

# Chronic Disease Management Programmes: an adequate response to patients' needs?

Mieke Rijken PhD,\* Nienke Bekkema MA,† Pauline Boeckxstaens MD,‡ François G. Schellevis MD PhD,§¶ Jan M. De Maeseneer MD PhD\*\* and Peter P. Groenewegen PhD††‡‡

\*Head of research programme, †PhD student, Netherlands Institute for Health Services Research (NIVEL), Utrecht, the Netherlands, ‡PhD student, Department of Family Medicine and Primary Health Care, Ghent University, Ghent, Belgium, §Professor, Department of General Practice, EMGO Institute for Health and Care Research, VU University Medical Centre, Amsterdam, the Netherlands; ¶Head of research department, Netherlands Institute for Health Services Research (NIVEL), Utrecht, the Netherlands; \*\*Professor, Department of Family Medicine and Primary Health Care, Ghent University, Ghent, Belgium;

††Professor, Department of Family Medicine and Primary Health Care, Ghent University, Ghent, Belgium and

‡‡Director, Netherlands Institute for Health Services Research (NIVEL), Utrecht, the Netherlands

## Abstract

### Correspondence

Mieke Rijken, PhD  
Netherlands Institute for Health  
Services Research (NIVEL)  
P.O. Box 1568  
3500 BN Utrecht  
the Netherlands  
E-mail: m.rijken@nivel.nl

### Accepted for publication

24 March 2012

**Keywords:** chronic illness, disease management, goal-oriented care, multi morbidity, patients' needs, self-management

**Background** Inspired by American examples, several European countries are now developing disease management programmes (DMPs) to improve the quality of care for patients with chronic diseases. Recently, questions have been raised whether the disease management approach is appropriate to respond to patient-defined needs.

**Objective** In this article we consider the responsiveness of current European DMPs to patients' needs defined in terms of multimorbidity, functional and participation problems, and self-management.

**Method** Information about existing DMPs was derived from a survey among country-experts. In addition, we made use of international scientific literature.

**Results** Most European DMPs do not have a solid answer yet to the problem of multimorbidity. Methods of linking DMPs, building extra modules to deal with the most prevalent comorbidities and integration of case management principles are introduced. Rehabilitation, psychosocial and reintegration support are not included in all DMPs, and the involvement of the social environment of the patient is uncommon. Interventions tailored to the needs of specific social or cultural patient groups are mostly not available. Few DMPs provide access to individualized patient information to strengthen self-management, including active engagement in decision making.

**Conclusion** To further improve the responsiveness of DMPs to patients' needs, we suggest to monitor 'patient relevant outcomes' that might be based on the ICF-model. To address the needs of patients with multimorbidity, we propose a generic comprehensive model, embedded in primary care. A goal-oriented approach provides the opportunity to prioritize goals that really matter to patients.

## Introduction

Health policy makers and health-care providers worldwide have become increasingly aware that chronic diseases form the greatest threat to population health of the 21<sup>st</sup> century. While many infectious and acute diseases were combated successfully in western countries, the incidence and prevalence of chronic diseases have grown steadily. Estimated percentages of people living with chronic conditions in the European Union range from about 20 to over 40%.<sup>1,2</sup> Among people diagnosed with a chronic disease, the proportion of people with more than one chronic disease has been estimated to be 25–50%<sup>3–5</sup> and is expected to increase further.<sup>6,7</sup>

Until recently chronic conditions were managed in the same way as acute diseases: the health-care process started when a patient presented his or her health complaints to a medical doctor and this professional reacted by diagnostic interventions and medical treatment aimed at reducing or solving the health problem. Preventive actions and proactive management were uncommon, the patient's role was confined to complying to the therapy, and involvement of other disciplines was not part of usual care. This so-called 'problem-oriented' model is well suited to the management of acute and curable diseases, but not useful when complete recovery is impossible.<sup>8</sup> As chronic diseases can by definition not be fully cured, the desired health state to strive for is less clear and will be different between individuals and at different points in time. In the case of chronic disease the patient's definition of health might differ from the medical point of view, and therefore health goals should be explored more explicitly by patients and health-care providers together. Several authors argue that a shift towards a more 'goal-oriented' model is needed in the management of chronic disease.<sup>8,9</sup>

In 1996 Wagner and colleagues developed the Chronic Care Model (CCM).<sup>10–12</sup> This model shows how health-care systems could be designed to be supportive to productive patient-provider interactions. CCM emphasizes that both patients and health-care practitioners need

to be facilitated to play their part in the management of the patient's condition. Patients are considered vital actors in the management of their illness who set their own treatment goals together with a multidisciplinary team of health-care providers. These health-care providers support the patient's self-management and manage the condition proactively, starting from the goals they have agreed upon with the patient and encompassing the total chain of care.

