

POLICY BRIEF 22

# How to strengthen patient-centredness in caring for people with multimorbidity in Europe?

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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.

## Contents

	page
Key terms / Key messages	7
Executive summary	9
Policy Brief	11
Introduction	11
Findings	13
Discussion	21
Conclusions	23
References	25
Appendix 1	27
Appendix 2	28

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**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](http://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 (this policy brief), use of eHealth technology [1], integration [2] and financing systems [3]. A final policy brief [4] 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.

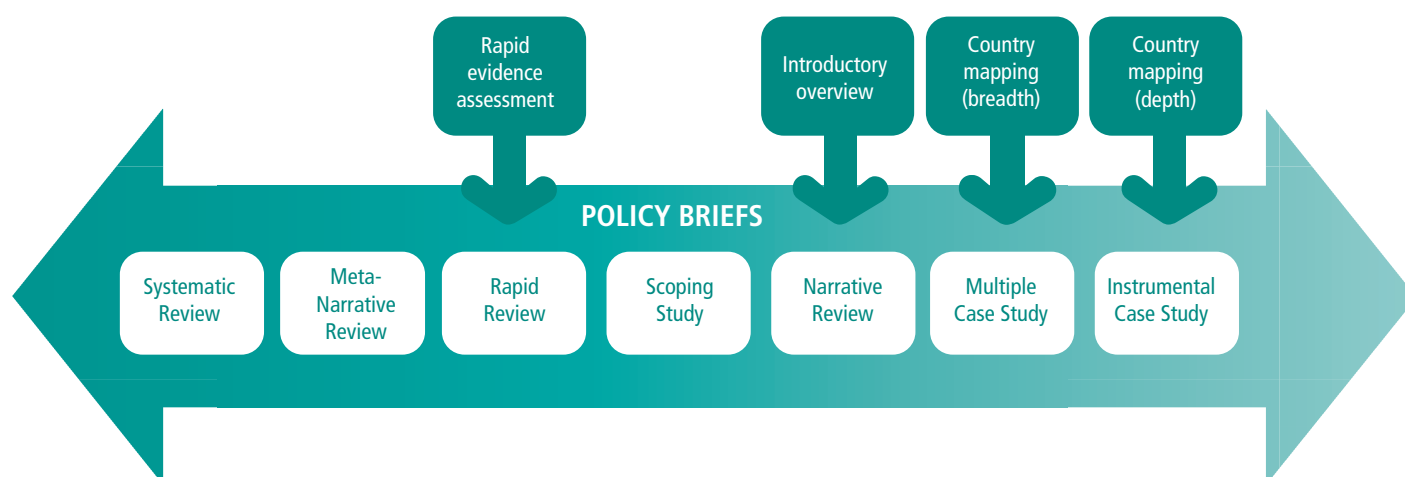
There are two main 'categories' of briefs that can be distinguished by method and further 'sub-sets' of briefs that can be mapped along a spectrum:

- **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

<b>EU</b>	European Union
<b>GP</b>	General practitioner
<b>ICARE4EU</b>	Innovating care for people with multiple chronic conditions in Europe
<b>INCA</b>	Integrated Care
<b>POTKU</b>	Potilas kuljettajan paikalle (Putting the Patient in the Driver's Seat)
<b>WHO</b>	World Health Organization

## Boxes and tables

### Boxes

<b>Box 1:</b> What is patient-centred care?	11
<b>Box 2:</b> What is integrated care?	11
<b>Box 3:</b> Methods	12
<b>Box 4:</b> The use of individualized care plans in the POTKU project	17
<b>Box 5:</b> The use of patient profiles to customize care in the POTKU project	18
<b>Box 6:</b> Integration of care in the Clinic Silkeborg programme	18
<b>Box 7:</b> Care coordination in the INCA model	19

### Tables

<b>Table 1:</b> Key elements of patient-centred care for people with multimorbidity	12
<b>Table 2:</b> (Potential) benefits of patient-centred care	14
<b>Table 3:</b> Strategies and barriers for providing patient-centred care for people with multimorbidity	15-16
<b>Table A:</b> Search strategies used in PubMed	27





## Key terms

- **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.
- **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.

## Key messages

- Making care focus on patients is a way of overcoming the fragmentation that results from the "disease orientation" of Europe's health systems, which still tend to organize around single medical specialties.
- Patient-centredness increases patient satisfaction and counters the problems associated with fragmented care, such as contradictory medical advice, over prescribing, over hospitalization and unresponsiveness.
- Patient-centredness requires a coordinated approach to the organization and delivery of care (and works well with integrated care initiatives).
- Innovative patient-centred programmes have often been grassroots initiatives that have come about despite, not because of, national regulations.
- Policy makers can foster innovation and effective collaboration by creating a supportive policy, regulatory and financial environment.
- Policy makers need to address blocks to patient-centeredness at the micro, meso and macro levels and can do this by:
  - Providing training for patients and professionals and making health information accessible including through eHealth tools (micro or individual level action)
  - Developing a shared vision of patient-centredness and assigning responsibility for coordination and for fostering links between sectors (meso or organization level action)
  - Ensuring monitoring and quality measurement reflect expectations and by tackling legislative and regulatory blocks to patient centredness (macro or system level initiatives).
- Decision makers might also consider other evidence informed measures including:
  - 'Care coordinator' roles – creating focal points for people with multimorbidity
  - Patient-relevant outcome indicators – ensuring performance measurement systems assess more than clinical or functional outcomes
  - Actively promoting collaboration with social care, patient organizations and carers
  - Shaping process and outcome evaluations so that the review of new approaches to patient-centred care identifies the contextual factors that contribute to their success and impact.



## Executive summary

### The policy issue: patient-centred care for people with multimorbidity

Currently, an estimated 50 million people in Europe live with multiple chronic conditions (multimorbidity) and this number is expected to increase in the next decade. Multimorbidity profoundly impacts the lives of individuals in terms of physical, psychological and social well-being. The comprehensive care needs of people with multimorbidity are a major challenge for European health systems, which tend to be organized around single medical specialties. Patient-centred care is considered more responsive to the needs of people with multimorbidity than disease-orientated care. Patient-centred care is respectful of and responsive to individual preferences, needs and values, and ensures that patient values guide all clinical decisions. Therefore, patients should be actively involved in the decision-making process concerning their care and treatment. Several studies suggest that providing patient-centred care may improve clinical outcomes, patient satisfaction and self-management. Less is known about the extent to which patient-centred care improves patient-relevant outcomes as formulated by patients themselves. This policy brief provides insight into how patient-centred care is currently incorporated in innovative care programmes in Europe for people with multimorbidity. It also outlines the types of strategy and policy that could support patient-centred care. The aim of this policy brief is to facilitate policy-makers in the development of policies directed at patient-centred care for people with multimorbidity.

