcomes for individuals with multimorbidity, and strengthen care organizations and health systems in Europe.

Box 1: Use of the term "patient-centredness"

The term "patient-centredness" will be used throughout this Policy Brief, and is synonymous with the term "person-centredness". The term "person-centredness" may better illustrate that a person with a chronic disease or multimorbidity is not solely considered a patient. However, since we focus here on the care provided to people with multimorbidity, we use the term "patient-centredness" for reasons of clarity.

Box 2: Definition of integrated care

Integrated care can be defined as "patient-centred, proactive and well-coordinated multidisciplinary care, using new technologies to support patients' self-management and improve collaboration between caregivers" [84]. Many other definitions exist, which all emphasize at least the coordination of care ("clinical integration"; see [65]) provided by care professionals from different disciplines working in the same or different organizations.

Box 3: Methods

For policy-making, insights and experiences from innovative practices elsewhere are useful and provide information on health care changes that can lead to more patient-centred integrated care. This policy brief synthesizes insights from four policy briefs of the ICARE4EU project on how care in European countries could be improved for citizens with multiple chronic conditions [1-4]. These policy briefs combine rapid reviews of the research literature with results from a survey.

As part of the ICARE4EU project, information was gathered on 101 innovative care programmes in 24 European countries, 8 of which were visited to obtain a more in-depth understanding of their particular characteristics. Appendix 1 provides detailed information on this research into innovative care programmes in European countries.

What is the policy question?

While there is strong consensus on the necessity and urgency of improving care for people with multiple chronic conditions in Europe, the policy question is how changes in clinical practice at the local or regional level could be supported in order to provide patient-centred integrated care, and how such changes could be encouraged and facilitated by reforms in the health and social care system(s) of European countries or regions. More specifically, this policy question relates to three sub-questions relating to different levels of action:

1. How can care professionals be supported to customize care in relation to the various and comprehensive needs of their patients with multimorbidity? And how can people with multimorbidity and their informal carers be supported to actively engage in the care process?
2. How can care organizations be encouraged and supported to provide integrated care for people with multiple chronic conditions at a local or regional level?
3. How can European countries or regions make adaptations to their care systems to facilitate the implementation of patient-centred integrated care for their citizens with multiple chronic conditions?

Findings

This section highlights approaches to improving care for people with multimorbidity at different levels, as described in the international literature, as well as the experiences from 101 innovative care programmes in European countries or regions that target patients with multimorbidity.

Framework of care for people with multimorbidity

The findings are structured according to a framework (Fig. 1) visualizing patient-centred integrated care for a person with multimorbidity, embedded in the health and social care system of a country or region, and how this care relates to a person's daily life. The framework is based on the Chronic Care Model [16] and other models emphasizing patient-centredness of care, such as the House of Care [17, 18] and the Generic Model of Self-management [19], and/or integrated care, such as the Development Model for Integrated Care [20]. The framework illustrates that the person with multimorbidity, rather than the health system, should be placed in the centre, and that this person's needs should be the starting point of the care process. It also shows that this person is not (only) a patient or client of health or social care, but a person living a life connected with other people and society. In this framework, the health goals set by a person with multimorbidity, relate to this "real world", explaining why daily functioning, autonomy, well-being and participation in society are highly relevant goals from a patient perspective.

In addition, the framework visualizes the different levels of care for people with multimorbidity. The inner circle illustrates the micro level: the person with multimorbidity in interaction with his or her informal carers and care professionals. The outer band illustrates the meso level, which consists of the local or regional network of care organizations, their structures, processes and tools to support their patients or clients with multimorbidity, the informal carers and the care professionals involved. The space outside the circle illustrates the macro level: the health and social care system(s), shaping the conditions that facilitate (or hinder) the provision of patient-centred integrated care in a region or country, as well as broader society.

Micro-level approaches to customizing care to the needs of people with multimorbidity

Periodic comprehensive needs assessment and individual care planning

People with multimorbidity may have comprehensive needs because of their complex medical condition, which not only affects their physical status but also their well-being in a broader sense. As multimorbidity is not a static condition, people have to adapt their lives continuously, which also implies reorientation on the life and health goals they strive for. For these reasons, periodic comprehensive needs assessments by a multidisciplinary team of care professionals are recommended [11]. Such assessments should entail an assessment of the patients' diseases and functioning, but also an evaluation of their values, goals, support network and other resources (see also [21, 22]).

