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Methodological note

## Development of a national position paper for chronic care: Example of Belgium<sup>☆</sup>



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### ABSTRACT

The management of chronic diseases is a prime challenge of most 21st century health care systems. Many Western countries have invested heavily in care plans oriented towards specific conditions and diseases, such as dementia and cancer. The major downside of this narrowly focused approach is that treatment of multimorbidity is ignored. This paper describes the development and main stance of a national position that proposes streamlined reforms of the Belgian health care system to improve care for patients with multiple chronic diseases. We used a combination of methods to develop this stance: literature review and stakeholders' consultation. The latter identified areas for improvement: efficiency of the health care system, coordination of care, investments in human care resources, informal caregivers' support, better accessibility, and changes in the financial payment system. The position paper lists 20 recommendations that are translated into about 50 action points to reform the health care system. Chronic care tailored to the patient's needs, including implementation of multidisciplinary teamwork, new functions, task delegation in primary care, and empowerment of the patient and informal caregivers are some major areas discussed. In addition, improved support, revised payment mechanisms, and setting up a quality system, along with the tailoring of patient care, can all facilitate delivery of high quality care in patients with chronic comorbidities.

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### 1. Chronic diseases: a growing challenge for all countries

Management of chronic diseases are a burgeoning challenge of the 21st century for most health care systems. The World Health Organisation (WHO) defines chronic diseases as “diseases of long duration and generally slow progression” [1]. This definition covers a wide range of health problems such as diabetes; cancer; and muscu-

loskeletal, respiratory, neurodegenerative, mental, and cardiovascular diseases. It is estimated that about 70–80% of all health care costs in European countries are directed towards treatment of chronic diseases [2].

Some countries have invested in national plans oriented towards a specific disease (e.g., diabetes, dementia), but these initiatives fail to consider frequently present multimorbidity. Indeed, 50 to 70% of the population older than 70 suffer from at least two chronic conditions [3]. A WHO publication confirms that disease-specific interventions are unlikely to bring about changes at the health care system level. They multiply investments in parallel programmes, narrowly focus on actions at the local level, and jeopardise implementation of long-term holistic strategies [4]. This is why some European countries have begun to develop a broader approach for treating and managing chronic diseases [5–10].

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## 2. Main features of the Belgian health care system, with a focus on chronic diseases

Belgian health care is based on a compulsory insurance plan: 99% of the population is covered for a wide range of health conditions, having generous benefits. There is equal support of both healthy and sick people, with no risk selection. Until recently, the Belgian health care system focused mainly on treatment of acute diseases and on care in hospital settings, like most other European countries. This narrow focus resulted in expensive, fragmented care for the chronically ill, accompanied by rising health care expenditures (10.55% of the GDP in 2010) [11]. Health care services in the community are mainly delivered by self-employed professionals whose remuneration is based on fee-for-service payments. The therapeutic freedom to opt for a treatment is important for both physicians and patients. Indeed, patients demand the freedom to choose their health care professionals. The decision-making processes (reimbursement, entitlement to services) are usually the result of negotiations between stakeholders' groups like professional unions, health care provider representatives, authorities, and those managing sickness funds.

International concern about the growing burden of managing chronic diseases is now shared by Belgian authorities. In 2008 a national programme entitled "Priority to chronic patients!" proposed dozens of measures, mainly in the domains of financial accessibility and patient information [12]. Other recent measures have been implemented, with a focus on integrated care and multidisciplinary cooperation, patients' pathways, care programmes, and networks [13]. However, these measures are disease specific (i.e., diabetes, chronic renal failure), rather than patient oriented.

A more global approach centred on the patient and considering all aspects of the health system was recognised. Hence in 2011, the Minister of Public Health commissioned the Belgian Health Care Knowledge Centre (KCE) to draft a position paper on chronic care. The aim of this position paper was to formulate proposals to reform in depth the organisation of care provided to the chronically ill.

## 3. Methodological steps for developing the position paper

The development of this position paper relied on many sources [14]. First, the researchers analysed publications of international institutions: World Health Organisation, European Commission, United Nations, and European Observatory for Health Care Systems [1,2,15–26]. They also scrutinised the national chronic disease plans of four leading countries or regions (Denmark; the Netherlands; Quebec, Canada; Pennsylvania, USA). The researchers conducted a systematic literature review of the best techniques that foster patient empowerment. They also searched the 'grey' literature for new roles and functions of health care professionals. Finally, they reviewed Belgian policy initiatives for chronic care as well as 43 previously published KCE reports dealing with policy recommendations for chronic care.

The researchers involved the main stakeholders in the development of the position paper: the National Institute for Health and Disability Insurance, the Federal Public Health Services, and representatives of other public health authorities. In addition, they conducted a two-step qualitative study to analyse the opinions of six groups of Belgian stakeholders on the strengths and weaknesses of the current organisation of care provided to chronic patients:

- First, four brainstorming sessions were conducted to collect information from patient associations, health care providers, and other professionals (e.g., managers) who work in primary or secondary care settings
- Second, discussion sessions with macro-level stakeholders (patient associations, authorities, academics, sickness funds, professional organisations) were used to inform the researchers on the feasibility of the ideas that emerged from the brainstorming sessions.