### Strategies

Strategies to support patient-centred care for people with multimorbidity relate to: customizing care to patients' needs, values, preferences and resources; involving informal carers as co-care providers and co-clients; the integration and coordination of care between care sectors and professional disciplines. Strategies can be formulated on three levels of care delivery (micro, meso and macro). These levels are intertwined because, in order to establish change at a certain level, actions at other levels may also be needed. The following strategies to strengthen patient-centred care for people with multimorbidity have been identified:

#### Care professional level (micro-level)

- Negotiation of potentially achievable health goals with the patient, across dimensions such as symptoms, functional status and social role functions.
- Discussing benefits and harms of treatment options with the patient as well as with informal carers in order to reach these goals.
- Actively encouraging the involvement of patients (and/or their important others) in decision-making about care and treatment options.

- Basing care and treatment decisions on a combination of patient goals and preferences, as well as resources and risk factors.
- Discussing what is needed to support self-management activities with the patient as well as with informal carers.
- Monitoring whether the patient's personal situation or goals have changed.
- Providing encouragement and advocacy to help the patient meet agreed goals.
- Making use of individualized care plans based on patient goals and needs in collaboration with other care professionals.
- Providing information, tailored to the patient's health literacy skills and information needs.

#### Organization (meso-level)

- Developing a conceptual and strategic vision on patient-centredness that is clearly defined and operationalized.
- Providing training for professionals in patient-centred care (including patient-centred communication).
- Providing accessible health care information for patients and informal carers.
- Providing electronic patient records that can be accessed by all care professionals involved.
- Providing support (including eHealth tools) for self-management and for communication between health care professionals.
- Assigning a person to be responsible for the coordination and adjustment of care between care professionals ('care coordinator') and assigning a person as the primary point of contact for the patient ('trusted doctor' or 'trusted nurse').
- Facilitating the use of individualized care plans (e.g. making time for providers to set up a care plan and IT support).
- Establishing collaboration with care professionals outside the health care sector.
- Facilitating flexible appointments adapted to the needs and preferences of patients.
- Designing a physical environment that is supportive to patients, informal carers and staff.
- Creating awareness of patient-centred care among managers and professional staff, and developing a shared vision on patient-centredness.

### System (macro-level)

- Facilitating a quality system and a financial incentive system for care that takes patient-relevant outcomes into account.
- Investing in a strong primary care system that facilitates patient-centred care.
- Enabling policy development, legislation and regulation that transcends sectors, in order to stimulate collaboration and coordination between health and social care.

### Patient-centredness in innovative care programmes in Europe

The ICARE4EU project identified 101 programmes that aimed to put integrated care for people with multimorbidity into practice, which all included elements of patient-centredness. Our inventory found that certain elements of patient-centred care, such as the involvement of patients in goal-setting and shared decision-making, and the use of individualized care plans, are not generally applied. The coordination of care and multidisciplinary collaboration are also important elements of patient-centred care, because this could, for example, reduce the risk of adverse effects of polypharmacy and lower the frequency of patient visits to care professionals. It could also enhance the tailoring of treatments and care to achieve disease-transcending and patient-relevant health goals. Among the selected innovative integrated care programmes, the improvement of care coordination and multidisciplinary collaboration is often the main objective. However, collaborations are more often established within the health care sector (although collaboration between primary and secondary care also remains difficult to establish) and less so with, for example, social care organizations, patient organizations and nursing homes. The involvement of informal carers (as both co-clients and co-care providers) is also limited. Nevertheless, the innovative care programmes provide inspiration for policy and practice; for example, with respect to the use of

patient profiles to determine patient needs and tailor care. Current innovative programmes are mainly organized bottom-up, in spite of rather than as a result of national regulations. The initiatives show that a supportive environment is essential for the organization of sustainable changes in the way health care is organized for people with multiple chronic conditions.

### Policy implications

To achieve better quality care for people with multiple chronic conditions, as well as greater efficiency in the use of resources, patient-centred care should be supported by policies. (Local/regional/national) governments looking for ways to support patient-centred care for people with multimorbidity could consider:

- The performance of specific roles by care professionals, such as that of care coordinator for multimorbidity patients, should be considered as an indicator of health care performance.
- Patient-relevant outcomes need to be included as indicators of health care performance.
- Adaptations at the national or regional health system level can facilitate collaboration across and within sectors in order to better meet the comprehensive needs of people with multimorbidity.
- Innovative initiatives that aim to establish patient-centred care for people with multimorbidity at a local, regional or national level can be supported, along with process and outcome evaluations of these initiatives.

In order to better support the development of patient-centred care policies, it is important that current and new initiatives are evaluated. This is essential for driving changes in health care organization and delivery in European countries. In addition, it is important that, besides the development of policies, care organizations and care professionals maintain or start with the development of practices that enhance patient-centred care for people with multimorbidity.

## Policy brief

### Introduction

#### Box 1: What is patient-centred care?

There are many definitions of patient-centred care but, in essence, patient-centred care is care that is respectful of and responsive to individual patients' preferences, needs and values, and ensures that patient values guide all clinical decisions [5,6].

The term 'patient-centredness' 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: What is integrated care?

Integrated care is patient-centred, proactive and well-coordinated care, making use of innovative technologies to support patients' self-management and improving multidisciplinary collaboration between care-givers [7,8].

The disease-specific way in which care is organized in European countries is not responsive to the needs of those who have multiple chronic conditions at the same time (multimorbidity). An estimated 50 million people in Europe have multimorbidity and this number is expected to increase in the future because of improvements in the early detection of chronic diseases and the development of increasingly effective treatments leading to higher survival rates [9], besides ageing, lifestyle and other factors. European health care systems are not responsive to the care needs of people with multiple chronic conditions, because care is organized and delivered in a fragmented and disease-orientated way. As a consequence, people with multimorbidity often receive incomplete, inefficient and ineffective care, which could lead to their receiving conflicting medical advice and to preventable hospitalizations [10–12]. Given the increasing number of people with multimorbidity, the discrepancy between the care needs of these patients and the way in which their care is organized is becoming increasingly visible.