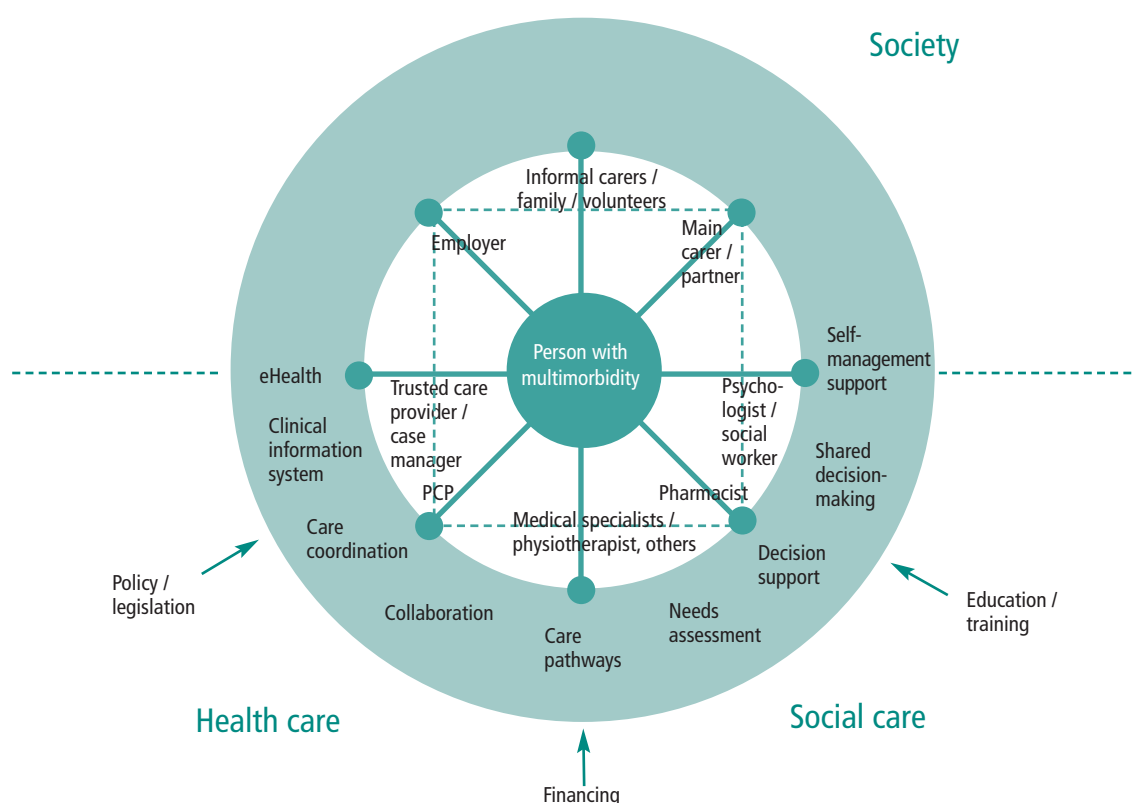


Fig. 1: Framework visualizing patient-centred integrated care for people with multimorbidity

Comprehensive needs assessments have been part of innovative care interventions for geriatric patients or frail elderly people [23-25]. In addition, they are used as the basis for individual care planning in chronic disease management. Since comprehensive needs assessments are usually part of “multicomponent” interventions to improve care for people with multimorbidity or frailty [7, 26], it is unclear what their specific contribution is to certain outcomes. Similarly, there is no evidence that the use of individual care plans in itself results in better outcomes in chronic illness care [27], because the development of such plans is usually part of more comprehensive interventions to improve patient-centredness. Individualized care planning, defined as “an anticipatory (forward-looking), negotiated discussion, or series of discussions, between a patient and a health professional (perhaps with other professionals or family members present) to clarify goals, options and care preferences and develop an agreed plan of action based on this mutual understanding”, appears to improve clinical and behavioural outcomes of (mainly primary care) patients with specific chronic diseases [28]. Such approaches may also be beneficial for people with multimorbidity.

The extent to which periodic comprehensive needs assessments and individual care plans are currently part of care for people with multimorbidity in European countries is unclear. In most of the 101 integrated care programmes with a multimorbidity focus identified in the ICARE4EU project, individual care plans were used but not always for all patients [29]. Moreover, the use of individual care plans does not guarantee that comprehensive needs are periodically assessed or include an evaluation of patients’ opinions and resources.

Decision support and shared decision-making

Decision support for care professionals

To decide on a care plan in collaboration with multimorbidity patients and their main informal carers, care professionals could benefit from decision support such as clinical guidelines. In the case of multimorbidity, the need for decision support may be increased because medical decision-making will usually be more complex: the medical treatment for a particular disease may impact on coexisting diseases as well, and medical treatments (e.g. medicines) for separate diseases may interact, resulting in unexpected treatment effects and possibly harmful side effects. It is therefore very important that multimorbidity is taken into account when using clinical guidelines. There are some efforts to integrate clinical guidelines for single diseases or to develop interaction matrices of guidelines [30-32].

In addition, care professionals need skills and (potentially eHealth) tools to support them in decision-making, as the complexity of decision-making in multimorbidity care requires them to take multiple clinical guidelines into consideration and to make decisions that transcend individual diseases. Until now, training care professionals in decision-making in the context of multimorbidity care has received little attention in European countries [33]. In the integrated care programmes identified by the ICARE4EU

project, promoting evidence-based practice or improving professional knowledge about multimorbidity were not considered main objectives of most programmes [29].