The authors of this article drafted a first version of proposals to reform the health care system, with a focus on chronic care. Many consultations were carried out with about 100 stakeholders from the above-mentioned groups to get input on the feasibility of the proposals, to facilitate their acceptance, and to facilitate their further implementation in the field.

## 4. Main themes of the national position paper on chronic care

The above-mentioned methodological steps identified many weaknesses in the Belgian health care system. In the sections below, we first present a summary of this critical analysis, followed by proposals of the position paper for policy changes and possible barriers to implementing these proposals in the Belgian health care context. The proposals target people who suffer from chronic diseases, as described by the WHO [1], focusing on their needs in a holistic manner.

## 5. Care tailored to the patient's needs

### 5.1. Shift from disease-based provision of services to needs-based provision of services

The stakeholders first noted that entitlement to specific services is usually based on the nature of the disease rather than on the patient's actual needs. These needs may be broad: medical (pain control, prevention of complications); social; or psychological [27]. The drawback of the current disease-based approach is that groups of chronically ill patients who have specific needs might be excluded, because their situation does not match the present entitlement criteria (disease duration, type).

The position paper proposes to design and produce individualised care plans, set up by the patients in collaboration with their primary care providers. Answers to the complex needs of chronically ill patients also require the intervention of a multidisciplinary care team that shares in the care plan. Teamwork necessitates that all providers have access to a common "chronic care section" in the patient's

electronic record. This part of the record should contain crucial information; for example, the care plan, follow-up elements, and evaluation of the patient's needs based on standardised tools.

The proposal to share a common care plan triggered stakeholders' concerns about privacy and selective access rights. Moreover, they stated that the patient might be reluctant to receive care from a team rather than from a preferred individual health professional. Additionally, current tools may hinder teamwork, since, for instance, professional groups (e.g., home care nurses and general practitioners) often use various non-compatible software packages to manage health care.

### 5.2. *The best environment adapted to the patient's condition*

The clinicians mentioned instances of chronic patients who are often needlessly institutionalised. Better organised psychosocial and medical care would have allowed these patients to remain at home. The position paper calls for solutions that strive to maintain the patient at home. Financial support, adaptation of the living environment, and case management are some solutions. When a patient's health condition is no longer compatible with home life (e.g., serious health conditions, severe mental disease), transfer to alternative living facilities or innovative solutions (like intergenerational environments) should prevent unnecessary admissions to hospital.

## 6. Adequate human resources

### 6.1. *Well-trained health professionals at the front line of care*

Stakeholders noted the lack of human resources in primary care, despite an increasing workload. In community settings, patients present with serious conditions that require complex care more often, thereby putting a strain on an already-overloaded health care system. Compounding this, there is an accompanying shortage of general practitioners and home nurses in some regions. They are also less available than before and perform an increasing number of tasks, such as coaching patients for self-management. Moreover, the training for health practitioners still focuses on caring for patients in hospital settings, even though there is an increasing need for highly skilled professionals in the first line of care.

The position paper formulates suggestions for new functions, task delegation, and task sharing in primary care. First, a health care system concerned with chronic care should promote nurse and general practitioner professions, making them more attractive to students considering a career in health care. Investment in academic training and promoting appealing work conditions are two key factors [28,29]. Second, general practitioners and nurses should increasingly share tasks. In Belgium, most general practitioners work in small practices lacking nursing support. Inclusion of nurses in this work environment requires the training and legal recognition of "advanced practice

nurses", to whom tasks such as self-management training and follow-up of patients with complex problems could be delegated. Along these same lines, the legal and financial context also should favour the delegation of simpler nursing tasks to nurse aides, who have less advance training.

The health professionals expressed reluctance to implement these proposals. This reluctance is mainly due to professional protectionism and the payment system, as explained below.

### 6.2. *Empowering and supporting patients and informal caregivers*

The stakeholders acknowledged that informal caregivers are valued resources in chronic care. However, caregiver overload and a lack of efficacious support may lead to acute episodes of unplanned hospitalisations or institutionalisations. In answer to this problem, the position paper emphasises the importance of providing accurate, relevant, and timely information on the disease, on therapeutic options, and on available support to encourage patients and informal caregivers to participate in the management of the chronic condition. Empowerment interventions are more likely to be successful, if [14] (1) they involve the informal caregivers together with the patient; (2) they are tailored to their specific needs; and (3) they are intensive and comprehensive, using a wide range of self-management approaches and multiple delivery strategies. Finally, psychosocial support and respite care can significantly alleviate the workload of informal caregivers.

The barriers to empowering patients seem cultural as well as operational. On the one hand, training that health professionals receive lacks strategies to foster empowerment, which should be promoted in high schools, universities, and continuing education courses. On the other hand, practical barriers mentioned by the stakeholders are similar to those mentioned in the literature: a lack of time and insufficient training [30].