People with multimorbidity need care that is patient-centred (see Box 1). Patient-centred care is intertwined with integrated care (see Box 2). Establishing integrated care is a global strategy of the World Health Organization (WHO) [13,14], because it is an effective way of improving the quality of care while also making more efficient use of resources. This is especially the case for those who have multiple chronic conditions [15].

This policy brief focuses on how patient-centred care for people with multimorbidity can be strengthened and supported by policy and practice. Policy-makers who aim to put patient-centred care for people with multimorbidity on the agenda, as well as those who aim to further develop integrated care for them, can use this brief to support their work.

### The policy issue: how to strengthen patient-centred care for people with multimorbidity

European countries recognize the challenge of providing care that meets the needs of people with multimorbidity and are searching for ways to make their health care systems more responsive to their needs. The adoption of a patient-centred approach is considered by many to be key to providing good quality care for people with multimorbidity [5,16], because it takes the needs, preferences and values of patients as a starting point in deciding on treatments and care, as opposed to desired disease-specific health outcomes. The latter are currently an important driver for treatment and care decisions, but are often not relevant or feasible for people with multimorbidity. Although patient-centred care is recognized as a precondition for good quality care, various challenges occur when giving shape to patient-centred care for people with multimorbidity.

#### Technical challenges include:

- Assessing patient-relevant outcomes to guide clinical decisions.
- Tailoring care to the needs of patients.
- Establishing structural collaborations between care professionals across and within sectors.
- Establishing structural coordination of care from various care professionals.
- Information-sharing among care professionals and between care professionals and patients and informal carers.

The technical challenges for collaboration between care professionals and the coordination of care are important, because people with multimorbidity often need care from multiple providers and various disciplines. Good collaboration between care professionals might reduce contradictory treatment and care decisions. Furthermore, it might enhance treatment and care decisions in line with the patient's health goals while taking the consequences of other conditions and the treatment of these into account. Good coordination of care is important for making care more efficient and less burdensome for patients. However, besides technical challenges, there are policy challenges in the organization of patient-centred care for people with multimorbidity.

#### Policy challenges include:

- Knowledge gaps in effective strategies to establish patient-centred care.
- Lack of clearly defined measurable goals for patient-centred care.
- Knowledge gaps in effective financing methods that may facilitate the integration of care or collaboration between different disciplines and sectors.
- Lack of management support to establish changes in care organizations.

In order to facilitate patient-centred care, policies should be in place that support changes at various levels of the care delivery process [5]. However, the development of evidence-informed policies to strengthen patient-centred care is difficult, because patient-centredness is a broad and multidimensional concept and has been operationalized in different ways. This policy brief therefore addresses the following questions:

- 1. *What are the key elements of patient-centred care for people with multimorbidity?*
- 2. *What are the benefits of patient-centred care for people with multimorbidity?*
- 3. *How can key elements of patient-centred care for people with multimorbidity be addressed in strategies to strengthen patient-centred care?*

**Box 3: Methods**

For policy-making, insights from practice and from scientific literature are both useful and provide information on health care changes that can lead to more patient-centred care [15]. Therefore, this policy brief also uses observations collected as part of the ICARE4EU project. It includes a rapid review of the research literature with results from a survey (see Appendices 1 and 2). The literature review focused on publications about patient-centred care in general as well as patient-centredness in the context of chronic care, but special attention was paid to publications that reflected on how patient-centredness is given shape in care for people with multimorbidity. However, studies on this topic were found to be scarce. Appendix I provides more information on the search strategy.

Under the ICARE4EU project, information was gathered on 101 innovative care programmes in 24 European countries. Eight of these programmes were considered to be especially innovative and were therefore visited to obtain a more in-depth understanding of their particular characteristics. Appendix 2 provides detailed information on the research into innovative care practices in European countries.

**Findings**

This policy brief provides insight into key elements of patient-centred care for people with multimorbidity, the benefits of patient-centred care and possible strategies to support patient-centred care.

**Key elements of patient-centred care for people with multimorbidity**

Although patient-centred care is relevant for all patients, it is especially relevant for people with multimorbidity. Furthermore, when taking multimorbidity care as the point of departure, patient-centred care may actually go beyond what is generally discussed in the scientific literature, which is most often concerned with single-diseases and short-term care. The key elements of patient-centred care for people with multimorbidity are summarized in Table 1 [5,17–24]. These elements can be grouped into three categories: 1) those related to responding to patients’ preferences, needs, values and resources; 2) those related to the involvement of informal carers; and 3) those related to the integration and coordination of care services.

**1. Customizing care to the needs, preferences, values and resources of patients**

Customizing care to the needs, preferences, values and resources of patients is central to a patient-centred care approach [17,25]. In current health care systems in Europe, the disease-orientated (or ‘what is the matter’) approach is most often the point of departure when care is provided. Moreover, evidence-based practice, often directed at improving clinical outcomes, is the usual answer with this approach [26]. However, this type of care will not always lead to the treatments and outcomes that are most responsive to the

**Table 1: Key elements of patient-centred care for people with multimorbidity**

**Customizing care to the needs, preferences, values and resources of patients**

- Together, care professionals and patients strive for improvements in patient-relevant outcomes.
- Care professionals acknowledge the patient’s expertise in his/her own life.
- Care professionals recognize ‘preference-sensitive’ decisions.
- Care professionals actively involve patients and informal carers in the process of decision-making concerning treatment and care, by clearly communicating potential benefits and risks, and helping patients to clarify their most valued health goals in order to prioritize care.
- Care professionals elicit the patient’s treatment preferences after sufficiently informing the patient.
- Care professionals take the patient’s risk profile into account when offering treatment options.
- Care professionals provide emotional support for patients and informal carers.

**Involving informal carers as co-clients and co-care providers**

- Informal carers are actively involved in the care process as co-clients.
- Informal carers are actively involved in the care process as co-care providers.

**Integration and coordination of care**

- Care from various providers, disciplines and sectors is integrated and coordinated (care professionals provide advocacy for the patient in the health care system and assure continuity).
- Patients receive self-management support adapted to their preferences and competencies.



needs of people with multimorbidity. For people with multimorbidity, the focus on evidence-based practice and on clinical outcomes might not be responsive to their needs for two reasons: 1) the evidence that certain treatment options are effective in patients with multimorbidity is often lacking; 2) clinical outcomes might be irrelevant or less relevant for these patients.