## Disease management

CCM has inspired many health policy makers and health-care providers to develop and implement innovations in (parts of) their health-care system. One of these innovations is known as disease management. This approach had been developed in the USA in the nineties and has recently been adopted, and adapted to the existing health-care system, in several European countries. Several definitions of disease management exist.<sup>13–17</sup> These definitions all emphasize the comprehensiveness and multidisciplinary of the disease management approach. Some definitions refer to both management and prevention of the disease, whereas in others prevention is not mentioned. Greß *et al.*<sup>18</sup> state that '[...], by definition, disease management programmes become active only after individuals have developed a particular chronic disease. As a consequence, disease management programmes are unable to prevent the advent of chronic conditions'. Hence, prevention as a component of disease management usually refers to prevention of complications rather than prevention of disease. The concept of disease management generally concerns the management of a single chronic condition, although a more recent definition<sup>17</sup> also mentions the possibility that it relates to more than one chronic disease. Some definitions also include financial arrangements. Regarding the goal of disease management, maximalization of treatment effectiveness is mentioned, but also efficiency and promotion of self-management.

Very recently, questions have been raised by clinicians and researchers whether disease management programmes (DMPs) are always

the best approach to respond to the many different problems related to chronic illness (care). In this article we address three issues, which have in common that they can be considered as challenges for disease management that closely relate to the needs for care and support from the patient perspective: 1. the management of multimorbidity, 2. the management of functional and participation problems and 3. self-management of chronically ill patients.

### Aims

The issue we want to reflect upon is how DMPs in Europe today respond to patients' needs defined in terms of multimorbidity, functional and participation problems, and self-management. We also aim to outline some directions to improve the responsiveness of chronic care to these patients' needs. We wish to emphasize here that this article should not be considered as an empirical research paper but rather as a reflection paper. We describe the three challenges in more detail below.

### Multimorbidity

One of the biggest challenges for the disease management approach is whether it can deliver optimal care for the millions of Europeans who suffer from multiple chronic diseases. Ritchie states that 'theoretically, people with multimorbidity face polypharmacy, fragmentation of care, competing or contradictory health-care recommendations and inattention to patient and family's values and preferences'.<sup>19</sup> The latter refers to patients' preferences in choosing between treatment options with different consequences for survival and quality of life, but it may also refer to patients' preferences when it comes to prioritizing which of their diseases (and related problems) should be addressed in the first place. For people with multimorbidity, single-disease programmes incorporate the threat of a too narrow focus on their health problems (the focus is on the disease the DMP has been designed for), a lack of evidence regarding treatment (because of exclusion of

patients with comorbidity from randomized controlled trials that underpin the guidelines) and subsequently also a lack of decision support (clinical practice guidelines may contradict each other and do not sufficiently address aspects of multimorbidity), inadequate coordination of care and interference of advised self-care for co-existing diseases.<sup>3,18,20,21</sup>

### Functional and participation problems

DMPs are designed to manage chronic disease (a biomedical condition), whereas from the patient perspective, people are dealing with chronic illness (the impact of the condition on the person<sup>22</sup>). This especially applies to older, frail people and people who experience functional problems as a consequence of ageing or chronic disease. It has been estimated that functional problems are present in half of all people with chronic conditions, with about 30% experiencing moderate to severe physical disability.<sup>23,24</sup>

Where (most) DMPs start from a medical diagnosis, the needs for care and support of patients are usually related to the functional and participation problems they experience. Von Korff *et al.*<sup>25</sup> state that: 'Providers usually define problems in terms of diagnosis, poor compliance with treatment, or continuation of unhealthy behaviors. [...] Patients are more likely to define problems in terms of pain, symptoms, interference with functioning, emotional distress, difficulty carrying out treatments or life style changes, or fears about unpredictable health consequences of illness.' Heijmans and colleagues demonstrated that diabetic patients generally judge their illness as less serious than their GPs with respect to its life-threatening nature, but more serious with respect to its intermittent course, pain and visible bodily changes. Diverging perceptions were associated with poor patient-rated health and a higher use of health care. According to these authors '[...], it is important that providers recognize the problems with which chronic disease patients are faced. Too often, providers are one-sided focused on the medical aspects of disease, neglecting the personal impact that a chronic disease had on the patient's life'.<sup>26</sup>