Shared decision-making

Research has demonstrated that involving patients in the decision-making process results in better outcomes [34, 35], such as increased patient satisfaction, better adherence to treatment regimens, improved functional status and optimized self-management [36-38]. Although research on the beneficial effects of actively involving patients with multimorbidity in decision-making processes is patchy, it could potentially have similar positive effects. Patients with multimorbidity are particularly likely to face trade-offs between receiving effective treatment for one condition or another, or prioritizing short-term or long-term benefits and harms [13, 31]. Such “preference sensitive” decision moments after a comprehensive needs assessment need to be recognized by care professionals and the benefits and harms of treatment options need to be made explicit. An important first step is to assess the patients’ attitudes and abilities towards shared decision-making [39]. Taking these into account, patients need to be sufficiently informed before their preferences for treatment options can be assessed, which could, in combination with clinical feasibility, inform treatment choices [13, 40]. In order to involve patients with multimorbidity in shared decision-making, care professionals need adequate communicative skills and may benefit from training in motivational interviewing techniques [34].

In the innovative care programmes identified by the ICARE4EU project, improving the involvement of patients in their care was a core objective of most programmes [30]. Approaches to achieving patient involvement included facilitating effective communication by care professionals to support patient participation in decision-making and organizing pre-treatment discussion sessions with the care professionals involved on how to motivate patients in decision-making [1]. Other approaches to support patient involvement were the provision of information leaflets with treatment options and the use of web-based tools [2]. However, decision support materials or tools for patients and their informal carers were not commonly used.

Self-management support

As people with multimorbidity (and/or their informal carers) not only need to participate in the decision-making process but also in the actual care and treatment process as laid down in their individual care plan, they also need self-management support. Self-management support can be defined as “a patient-centred collaborative approach to care to promote patient activation, education and empowerment” [41]. Self-management support therefore entails more than just traditional patient education. It also emphasizes that self-management is not the sole responsibility of a patient; it is shared with care professionals [42]. In addition to the self-management support provided by the patient’s main care professionals, other supportive interventions could be applied, such as group courses or individual web-based

interactive programmes, which aim to improve patients' knowledge, motivation and self-efficacy to manage their conditions. There is extensive literature on the (small) positive effects self-management support has on the mental and physical health, health behaviours and social life of people with chronic diseases [43, 44]. However, current self-management support programmes or tools are often disease-specific, which limits their relevance for patients with multimorbidity [45]. Some programmes have a more generic approach, such as the Chronic Disease Self-management Program developed at Stanford University [46]. This programme has been tested, adapted and implemented worldwide, including in European countries [47-49]. Self-management support could also include assistive technologies to optimize chronically ill or older people's functional abilities and/or facilitate treatment or follow-up care at home, overcoming problems with travelling to and accessing health services, especially for people living in deprived areas with low coverage of care services [50-52].

Integrated care programmes targeting people with multimorbidity in European countries have implemented various supportive programmes or tools for the self-monitoring of symptoms, making lifestyle changes or coping with illness [29]. eHealth applications are often used, and include electronic reminders (e.g. for appointments, medication adherence), digital systems for monitoring symptoms and health status, and for supporting a healthy lifestyle and behavioural changes. In some integrated care programmes eHealth applications are also used to exchange information between care professionals and patients [2].

Barriers to implementing patient-centred care

In the ICARE4EU project, several barriers to the structural implementation of a patient-centred approach in multimorbidity care were identified. Among these were a lack of managerial vision of patient-centredness in care organizations, a lack of knowledge and skills among both patients and care professionals, a lack of time among care professionals and inadequate financing of patient-supportive interventions [1]. Where technology might improve integration, specific barriers to the use of eHealth to improve patient-centredness were given as: a lack of computer skills among care professionals and patients, inadequate ICT infrastructure and inadequate funding for structural implementation and innovation in supportive eHealth tools [2].

Approaches to provide integrated care to people with multimorbidity at the meso level

As people with multiple chronic conditions often have comprehensive needs that require care and support from different professional disciplines, they require integrated care. This could include care coordination, multiprofessional collaboration and/or inter-organizational collaboration.

Care coordination

Studies in chronic illness care emphasize the importance of care coordination to achieve better care delivery and outcomes [53-55]. In the case of multimorbidity, care

coordination may be even more important, as uncoordinated care may result in both gaps and overlaps in the care provided, and consequently in inefficient use of resources and a poor quality of care.

Based on the individual care plan resulting from the shared decision-making process, a care trajectory can be planned and a care coordinator assigned. When the care trajectory is simple and the patient or their informal carer has sufficient skills, the patient or informal carer could take up the role of care coordinator themselves. In the case of multimorbidity, a care professional will usually be needed for the coordination of care. In countries where patients are registered with primary care practices and primary care physicians function as gatekeepers, it may be a primary care physician or nurse who is responsible for care coordination. Elsewhere, other care models may be more applicable and other care professionals could have the coordinating role. For patients with very complex care needs, a professional case manager may be appointed. Case managers have often been considered the best solution for care coordination [56, 57], but not all people with multimorbidity require case management. The need for case management should become clear from the regular comprehensive needs assessments and the individual care plan developed together with the patient and their main informal carer(s). In the 101 integrated care programmes identified in the ICARE4EU project, case managers were assigned to at least some patients in 41% of the programmes [3, 29].