The challenges of using single-disease, evidence-based guidelines for people with multimorbidity, a population that has been rarely represented in the efficacy trials underlying guideline recommendations and is vulnerable to the risks of polypharmacy, are increasingly being recognized [27–29]. Clinical practice guidelines that focus on the management of a single disease can be impractical, irrelevant or even harmful for people with multimorbidity [30]. Moreover, patients might attach great value to the ability to walk pain-free or to be able to get dressed without help, but little value to clinical outcomes, such as having good average blood glucose levels. In other words, the outcomes of care that people with multimorbidity consider to be relevant may be very different from the outcomes considered to be relevant by care professionals. Therefore, the ‘what matters to you’ (or goal-orientated) approach is a more suitable point of departure than the ‘what is the matter’ approach in care for people with multimorbidity, because it transcends specific diseases and focuses on the needs and goals of individuals (patient-relevant outcomes) rather than clinical outcomes. Patient-relevant or goal-orientated patient care outcomes can include physical functioning, severity of symptoms, quality of life, role and social functioning, and emotional status [31,32].

Patient-centred care for people with multimorbidity therefore requires a shift in thinking and acting in terms of clinical outcomes to thinking and acting in terms of patient-relevant outcomes. The outcomes that patients want to achieve should guide decisions on treatments. When patient-relevant outcomes have been identified, treatment options to achieve these outcomes can be discussed [33]. Patients with multimorbidity are likely to be confronted with ‘preference-sensitive’ decisions, which include therapy that may improve one condition but make another worse or may lead to long-term benefits but to short-term harm [20,30]. These ‘preference-sensitive’ decision moments should be recognized by care professionals [30] and the benefits and harms of treatment options should be made explicit to make sure that patients understand the balance between the potential benefits and harms of treatments [30]. After sufficiently informing patients, their preferences with respect to treatment and care options can be assessed and could, in combination with clinical feasibility, inform treatment choices [30,34]. Explicitly inviting patients (and/or their informal carers) to participate in the decision-making process and encouraging them to express their goals and concerns, as well as to ask questions concerning their care and treatment, are all important elements of patient-centred care [35].

Additionally, to customize care to the needs of patients, it is not only important to take the patients’ preferred outcomes

and treatment options into account when making treatment decisions; it is also important to take into account their resources, as well as their health and personal histories [13,25]. Patients’ resources include, for example, their self-efficacy, literacy skills and options for social support. Patients with strong self-efficacy and a strong social network might be more able to perform self-management tasks than those with low self-efficacy and a weak social network. These patients might need more support from care professionals.

## **2. Involving informal carers as co-clients and co-care providers**

Many patients with multimorbidity receive support from their family or friends (informal carers) in their care, which mainly occurs outside the health care setting. When a person becomes chronically ill, this not only affects their own life but also that of their family and friends [36]. Often, the partner and/or children will support their loved one in coping with his or her chronic conditions, fulfilling the role of caregiver [37]. At the same time, the chronic conditions can impact on relationships between the person with the conditions and their partner and/or children. It can be burdensome for informal carers to take care of their loved ones on a long-term basis [37]. Furthermore, multimorbidity is common among elderly people and they frequently receive support from their elderly partners [38,39]. Care professionals should be aware of these issues and should recognize informal carers as a group with emotional support needs and care needs of their own. Informal carers have a double role as co-care provider and co-client. They stand between the needs, preferences and values of the patient on the one hand and the integration and coordination of care on the other. Informal carers need to be adequately informed, involved in treatment decision-making, given emotional support and involved in the coordination of care between various care professionals [37].

## **3. Integration and coordination of care**

People with multimorbidity often need care from professionals from various disciplines. Receiving care from different care professionals that are all working to their own disease-specific treatment plans can be burdensome for patients, because they have to follow different treatment regimens and may need to visit various specialists on a regular basis [27]. In some cases, it can even introduce health risks for patients when they receive conflicting treatments from different providers [27]. Collaboration between the various disciplines and care professionals, as well as good coordination of care, are therefore of great importance and key elements in patient-centred care for people with multimorbidity [40]. The creation of effective links between primary and specialist services is important to enable more effective diagnosis, faster referrals and smoother care transitions [14]. Coordination of care not only concerns coordination across care professionals but also the coordinating of care over time [41]; for example, through improved information flows and establishing long-term collaborations between providers [41].

People with multimorbidity may not need only health care but may also require social care, such as support at work or at home. Multimorbidity does not only impact a person's health but also affects their ability to function in society, including being in the workforce. This means that the social domain should also be part of the integration and coordination of care: care should be integrated across sectors. This could, for example, be done by including social workers as key members of primary care teams [2,14].

In order to coordinate care from multiple care professionals and disciplines, it may be effective to appoint one person as the care coordinator [41]. The general practitioner (GP) could take up this role or alternatively a new function could be created. The integration of care may require new functions that go beyond a single-disease focus [41].

### Benefits of patient-centred care for people with multimorbidity

Some perceive patient-centred care as an intrinsically good way of providing care, regardless of whether it achieves other instrumental or pragmatic goals, because it fulfils the obligation of health care professionals to place the interests of the patient above everything else [42]. Research on the effects of patient-centred care is scarce and, to our knowledge, not available in the context of multimorbidity. Nevertheless, studies on patient-centred care in general suggest that it has beneficial outcomes; for example, in terms of patient satisfaction with care, improved self-management and the more efficient use of resources [21,31,32]. There are also many other potential benefits described in the literature (see Table 2) [14,24].