## 7. Coordination to enhance the efficiency of health care services

### 7.1. *Efficiency of the health care system*

Analysis of the health care system revealed global inefficiency. Some health care services may be underused in one region, whilst in other regions they overlap, in particular when a range of providers target similar populations. The position paper calls for harmonisation among existing coordination structures that currently operate in parallel, but with little cooperation. Structures at the "meso" level (e.g., small cities) are important for coordinating social and medical interventions in defined territories without redundancy. They should function under a larger umbrella structure (e.g., at large city or province levels). At the highest (macro) level, one coordination unit must ensure coherence between all structures and initiatives [4].

## 7.2. Coordination and seamless care focused on the patient

The stakeholders pointed out the need for coordination to ensure concerted actions between medical and psychosocial services in the community setting. They also mentioned a need for seamless care between care settings. The position paper emphasises that interactions between medical and social services are necessary. A case manager from the primary care team can help optimise the impact of diverse interventions. Coordination structures are also crucial for supporting care providers and case managers within local networks. Seamless care requires the development of shared protocols, shared electronic medical records, and the intervention of a discharge manager who collaborates with home care providers when the patient returns home after hospitalisation.

One frequent barrier that was mentioned by health professionals and by patient associations is the lack of communication between the providers and between the settings. This problem partly arises from the professional culture that emphasises independence in health professionals. Practical constraints like software incompatibility and few common tools (e.g., multidisciplinary pathways) also hinder the communication among disciplines and care settings.

## 8. High quality care

### 8.1. Accessibility issues

The stakeholders mentioned some accessibility issues, such as waiting lists for nursing homes and reimbursement conditions that exclude specific groups of chronic patients. Solutions already have been discussed above: for example, efforts to support the patient and informal caregivers at home and care based on needs instead of care based on disease criteria.

### 8.2. Caution with unnecessary interventions

Another pitfall mentioned during the sessions was the overtreatment of chronic patients, causing more harm than the disease itself. The position paper emphasises the role of health care providers in detecting the first symptoms of a chronic disease or in anticipating disease complications. However, they should avoid unnecessary screening, diagnostic tests, and treatments that may degrade quality of life.

### 8.3. Implementation of a quality system

Three previous KCE reports stressed the need to implement a quality system at the health care system level [31–33]. This set up requires the definition of goals; the definition of the potential consequences (financial incentives, disclosure); and the definition of relevant quality indicators. The implementation of a data collection system should use, if possible, existing databases, while guaranteeing confidentiality and proper ethics. Feedback to the professionals concerned is crucial for the efficacy of this system.

Nonetheless, the professionals were quite reluctant to support proposals to measure the quality of care. In their view, supporting such measures could infringe on their usual therapeutic freedoms, may lead to dire financial consequences, or even may threaten their reputation.

## 9. Financial reforms

The Belgian health care system mainly relies on fee-for-service payment. The stakeholders perceived this system to be a barrier to high quality chronic care, as it does not foster coordination, task delegation, and teamwork. The position paper formulates suggestions for new payment mechanisms, in particular a combination of diverse payment systems and incentives for quality care. Investing in the primary care sector also ensures high quality daily care for all chronic patients. This proposal drew contrary response from the representatives of professional unions, which argued that a fee-for-service system does indeed guarantee high quality care for each individual patient. In addition, care providers feared that a combined payment system would be even more complex than the current one.

## 10. From position paper to concrete actions

The position paper on chronic care introduces a new mode for developing Belgian health care policies. This is the first time the Ministry of Health has commissioned an independent agency like the KCE to devise a system-level framework, guiding policymaking for the next 10–15 years. The approach is innovative, as it combines evidence emerging from the literature and experience from other countries with a formalised stakeholder involvement approach. This clearly differs from how health care policymaking in Belgium usually takes place (i.e., negotiation between different interest groups). The 20 recommendations and 50 action points published in the position paper offer a clear framework in which the traditional negotiation process can take place [14].

Implementation and operationalisation have already started. Different stakeholders—patient and health care professional representatives; representatives of sickness funds, national health insurance, and care institutions; and policymakers—have convened in brainstorming sessions. The objective of these groups is to formulate concrete proposals salient to their sector and competences (e.g., education, information and communication technology). The results of these workshops as well as this position paper will be presented at a national conference in mid-2013.

The next steps will be to evaluate and monitor the implementation of the recommendations outlined in the position paper. Also, relevant indicators for crucial domains, such as the quality of care, health care budget, and administrative burden will be defined. Along with representatives of the main stakeholders, the newly formed Observatory of Chronic Diseases [34] will play a key role in assessing the accomplished work. The position paper is a touchstone for all these steps. It will clearly contribute to evidence-based policymaking, resulting in relevant changes at the system level.

## Author contributions

The authors of this paper are the lead authors of the national position paper on chronic care. They all contributed to the design of the study and the writing of this manuscript. About 15 other authors also contributed to one or more chapters of the scientific report used as input for writing the position paper. The original report can be viewed at <https://kce.fgov.be/publication/report/position-paper-organisation-of-care-for-chronic-patients-in-belgium>

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