Regardless of which model is applied, it is always important that responsibility for care coordination (both within and between organizations) is clearly defined. However, the coordination of complex care between multiple care professionals may be a challenging task for a single professional. The recognition of both the importance, but also the challenge of care coordination is reflected in the finding that 70% of the 101 integrated care programmes identified in the ICARE4EU project reported improved care coordination as being among their main objectives [3]. In one of these programmes (in the Valencia region in Spain), positive experiences have been gained with a "two case managers" model: two nurses, one from primary care and one from hospital care, are assigned as case managers for each patient with complex care needs and these nurses work in close collaboration to guarantee integrated and continuous care [58, 59].

Multiprofessional collaboration

Collaboration between different professionals, such as primary care physicians, hospital specialists, nurses and social workers is at the heart of integrated care for people with multimorbidity [60, 61]. The importance as well as the complexity of multiprofessional collaboration are reflected in the finding that improving multiprofessional collaboration was a core objective of almost 80% of the 101 integrated care programmes identified in the ICARE4EU project [3]. For many of these programmes, it was reported that they had succeeded in improving the collaboration between different care professionals. For instance, in the Clinic of

Multimorbidity and Polypharmacy in the Silkeborg Hospital in Denmark, multidisciplinary collaboration has been achieved by organizing meetings of medical specialists from different disciplines with nurses, pharmacists, physiotherapists and occupational therapists based on the flexible ad hoc Plastic Organic Groups method [62]. Meetings about the needs and care plan of a specific (multimorbidity or polypharmacy) patient are arranged during lunch breaks and the participation of the care professionals is on the basis of equality and focused on the specific needs of the patient, which reduced obstacles such as a lack of time or bureaucracy. This clinic also cooperates with primary care, because primary care physicians refer their patients with complex care needs to the clinic for a comprehensive needs assessment and get support from the clinic afterwards to provide the necessary care in their practice.

The development of a care pathway may help to guide the delivery of integrated care for specific groups of patients and it may clarify roles and responsibilities in the care process. However, developing common care pathways is challenging as it requires a shared vision, acknowledgement of co-care professionals' roles and more formal agreements on structural collaboration for a specific group of patients. The ICARE4EU project findings show that in integrated care programmes that included the development of a care pathway, the cooperation competences of care professionals and the balance of power positions (e.g. in multiprofessional teams) were deemed stronger than in programmes that did not include care pathway development [3]. Collaboration asks for partnership, as opposed to leadership, which implies that care professionals need to support each other based on their complementary strengths and capabilities [63]. However, building effective partnerships is time consuming, resource intensive and difficult because it requires relationships, procedures and structures that can be different from usual ways of working [63].

Multiprofessional collaboration could be supported by sharing the electronic health records of patients among all care professionals involved in the care process. This is not yet common practice, but several programmes, such as the *Gesundes Kinzigtal* programme in Germany [64] and the *Strategy for Chronic Care* in the Valencia region of Spain [59] show the potential of shared electronic health records. Digital communication (e.g. video-calls and text messages) could also enhance multiprofessional collaboration, but, as with shared electronic health records, the use of digital communication facilities in integrated care programmes in Europe for people with multimorbidity is still limited [2].

Inter-organizational collaboration

Even more complicated than multiprofessional collaboration within a care organization may be inter-organizational collaboration, due to additional cultural, managerial, structural and financial differences and boundaries between care organizations. The 101 integrated care programmes in European countries identified by the ICARE4EU project show that multiprofessional and/or inter-organizational collaboration was mainly established within primary care and between primary care and hospital care, whereas social care and community services (including patient and volunteer

organizations) were less often involved [3, 29]. Given that people with multimorbidity have several chronic diseases, the focus on medical care is understandable, but the non-medical needs of these people may not be satisfactorily addressed in this way.

The “two case managers” model in the Valencia region in Spain [59] is an example of functional collaboration in daily practice bridging the gap between the “silos” of primary care and hospital care. It is also an example of collaboration between different care organizations by linking professionals at the same level, which guards against professional and status-based obstacles to collaboration. An important characteristic of this Valencian model is the efficient use of ICTs for communication between professionals and an effective regional electronic health record system: both case managers, as well as all care professionals (doctors, nurses, social workers, etc.), have continuous online access to the electronic health records of their “shared clients”, which facilitates continuity of care [2].