**Table 2: (Potential) benefits of patient-centred care**

Group	Benefits	Supported by evidence?
Patients	<ul style="list-style-type: none"> <li>• Increased satisfaction with care</li> <li>• Increased well-being</li> <li>• Increased treatment adherence</li> <li>• Better self-management</li> <li>• Increased trust</li> <li>• May improve clinical outcomes</li> <li>• Reduced hospital readmissions and complications</li> <li>• Higher self-rated mental health</li> <li>• Less decisional regret</li> <li>• Improved functional outcomes identified as important by the patient (e.g. ability to get dressed without help)</li> <li>• Better relationship with care professionals</li> </ul>	Yes Yes Yes Yes Yes Yes Yes Yes No No No
Informal care-givers	<ul style="list-style-type: none"> <li>• Increased involvement in decision-making concerning care and treatment</li> <li>• Clear care tasks, which are formulated in dialogue with care professionals</li> <li>• Less insecurity due to the single care professional as contact person</li> <li>• Increased satisfaction with care</li> </ul>	No No No No
Health care professionals	<ul style="list-style-type: none"> <li>• Improved job satisfaction</li> <li>• Opportunities to learn new skills, such as working in a multidisciplinary team</li> <li>• Improved patient treatment adherence through the use of an individualized care plan</li> </ul>	No No No
Health care organizations	<ul style="list-style-type: none"> <li>• Reduced unnecessary use of care</li> <li>• Through collaboration, reduced risk of duplication of investment and services</li> </ul>	No No
Health care systems	<ul style="list-style-type: none"> <li>• Through better management and coordination of care, costs can be reduced due to the prevention of hospitalizations, reduced lengths of stay and better self-management support</li> </ul>	Yes

Source: Adapted from [14,21,24,31,32,43].



### Strategies to strengthen patient-centred care for people with multimorbidity

In this section, patient-centred care is translated into strategies, in part based on the WHO global strategy for integrated and people-centred care (2015) [13,14] and on insights from the review of international scientific literature [24,31,32,44–46]. Strategies are proposed on three levels, as described in Table 3: that of the care professional (micro-level), the organization (meso-level) and the system (macro-level). It is important to focus not only on the changes that can be made at the care professional level, because whether care professionals are able to provide high-quality care greatly depends on organizations and systems [24]. The three levels are intertwined, as strategies at a certain level often require actions on other levels; for example, in order for organizations to establish integration or coordination of care (meso-level), appropriate legal frameworks are often required (macro-level).

Strategies that are particularly important to support patient-centred care for people with multimorbidity include: firstly, using patient-relevant outcomes as the basis for treatment decisions; and, secondly, using patient-relevant outcomes as

indicators of health care performance. Namely, improvements in disease-specific outcomes are neither likely to be feasible nor relevant for this patient group. A third strategy that is especially important for people with multimorbidity is assigning to the patient a single contact person (e.g. a ‘trusted doctor’ or ‘trusted nurse’) to coordinate care from various providers. Finally, in order to support collaboration across disciplines and sectors (which is especially important for people with multimorbidity), policy, legislation and regulation that go beyond individual sectors need to be established [3].

The implementation of strategies can be hampered by various structural or individual barriers, which are also listed in Table 3. Apart from these barriers, country-specific characteristics can also affect the extent to which certain strategies can be implemented; for example, in countries with a strong primary care system, it might be easier to integrate and coordinate care, by having the GP as the central coordinating point for care professionals, than it would be in countries with a weak primary care system. Furthermore, some countries might have more resources to enable the implementation of strategies than others [47].

**Table 3: Strategies and barriers for providing patient-centred care for people with multimorbidity\***

Level	Strategies	Barriers
Care professional (micro-level)	<ul style="list-style-type: none"> <li>• Negotiation of potentially achievable health goals with the patient, across dimensions such as symptoms, functional status, social and role functions</li> <li>• Discussing benefits and harms of treatment options with the patient and informal carers in order to reach these goals</li> <li>• Actively encouraging the involvement of patients (and/or their important others) in decision-making about care and treatment options</li> <li>• Basing care and treatment decisions on a combination of the patient's goals and preferences, the patient's resources and any risk factors</li> <li>• Discussing what is needed to support patient self-management</li> <li>• Monitoring whether the patient's personal situation, goals or preferences have changed</li> <li>• Providing encouragement and advocacy to help the patient meet agreed goals</li> <li>• Making use of individualized care plans based on patient-relevant outcomes in collaboration with other care professionals</li> <li>• Providing information tailored to the patient's health literacy skills and information needs</li> </ul>	<ul style="list-style-type: none"> <li>• Patients may prefer not to make specific decisions, may not be capable of making decisions, or are not sufficiently well-informed to make decisions</li> <li>• Prioritizing care can be complex when multiple conditions are involved</li> <li>• The patient's situation may change, leading to uncertainty about whether certain care decisions remain the most suitable</li> <li>• The development of personalized care plans is time-consuming</li> <li>• Balancing evidence-based medicine with patient-centred care can be difficult</li> <li>• Care professionals are not used to working across disciplines</li> </ul>

*Continued on next page >*

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Level	Strategies	Barriers
Organization (meso-level)	<ul style="list-style-type: none"> <li>• Developing a conceptual and strategic vision of patient-centredness that is clearly defined and operationalized</li> <li>• Investing in the development of care professionals' competencies, e.g. providing training in patient-centred care provision (including patient-centred communication)</li> <li>• Developing accessible information sources for patients and informal carers</li> <li>• Providing electronic patient records with access for all care professionals involved</li> <li>• Providing support (including eHealth tools) for self-management and for communication between care professionals</li> <li>• Facilitating specific roles for care professionals, such as the role of care coordinator or trusted doctor/nurse (as the primary point of contact for patients), and using these as indicators of health care performance</li> <li>• Facilitating the use of individualized care plans (e.g. provide time for professionals to set up a care plan)</li> <li>• Establishing collaborations between care professionals from various disciplines or sectors</li> <li>• Facilitating flexible appointments (e.g. longer time slots or appointments for more than one patient)</li> <li>• Designing a physical environment that is supportive to patients, informal carers and staff</li> <li>• Creating awareness of patient-centred care among managers and professional staff, and developing a shared vision of patient-centredness</li> </ul>	<ul style="list-style-type: none"> <li>• National regulations for the use of electronic patient records and assuring patient confidentiality</li> <li>• Lack of financial and structural resources to support patient-centred care (e.g. case managers, self-management support, development of care plans)</li> <li>• Care professionals may not be skilled or motivated to provide patient-centred care</li> <li>• Difficulties in establishing collaborations between professionals and organizations due to, for example, the use of other systems and being subject to other regulations</li> <li>• No support from management due to a lack of shared vision on patient-centredness, a lack of insight into effective strategies to establish patient-centred care, or other reasons</li> <li>• Inadequate management of care processes: managers do not allocate enough staff resources and/or sufficiently qualified staff to provide patient-centred care</li> </ul>
System (macro-level)	<ul style="list-style-type: none"> <li>• Facilitating quality control and financial reward systems for care, which take into account patient-relevant outcomes</li> <li>• Investing in strengthening primary care, which can facilitate patient-centred care</li> <li>• Enabling policy development, legislation and regulation that transcends sectors, in order to stimulate collaboration and coordination between health and social care</li> </ul>	<ul style="list-style-type: none"> <li>• Patient-relevant outcomes may be more trivial than clinical outcomes</li> <li>• The way health care is organized may complicate the integration of services: decentralized health care systems provide more room for changes in health care delivery than systems that are centrally organized</li> <li>• Political and funding difficulties in formalizing relationships between different parts of government, especially when local authorities and health authorities cover different jurisdictions</li> <li>• It may be unclear who is responsible for the organization of patient-centred care and whether changes should be made bottom-up or top-down</li> </ul>

\* Source: Based on [2,13,24,31,32,41,44–46].

## Patient-centredness in innovative care programmes in Europe

An important finding of the ICARE4EU project is that there are currently few programmes in European countries that have been evaluated, so it is difficult to assess their impact. Furthermore, findings from the ICARE4EU project show that few national or regional policies or strategies are available to support patient-centred care for people with multimorbidity in European countries. Consequently, initiatives are currently being organized at the grassroots level.

### 1. Customizing care to the needs, preferences, values and resources of patients

Current programmes in European countries customize care to the needs, preferences and values of patients in various ways. The basis for providing patient-centred care is communication with patients and informal carers to assess their needs and preferences, and to discuss possible treatment options to reach their goals, while taking their personal resources into account.

#### *Assessment of needs, preferences and values*

Current innovative programmes use several tools to assess patients' needs, preferences and values and to involve them in decision-making about their treatment, care and preferred outcomes. These tools mainly comprise motivational interviewing and providing information leaflets. Other tools include: the use of narrative counselling techniques in order to understand patient needs; pre-treatment discussion sessions among treating doctors on how to motivate patients to participate in decision-making; assessing the knowledge of patients and their informal carers.

#### *Individualized care plans*

When the patient and their care professional have agreed their health goals, as well as care and treatment options, an individualized care plan can be used to record the decisions. Most of the selected innovative programmes included an individualized care plan for all patients, or for a specific group of patients (such as especially complex cases or vulnerable/frail patients). In the Belgian ADS project, priorities in the individualized care plan are being set by the patients themselves [48]. A second example in which a personalized care plan is used, is the Dutch INCA model [49]. In this model, treatment plans are developed with each individual patient, adapted to the patient's specific profile and personal preferences concerning not only the disease(s) he or she has but also taking into account health behaviours and psychological issues. Agreements between the physician and the patient are noted in the care plan. In the Finnish POTKU project, the patient's health status and self-management support needs are assessed during an appointment with a nurse and an individualized care plan is developed with this nurse (see Box 4) [50]. In this project, the use of the care plan was found to have a positive effect on patient satisfaction with care.

#### **Box 4: The use of individualized care plans in the POTKU project [50]**

In the Finnish POTKU project, the patient and the nurse jointly develop an individualized care plan, which is agreed by the physician in charge. The care plan is continuously evaluated and adapted according to the patient's needs. Furthermore, it is structured according to the following themes:

1. My needs (health-related problems identified by the patient with the support of a health professional).
2. My goals (What change in health status is aimed for? Which outcome of the jointly agreed treatment is sought?).
3. My measures (Which health services and planned patient measures are related to these goals?).
4. Follow-up and assessment (follow-up appointments to evaluate the implementation of the health care plan and its results).
5. Medication, diagnoses and contact person.

The programme also enables care professionals to check the quality of the developed health care plan by the use of a checklist [50].

#### *Taking patients' resources into account*

People with more resources, such as knowledge, skills and a strong social network, might need less support from care professionals than those who have fewer resources. Of course, patients' care needs also depend on their health status. Some innovative programmes pay specific attention to the needs of vulnerable subgroups, such as ethnic minorities, people with lower health literacy, people with mental disabilities, people who live in socially deprived areas or people from low income groups. Furthermore, some programmes pay specific attention to so-called 'complex cases', i.e. those patients who have extensive care needs because of severe morbidities and limited resources (e.g. limited social support).

A programme that was developed and implemented in the Valencia region of Spain adopted an approach based on the Kaiser's Stratification Risk Pyramid to define complex patients [51]. In identifying complex cases, the care professionals in this programme take various factors into account, including availability of family support and social and economic needs. The goals of tailoring care to the needs of complex cases are to improve the quality of care for these patients and to keep them in the community as long as possible. This approach of patient stratification according to complexity is similar to the approach of the Finnish POTKU project [50]. In the POTKU project, patients' resources are explicitly taken into account when customizing care to their needs, and various 'clientships' are developed that guide the care professional in arranging care (see Box 5).

**Box 5: The use of patient profiles to customize care in the POTKU project [50]**

In the Finnish POTKU project, care is customized according to patient profiles that are based on: 1) the complexity of the needed treatment; and 2) the resources patients have at their disposal to cope with their condition and their treatment (good/poor).

Combining these dimensions results in one of four clientships:

1. Self-management clientship (medical problem not complex, good resources).
2. Cooperation clientship (medical problem complex, good resources).
3. Community clientship (medical problem not complex, poor resources).
4. Network clientship (medical problem complex, poor resources).

This profile is drafted by the care professional in cooperation with the patient. Identifying the clientship type of a patient guides the care professional in specifying how the care should be arranged, e.g. who is responsible for the coordination of care and what kind of supportive tools can be offered to the patient. For example, in the case of self-management clientship, the tools might be health coaching, access to a health library and/or electronic contact; in the case of cooperation clientship, the tools could include a joint consultation (with multiple disciplines) and/or an electronic consultation; in the case of community clientship, there might be a visit to a nurse and/or peer support group; and in the case of network clientship, the tools might be input from a multiprofessional care team and/or involving informal carers.

**2. Involving informal carers as co-clients and co-care providers**

In almost half of the selected innovative care programmes, the involvement of informal carers was described as an objective. Recognizing the needs of informal carers is an important first step in taking them into account as co-clients. Informal carers are addressed as co-clients in, for example, the Belgian ADS project, which assesses the burden on the informal care-givers as part of the total needs assessment of the eligible patients [48]. At the same time, this programme involves informal carers as co-care providers, by including them in the discussion of individualized care plans, which include actively supportive activities for informal carers. The re-evaluation of the ability of informal carers to provide care is a point of attention in this project.