Providing integrated care at a local or regional level could also be achieved by the integration of care units or organizations. In the 101 integrated care programmes, the integration of care units or organizations was less often the aim than clinical or functional collaboration [65]. Improving integration of different units or different organizations was mentioned among the main objectives of 55% and 48% of the programmes respectively [3, 29]. For 19% of the 101 programmes it was reported that the merging of different units had been achieved, for 22% different organizations had been merged [29].

Meso-level barriers to providing integrated care

Several barriers for the provision of integrated care (at different levels) are mentioned in the literature and were also reported from the 101 programmes identified within the ICARE4EU project. Among these were a lack of a shared vision among managers and care professionals within and across care organizations; a lack of knowledge among care professionals about each other's expertise and organization; unequal power relationships; a lack of mutual trust; inflexible care delivery systems; a lack of financing for coordination activities; different opinions about the responsibilities of care professionals for the whole care trajectory of a patient; a lack of dedicated ICT-based tools (and digital competences for using them); and incompatible information systems.

Approaches to facilitate patient-centred integrated care by reforms at the macro level of the health and social care system

Education and professional training

The education and basic training of professionals in health and social care needs to be adapted, as current curricula draw too little attention to the care of multimorbidity patients as well as to working in teams, coordinating care across sectors and communication skills. Besides adaptations in basic training, periodic training of all professionals working in care organizations providing integrated care is needed to prepare them for the particular challenges related

to working with multimorbidity patients [66]. Previous research suggested that additional training for professionals working with multimorbidity patients should include opportunities to learn – for example – communication skills to promote team work, how to integrate different treatment plans, patient-centred approaches, polypharmacy and team management [67-70].

Policy and legislation

To enable successful implementation of integrated care for people with multimorbidity, policies and/or legislation need to address the following elements: new professional roles, privacy and data protection and financing. To shift the management of health and social services for people with multimorbidity towards more patient-centred integrated care, legislation may support investment in developing a multiprofessional workforce and the development of, as well as training in, new roles (e.g. care coordination) or professions (e.g. case managers) [71].

Collaboration between care professionals could be facilitated by implementing eHealth options to enhance information exchange between professionals. However, the exchange of patient information remains difficult in practice, partly because of privacy protection legislation. Revisions to the privacy and data protection legislation may be needed to enable multiple care professionals to share patient information. Legislation also needs to allow public reporting of outcomes at the level of care organizations [2, 72]. Legislation alone, however, will not be sufficient to implement a shared electronic health records system in a region or country; it also requires a basis of profound mutual trust among all the care professionals and patients involved, as was shown in the *Gesundes Kinzigtal* programme in Germany [64].

Policy reforms could include making integrated care programmes conduct regular comprehensive, rigorous and systematic evaluations to enable the clear measurement of effectiveness indicators and a systematic comparison of outcomes in order to inform the development of future integrated care programmes [4, 73].

Financing

Given that payment mechanisms have implications for the nature and quality of services provided and can generate incentives for payers/purchasers, providers and patients [74], they are of particular importance for fostering integrated care for people with multimorbidity. However, the findings of the ICARE4EU project suggest that currently specific payment mechanisms are rarely used to foster integrated care for people with multimorbidity. Policy-makers often assume that integrated funding will promote integrated

care, and will automatically lead to better health outcomes and lower costs [75]. Nevertheless, only 10 programmes identified in the ICARE4EU project use some form of bundled payment for either all or a share of funding for care organizations. The size of the payment is mostly based on fixed prices/agreements; in only four programmes was it reported that active negotiations took place between payers and care organizations.

Of the 101 identified programmes in the ICARE4EU project, 45 reported achieving cost savings, of which 16 shared the savings among care professionals. Savings were mainly attributed to (1) increased multiprofessional collaboration, (2) the use of new technologies and (3) the reduction of medication overtreatment and medicines optimization. Programme managers reported multiprofessional collaboration and working in multidisciplinary teams to have contributed most to the achieved cost savings [4].

To improve collaboration and stimulate improvements in quality of care, payments could be linked to certain indicators [76, 77]. An example of improving collaboration between care organizations can be found in the *Gesundes Kinzigtal* programme in Germany. To distribute responsibilities and enhance collaboration across disciplines and sectors, care organizations received incentives for better care coordination via the implementation of an additional information system tool to exchange information among care organizations [64].

System-related barriers to implement integrated care for patients with multimorbidity

With the introduction of integrated care for multimorbidity patients, professional roles shift and new care approaches are applied. This also implies that systems have to change. Traditional norms, values and work processes can become a barrier to the implementation of patient-centred integrated care [59, 66, 78, 79]. Excessive or unclear external legal requirements can also form a barrier to implementation of integrated care programmes for people with multimorbidity [80]. Bureaucratic barriers in the health and social care system(s) can hinder the successful implementation of newly developed integrated care projects, for example because the focus is on short-term interventions and time-limited contracts [81]. In addition, limited evidence on how integrated care for people with multimorbidity can best be achieved creates a barrier for programme managers to learn from the experience of other similar programmes. The lack of rigorous evaluations of integrated care programmes, including analyses of their success factors, therefore constitutes a barrier to further development and implementation of integrated care for people with complex health and social care needs [82, 83].