Furthermore, the programme from the Valencia region supports informal carers as co-care providers by offering them the possibility of direct contact with professionals to clarify daily care issues. In order for informal carers to be recognized and supported as co-care givers, a formal cooperation between informal and formal care-givers might be helpful. However, the selected innovative care programmes indicate that a formal cooperation between informal and formal care-givers is still infrequently established.

**3. Integration and coordination of care**

In order to provide good quality care (e.g. to avoid overlap in treatments and polypharmacy), integration of care from various disciplines and/or organizations is important. Findings from the ICARE4EU project concerning the integration and coordination of care are described in more detail in another policy brief in this series [2]. The following section therefore only addresses the key aspects of integration and coordination of care.

***Integration of care from multiple disciplines***

Improving the integration of different units within an organization was the main objective of most of the 101 selected innovative programmes, while improving the integration of different organizations was an important objective for almost half of the selected programmes. The merging of different units or different organizations remained difficult, however, and was established in less than a quarter of the 101 selected programmes. The 101 selected innovative programmes most often involved GPs and primary care practices. Care professionals outside the health sector, such as home helps and social workers, were still relatively infrequently involved. Organizations such as social care organizations, patient organizations, community/home care organizations, nursing homes, pharmacies and insurers, were also infrequently included as stakeholders in the programmes. In addition, government structures were also infrequently partners in the selected programmes. However, the integration of care from different disciplines can be established, as illustrated by the Danish Clinic Silkeborg programme (see Box 6) [52].

**Box 6: Integration of care in the Clinic Silkeborg programme [52]**

Patients that participate in the Danish Clinic Silkeborg programme receive a one-day consultation conducted by a multidisciplinary team. During this day, the patient is seen by various care professionals and at the end of the day all these providers exchange information in a meeting. A medical doctor discusses the outcomes of the meeting with the patient and reports the decisions in a care plan that is forwarded to the patient's GP. This approach saves time for the patient as the clinic is the central place for all the examinations required from different health care professionals. Furthermore, it improves collaboration between GPs and specialists working in hospitals.

Improving coordination of care is a main objective in most of the included programmes. Because patients with multimorbidity often receive care from multiple care professionals, having a single contact person who manages the care process is thought to increase the quality of care. In most of the selected programmes, one specific care professional was appointed to be responsible for general communication to the patient and for answering any questions they might have.

Patients being registered with a (primary care) physician of their choice, sometimes referred to as a list system, is an important feature that distinguishes certain health systems in different countries. Germany is a country in which such a system is not in place. However, through the introduction of the 'trusted doctor', the *Gesundes Kinzigtal* programme has been able to realize a kind of list system, which is known to be beneficial for coordinating care and avoiding unnecessary interventions [53]. In order to provide freedom of choice, patients can choose their trusted doctor from among GPs, specialists and psychotherapists.

In the Valencia region, a programme is available that integrates hospital, primary and community health services [51]. The programme introduces roles for two nurses who act as the hospital nurse case manager or the community nurse case manager. These are jointly responsible for monitoring the patient and interacting with other professionals as well as for checking the appropriateness of care received. The case management approach enhances patient-centredness by taking into consideration the patient's own wishes and needs.

Digital communication systems can be effective in supporting the coordination of care between care professionals and are used in various ways in different programmes to achieve this, including: e-medication (a communication channel between doctors and pharmacists); video conferences for care professionals to exchange information; a joint platform for documentation by specialists and GPs. The programmes that include these communication systems are in Croatia, Finland and Germany. Electronic patient records are used in most of the programmes, providing access to relevant care

professionals. The Valencia region programme is supported by an information system that is shared by all the actors involved in the care process, with the system containing, for example, the patients' clinical documents and diagnoses. In the Belgium SOM+ programme, a comprehensive electronic system for patient monitoring has been developed, in which all care professionals involved in the project can find all relevant documents regarding the client (e.g. care plan, actions implemented) [48]. In the Dutch INCA model, the patients' goals and treatment plans are communicated among all involved providers through a personal data store (see Box 7) [49].

#### **Box 7: Care coordination in the INCA model [49]**

In the Dutch INCA model, a risk profile is created for each patient based on patient assessments using the patient's medical record, health behaviour data, as well as the patient's personal perspective regarding their health problems. Motivational interviewing is used to gain insight into their health behaviours and any psychosocial issues. Afterwards, all information is recorded in a digital file. Based on the combined information in this digital file, health risks can be calculated for each patient. The outcomes are presented to the patient in a so-called Patient Health Issue Web, visualizing the patient's health risks. In this way, health risks are easier to detect, for both patients and providers. There is an important coordinating role for a central care professional – the practice nurse. Practice nurses are trained in case management skills, motivational interviewing and the specific content of the stepped care modules. All the care professionals involved have access to the digital files of their patients, enabling communication between the care professionals. The information on the individualized care plan is accessible to the patient and all the care professionals involved.





## Discussion

Based on international scientific literature, as well as policy and strategy documents, this policy brief outlines elements of patient-centred care relating to: customizing care to the needs, preferences, values and resources of patients; including informal carers as co-clients and co-care providers; and the integration and coordination of care. In line with these elements, a number of strategies have been outlined in order to improve patient-centredness in caring for people with multiple chronic conditions, at the levels of: the care professional (micro-level); care organizations (meso-level); and the health system (macro-level). Insights from scientific literature are complemented with observations from the ICARE4EU project, which can serve as an inspiration for both (local) governments as well as care organizations and providers that wish to strengthen patient-centred care for people with multiple chronic conditions.

## Limitations

Although we have identified a substantial number of innovative and potentially effective approaches to improving patient-centredness of multimorbidity care in European countries, there remains a lack of evidence on their effectiveness and effective components. This is due to the fact that most of these programmes have not been well evaluated. Data on process indicators are usually collected but this is far less often the case when it comes to outcomes. And when data on outcomes are collected, they often do not include outcomes that reflect what matters to patients themselves. Unfortunately, the scientific studies described in the international (mostly non-European) literature also do not provide much evidence on the effectiveness of various interventions to improve patient-centredness in multimorbidity care. This is because: 1) patient-centred care has been operationalized in many different ways, which makes it difficult to identify the effective components of patient-centred care; and 2) most studies on the effects of patient-centred care have not specifically targeted people with multimorbidity. Therefore, it remains unclear whether the (suggested) benefits of the studied patient-centred care approaches also apply to people with multimorbidity. Finally, a limitation of the ICARE4EU project itself was that we could not visit all the identified relevant programmes. So, it often remained unclear how patient-centredness was addressed in practice. Nevertheless, based on the current state of the scientific literature, as well as on the insights gained by studying the care approaches targeting patients with multimorbidity developed in European countries, a number of possible policy directions could be considered.