Discussion

Findings of the ICARE4EU project show that there is unexploited potential to improve care for people with multimorbidity.

Policy implications at the level of care organizations

Customizing care to the various and comprehensive needs of people with multimorbidity and supporting patients and informal carers to actively engage in the care process require policies and strategies at the level of care organizations. Policies and strategies are also needed to improve care coordination and collaboration at a local or regional level.

Vision development

Policies and strategies that care organizations could apply to improve care for people with multimorbidity need to be based on a clear conceptual and strategic vision of patient-centredness, shared by both the management and all care professionals involved. The adoption of such a shared vision can be seen as an essential first step, because it guides the following steps in policy development and the implementation of interventions. The involvement of patient representatives in the development of a shared vision, in addition to managers and care professionals of different disciplines would build integration and cooperation from the very beginning of the process.

Training for care professionals

Investing in the development of care professionals' knowledge and competencies to provide patient-centred integrated care may also be necessary. To better customize care to patients' needs, personal goals and care preferences, care professionals might need additional training in patient-centred communication techniques, such as motivational interviewing. In addition, care professionals responsible for the development and evaluation of patients' individual care plans and/or the regular comprehensive needs assessments, need to have the competencies to encourage and support patients and their informal carers to actively participate in decision-making and self-management. In order to stimulate the delivery of integrated care, care professionals could be offered training in working in multiprofessional and/or inter-organizational teams and in working with informal carers. Care professionals could also potentially benefit from additional training in using eHealth tools.

Access to decision support

Care professionals need access to relevant and up-to-date decision support to decide together with people with multimorbidity and their informal carers on the most appropriate medical treatment and care. Care organizations could implement decision support systems that highlight potentially appropriate treatment options for individual patients by matching relevant clinical recommendations and best practices with the complex profile of their multimorbidity patients.

Individualized care planning

The implementation of individualized care planning, including regular comprehensive needs assessments for all patients or clients with multimorbidity, is also needed. This requires specific competencies among care professionals, but other interventions may be necessary as well. For example, the delivery system of an organization may need to be adapted allowing patient consultations of a more flexible duration: longer visits to develop and evaluate individual care plans, shorter visits for follow-up and/or e-visits in between. Moreover, to facilitate implementation, patients' individual care plans could be integrated into their electronic health records to minimize the administrative burden and be sure that care professionals have access to all relevant data at any time. For this purpose, all involved care professionals would need to have access to all the relevant health information of a patient, including information from other care professionals or organizations involved in their care. For allowing electronic health information exchange, legislation may need to be revised.

Support for patients and informal carers

Care organizations need to support patients with multimorbidity, and often also their informal carers, in improving their knowledge and skills and encouraging them to actively participate in decision-making and self-management. Professionals providing medical or social care are the primary resources for this support, but patients may benefit from additional support, such as informational leaflets, face-to-face or online support groups moderated by patient experts, nurses or psychologists, patient portals, etc. Care organizations may need to offer different support materials, interventions or tools for different subgroups of patients, depending on the patients' disease patterns and complexity, but also on their personal goals, resources and care preferences. Special attention should be paid to patients with low health literacy and patients from minority ethnic groups who may have additional requirements. Older patients (75+) may also need specific support, as they often have multimorbidity as well as a declining functional status and support network. They may also need assistance in using supportive eHealth tools.

Care organizations could seek available support at a national, regional or local level. Cooperation with local or regional patient organizations or informal carers or volunteer groups may also be useful for this purpose. An online overview or toolbox containing information about existing support in the region, which can be easily accessed, may be helpful. In considering the development of an online overview or toolbox, continuous updating and quality control should be taken into account.

Redesign of the care delivery process

Care organizations need to redesign their processes of care delivery to people with multimorbidity starting from a patient-centred perspective resulting from shared vision development. For this purpose, care pathways could be developed, preferably in collaboration with other care

organizations and sectors. Target group segmentation, based on patients' disease patterns and complexity as well as patients' resources for managing their condition(s) may be useful to guide the development of a coherent set of basic care pathways. To develop and implement such care pathways, care organizations need to allocate sufficient staff (expertise, time) and other resources (e.g. finances, ICT capacity). Furthermore, new care professions or roles may be needed, such as care coordinators, trusted care professionals and case manager(s), to improve the care delivery process for people with multimorbidity. Care organizations need to assign these specific roles to care professionals trained for these roles and/or appoint additional staff and determine new function profiles.

To improve continuity of care across care organizations or sectors and/or develop common care pathways, care organizations could start by identifying potential partners at a local or regional level (including patient groups, informal carer groups and volunteer groups). As a second step, mutual knowledge and trust need to be created, for example by organizing regular face-to-face meetings. When organizations decide to collaborate in the development and implementation of a care pathway, formal agreements need to be made regarding each partner's contribution to the care for a specific target group. To enhance coordination of care and collaboration between care organizations, the linking of same-level professionals in different care organizations may be considered, as this might prevent unequal power relationships. Another way in which care organizations could facilitate care coordination and multiprofessional or inter-organizational collaboration is by implementing digital communication systems, which make it easier to keep partners informed and organize online meetings.