## Policy implications

The performance of specific roles by care professionals, such as that of care coordinator (responsible for continuity and adjustment of care between care professionals) and of 'trusted doctor' or 'trusted nurse' (the primary point of contact for the patient) should be considered as indicators of health care performance.

It is currently difficult for care professionals from different disciplines and sectors to collaborate, partly because different financing methods are used [3]. This is also reflected in the selected programmes from the ICARE4EU project; collaborations between health care and social care were infrequently established. In order to provide good quality care that is responsive to the needs of patients with multimorbidity, these collaborations need to be facilitated.

**Patient-relevant outcomes need to be included as indicators of health care performance.** Currently applied quality of care measurements address preventive and disease-specific care processes, disease-specific outcome indicators or overall mortality. For people with multiple chronic conditions, the overall quality of care depends on more than disease-specific processes and outcomes [31,32]; for example, quality can be dependent on the extent to which care is responsive to the needs and goals of patients.

**Adaptations at the national or regional health system level can facilitate collaboration across and within sectors in order to better meet the comprehensive needs of people with multimorbidity.** People with multimorbidity often need care from various care professionals. New roles for care professionals, such as 'care coordinator' or 'trusted doctor' could improve the quality of care for people with multimorbidity by, for example, reducing overlap in care and signalling problems patients might face earlier. When informal carers are involved, the care coordinator should be in close contact with them to ensure that a good collaboration between formal and informal care is established.

**Innovative initiatives that aim to establish patient-centred care for people with multimorbidity at a local, regional or national level can be supported, along with process and outcome evaluations of these initiatives (e.g. an evaluation from the start based on patient-relevant outcomes).** The ICARE4EU project found that the evaluation of innovative programmes is often lacking. Evaluations are important to gain insight into effective or ineffective ways of providing care that is responsive to the needs of patients with multimorbidity.





## Conclusions

The burden of multimorbidity on patients and health care systems in Europe is increasing. This demands changes in health systems. A patient-centred care approach seems essential in meeting the needs of people with multimorbidity, but will also be beneficial to single-disease patients. Although many elements of patient-centred care apply to all patients, some are specifically important for people with multimorbidity; for example, good coordination and integration of services and a goal-orientated approach to care.

Based on the literature, there are several knowledge gaps when it comes to patient-centred care for people with multimorbidity. First, information on the effectiveness of patient-centred approaches to the care for people with multimorbidity is scarce. Especially in Europe, little effort has been made to study the effectiveness in practice of initiatives that have been implemented. Also, the lack of knowledge on effective strategies for implementing a patient-centred care approach results in weak guidance for policy-makers when developing reform plans [54].

Secondly, studies on the effects of patient-centred care seem to report mostly on the effects on the patient. Little is known about the potential impacts of patient-centred care on the care professional, health care organizations and health care systems. It is important to study the effects of patient-centred care at these levels as well.

Based on findings from the ICARE4EU project, it can be concluded that efforts are being undertaken in many

European countries to improve the quality of care for people with multimorbidity by incorporating elements of patient-centred care. Nevertheless, certain elements of patient-centred care, such as the involvement of patients in shared goal-setting, the use of personalized care plans and the involvement of informal carers as co-clients and co-care givers are not yet generally applied. Furthermore, the improvement of care coordination and multidisciplinary collaboration is often the main objective of the programmes. However, collaborations are most often established within the same health care domain and not with social care organizations, patient organizations, nursing homes or informal carers.

Another conclusion that can be drawn, based on the findings from the ICARE4EU project, is that currently most innovative programmes are initiated bottom-up. In order to establish durable patient-centred care for people with multimorbidity, regulations that drive change top-down may be helpful. Only when shifts in the organization and delivery of care are made on all levels of the health care system, is it possible to drive lasting changes. The case studies from the ICARE4EU project can function as inspiring examples of how some countries and regions in Europe have given shape to patient-centred care for people with multimorbidity and can clearly indicate what the barriers to providing patient-centred care are.

The challenge health systems in Europe face is in managing the uniqueness of each patient on a large scale with limited health care budgets. This needs to be achieved by integrating health care with social care (e.g. home care) and the social environment of patients (e.g. informal carers and patient associations).



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## Appendix 1

### Rapid review of the literature

For this policy brief we used data from various sources. First, we included European, national and regional policy and strategy documents directed at multimorbidity care, integrated care, and/or patient-centred care, provided by the participating country expert organizations and/or identified

via the websites of the European Commission, WHO and Institute of Medicine. Second, we searched for relevant scientific publications via the online search engine PubMed. The search strategies that were used are presented in Table A. We repeated these strategies using the UK English spelling (patient-centred care, patient-centred approach) and included two additional review papers. Finally, publications identified from the reference lists of the studies found on PubMed were also included.

**Table A: Search strategies used in PubMed**

Search directed at:	PubMed search strategy	Hits	Studies included
Reviews on patient-centred care	("patient centered care"[Title] AND "review"[Publication Type]) AND ("2005/01/10"[PDAT]: "3000"[PDAT])	46	10
Studies on patient-centredness in chronic care	("patient centered care"[Title/Abstract] OR "patient centered approach"[Title/Abstract]) AND "chronic care"[Title/Abstract])	26	5
Reviews on patient-centred care and multimorbidity	("patient centered care"[Title] OR "patient centered approach"[Title]) AND "multimorbidity"[Title/Abstract]) AND "review"[Publication Type])	1	1
Studies on patient-centred care and multimorbidity	("patient centered care"[Title/Abstract] OR "patient centered approach"[Title/Abstract]) AND "multimorbidity"[Title/Abstract])	17	4

Search date: November 2015.

## Appendix 2

### Selection of innovative approaches in European countries by 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 predetermined 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 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. 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](http://www.icare4eu.org)).

### Selection criteria

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

- 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.
- Involves cooperation between at least two services; these services may be part of the same organization (for example, different services within a hospital) or part of different organizations (for example, medical care and social care).
- Has some formal status/formalized cooperation (any form).
- Will be or has been evaluated.
- Currently running (in 2014), or finished less than 24 months ago, or will 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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