Policy implications at the macro level of national or regional health systems

Customizing care in relation to the medical needs, personal goals and care preferences of people with multimorbidity also requires policies and strategies at the level of the health and social care system(s) of countries or regions. Although awareness of the need to provide better care to people with multimorbidity has increased, it has not yet resulted in comprehensive multimorbidity policies at a national or regional level in most countries [29].

Vision development

As detailed in [1], developing a strategic vision of patient-centredness with all national or regional stakeholders in health and social care might be a first step towards improving the care for people with multimorbidity. This vision could be disseminated by supporting local, regional or national initiatives directed at enhancing patient-centred integrated care for those with multimorbidity and by public commitment to improvements in this area.

Adaptation of curricula for care professions

At a national level, revisions of the undergraduate and graduate curricula for health professionals and social workers are needed. More awareness of multimorbidity and

knowledge of how somatic diseases and/or psychiatric disorders interact are important for all care professionals, each from their own professional perspective. Moreover, communication skills and other professional competencies needed in multimorbidity care, such as multiprofessional and inter-sectoral collaboration competences, can be improved by basic training. A holistic view of people with multimorbidity, an ability to share patient information and care knowledge across professional and organizational boundaries, and ability to work in multidisciplinary teams will be core competences of all future care professionals. Thus initiatives to promote skill-mix orientation in education and curriculum planning are needed. In addition, continuous education programmes for new professional roles, such as care coordinators, or functions, such as care managers, are required. At European Union (EU) level, policy-makers could emphasize the importance of professional development to improve care for EU citizens with multiple chronic conditions as part of the European Commission's policy to promote continuous professional development of the health workforce.

Decision support

Strengthening the evidence base regarding the effectiveness of medical treatments and care for multimorbidity will be needed to improve health outcomes in patients with multiple chronic conditions and to provide decision support for care professionals. Efforts to develop national multidisciplinary guidelines for the care of patients with specific combinations of prevalent chronic diseases or disabilities need to be stimulated as well as integration of current guidelines for single diseases and the development of interaction matrices or guidelines.

Together with guideline development, the use of electronic decision support systems could be facilitated. The adoption and implementation of decision support systems could significantly improve the clinical decision-making process and the development of appropriate individualized care plans, based on available evidence. To develop good sustainable databases and intelligent systems that are able to match patients' health data with possible treatments, a strong partnership between care organizations and professionals, research institutes and IT companies is required. Decision support systems need to be integrated into clinical information systems to be used by multiple care professionals. Regional and national policy-makers could establish technical and clinical standards for decision support systems and promote their adoption by care professionals in primary, hospital and long-term care.

Adaptation of quality and financing systems

To provide incentives for better quality of care, innovative payment/incentive methods may be used, in addition to pay for performance (P4P) or more traditional payment methods (e.g. salaries, budgets, capitation, diagnosis-related groups [DRGs] and fee-for-service). Innovative payment/incentive methods include: pay for coordination (PFC), bundled payments, and shared-savings models, or various combinations of these. P4P can be used with extra payments for care

organizations achieving better quality of care, in terms of structure, process and outcome quality. In doing this, it is very important that such quality incentives are carefully selected and reflect the patient perspective. Additional structure and process indicators that relate to the interpretation of new professional functions and roles, such as care coordinators or case managers, may also be included. For outcome indicators, both patient-relevant outcomes and clinical outcomes need to be taken into account. Care organizations may receive a documentation bonus to make quality of care for people with multimorbidity more measurable and transparent.

To foster the development of integrated care programmes for people with multimorbidity, policy-makers could provide funding mechanisms that guarantee short- and longer-term use or the prospect of rapid inclusion in the usual care system and access to its funding. This would give stakeholders financial planning security. Furthermore, reforms could introduce start-up funding for innovative programmes focusing on aspects with particular relevance for people with multimorbidity, such as improved polypharmacy management and drug safety programmes, or comprehensive needs assessments and individualized care planning.

Innovation and research

In general, research on the implementation and effectiveness of patient-centred integrated care for people with multimorbidity is scarce. European countries, but also the

European Commission, could promote innovation and research to improve patient-centred integrated care targeting patients with multimorbidity and/or other comprehensive or complex needs. Innovative approaches at a local or regional level may be stimulated by programming and funding, which allows them to ensure that conditions encourage the use of validated patient-relevant outcome measures; to promote collaboration between innovators, patient representatives/organizations and researchers; and to guarantee solid process and outcome evaluation, including economic evaluation (in particular, cost–utility analyses, taking into account patient values regarding their quality of life). In addition, innovative research at a national or EU level that generates evidence for specific interventions among people with multimorbidity may be supported, as well as research and strategies to support the standardization of valid measuring instruments for needs assessment and patient target group segmentation.

Legislation

To shift the management of health and social services for people with multimorbidity towards a more patient-centred and integrated approach, legislation would need to support investment in developing a sufficiently large and well-trained workforce to meet the comprehensive needs of the increasing numbers of multimorbidity cases in European countries. Revisions to the privacy and data protection legislation may also be needed to enable multiple care professionals to share patient information.

Conclusions

The transition from a disease-centred care approach, to a patient-centred care approach is ongoing, but appears to be complex in general and particularly in the context of multimorbidity care. Such a complex change, which requires new ways of thinking and acting among policy-makers, care organizations and care professionals, as well as patients and informal carers, can only be achieved step by step. Research is needed to demonstrate which elements of patient-centred integrated care for people with multimorbidity can be generally applied, and which elements need tailored implementation. Extensive evaluations of current and future programmes are therefore of the utmost importance, because these will provide insights into what does and what does not work. Care innovation is driven by people who are motivated to innovate, regardless of the many barriers to change. European regions or countries could encourage innovators, because by stimulating their work, patient-centred integrated care for people with multimorbidity can be achieved.

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Appendix

Selection of innovative approaches to integrated care for people with multimorbidity in European countries in the ICARE4EU project

In 2014, data on innovative care approaches at a national, regional or local level were collected via country expert organizations in 31 European countries. These organizations were asked to search for and report on all integrated care programmes that focus on multimorbidity within their country. The term “programmes” refers to initiatives that (aim to) put integrated care for people with multimorbidity into practice. Initially, 178 programmes were identified by the country experts. Based on pre-determined selection criteria, the ICARE4EU project partners considered 101 ongoing programmes, in 24 countries, to be eligible for inclusion in the database. Via the country experts, an online questionnaire, available in 11 languages, was provided to managers of the 101 selected programmes to collect detailed programme characteristics and outcomes.

Next, these 101 programmes were evaluated by the project team. Each programme was scored in five dimensions: a general score (assessing general aspects such as its evaluation design, perceived sustainability and transferability) and four scores that provided an indication of its level of (1) patient-centredness, (2) integration of care, (3) use of eHealth technologies and (4) innovativeness in financing mechanisms for integrated care services as these aspects had been selected by the project team as different study perspectives on multimorbidity care. Based on these scores, members of the project team built a long list of 25 programmes that had high scores. The second evaluation of these 25 programmes was based on the descriptive information gathered via the survey (e.g. the description of the aims of the programme, reported strengths and weaknesses) and any published evaluation reports. This resulted in a short list of so-called “high potential” programmes. To decide whether or not to select a programme from this list for further study, the project team checked with the country expert and/or verified information by contacting the programme coordinator. In this way, eight programmes were selected for a site visit. The eight programmes visited were operational in Belgium, Bulgaria, Cyprus, Denmark, Germany, Finland, the Netherlands and Spain. The results of these visits are described in eight case reports published on the ICARE4EU website (www.icare4eu.org).

Selection criteria

Programmes were considered for inclusion in the ICARE4EU project if they met the following criteria:

- They should be aimed at a patient target group consisting of people aged 18 and older, with two or more medically (i.e. somatic, psychiatric) diagnosed chronic (not fully curable) or long lasting (at least six months) diseases, of which at least one has a (primarily) somatic/physical nature.
- They involve cooperation between at least two services (these services may be part of the same organization, for example services within a hospital, or may be part of different organizations, for example between medical care and social care).
- They have some formal status/formalized cooperation (any form).
- They will be or have been evaluated.
- They are currently running (2014), or finished less than 24 months ago, or start within the next 12 months.

ICARE4EU Policy Briefs

22. *How to strengthen patient-centredness in caring for people with multimorbidity in Europe?* Iris van der Heide, Sanne P Snoeijs, Wienke GW Boerma, François GW Schellevis, Mieke P Rijken. On behalf of the ICARE4EU consortium
23. *How to improve care for people with multimorbidity in Europe?* Mieke Rijken, Verena Struckmann, Iris van der Heide, Anneli Hujala, Francesco Barbabella, Ewout van Ginneken, François Schellevis. On behalf of the ICARE4EU consortium
24. *How to strengthen financing mechanisms to promote care for people with multimorbidity in Europe?* Verena Struckmann, Wilm Quentin, Reinhard Busse, Ewout van Ginneken. On behalf of the ICARE4EU consortium
25. *How can eHealth improve care for people with multimorbidity in Europe?* Francesco Barbabella, Maria Gabriella Melchiorre, Sabrina Quattrini, Roberta Papa, Giovanni Lamura. On behalf of the ICARE4EU consortium
26. *How to support integration to promote care for people with multimorbidity in Europe?* Anneli Hujala, Helena Taskinen, Sari Rissanen. On behalf of the ICARE4EU consortium

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