## Self-management

The third challenge we address is the ability of DMPs to promote self-management of patients. Self-management has been described as a collaborative activity between patients and health-care practitioners.<sup>27</sup> It is aimed to minimize the impact of chronic disease on physical health status and functioning, and to enable people to cope with the psychological effects of the illness.<sup>28</sup> It is important to notice that self-management not only involves managing symptoms, treating the condition and changing lifestyle, but also adapting life goals and social roles, coping with the physical and psychosocial consequences inherent in living with a chronic condition, and communication with health-care providers including participation in decision making.<sup>29</sup> In this respect, it has been stated that a narrow interpretation of self-management as only compliance with medical instructions inhibits effective patient-centred consultations.<sup>30</sup>

Despite the general recognition of self-management support as an essential component of chronic care, there may be doubts whether this is really an integral part of disease management today. Enrolment in self-management programmes often depends on the interests of individual health-care providers. Moreover, in health-care systems in which providers are rewarded to see patients, self-management is not promoted. In a number of countries financial incentives are now used to drive changes in how chronically ill patients are supported, but then still providers need a positive attitude and skills to support self-management.<sup>29</sup> In this respect it is noteworthy that self-management and disease management are sometimes viewed as competing rather than complementary strategies.<sup>25</sup> This relates to the already mentioned different perspective of health-care providers and patients on the problems that have to be addressed.

## Method

We will address the selected challenges for disease management by making use of data from a survey of existing DMPs in ten European

countries in 2010.<sup>31</sup> In order to create an overview of the 'state of the art' regarding disease management in Europe, country-experts were asked to report on programmes that: (i) manage defined chronic conditions; (ii) incorporate a systematic and coherent approach; (iii) offer multidisciplinary, collaborative care; (iv) focus on an active role for patients and (v) strive for maximal effectiveness and continuous improvement of quality of care. The country-experts were invited to report on DMPs that cover the management of arthritis, cancer, cardiovascular disease, chronic obstructive pulmonary disease (COPD), depression and diabetes mellitus. To be concise, we mainly use information about the reported DMPs covering diabetes or COPD care here (see Table 1). The reason for focusing on diabetes and COPD is that for these diseases DMPs have already existed in several European countries for some years.\* The different nature of the two diseases may be reflected in the components of the programmes and the disciplines involved. Hence, by providing examples of DMPs for diabetes and COPD, we can get some idea whether our observations are of a disease-specific or a more generic kind. In addition to these survey data, we make use of international literature. Also for the literature review we want to emphasize that we do not pretend to give a complete overview of relevant studies.

## Management of multimorbidity

Our observations (Table 2) endorse the notion of Greß *et al.*<sup>18</sup> that most DMPs constitute a single-disease approach and 'tend to neglect co-morbidities'. For instance, in the German DMPs for diabetes co-morbidity is not taken into account. However, there are some developments towards more horizontal attunement of single-disease DMPs and even a few approaches that deal with multimorbidity.

\*This also holds for cardiovascular conditions, but these DMPs show more heterogeneity regarding the particular conditions they address (e.g. cardiovascular risk factors, coronary heart disease, heart failure).

**Table 1** DMPs covering care for patients with diabetes or COPD, reported by country-experts

Chronic disease	Country	DMP	
Diabetes	Belgium	National Care pathway diabetes type 2 (2009)	
	France	National policy Sophia: diabetes type 1 and 2 (since 2008 regional pilots, national implementation in progress)	
	Germany	National policy diabetes type 1 (2004) and 2 (2002), regional DMPs ( <i>provided example: regional DMP North-Rhine</i> )	
	Italy	National policy Integrazione, Gestione e Assistenza per la malattia diabetica: diabetes type 2 (2006) Region Tuscany's plan 'From On-Demand to Proactive Primary Care': diabetes type 2 and heart failure (2010), COPD, stroke and hypertension (from 2011) Local plan Leonardo: diabetes type 1 and 2, heart failure, cardiovascular risk (2006), in one health authority, planned extension to whole Apulia region	
	The Netherlands	Nationaal Actieprogramma Diabetes, Netherlands Diabetes Federation care standard diabetes (2007): diabetes type 1 and 2 (2009), regional DMPs ( <i>provided example: Diabetes Care System West-Friesland, 1996</i> )	
	Spain	National policy Estrategia en diabetes del Sistema Nacional de Salud: diabetes type 1 and 2 (2006), regional DMPs	
	UK (England)	National Service Framework for Diabetes: diabetes type 1 and 2 (2001)	
	COPD	Germany	National policy COPD (2005), regional DMPs
		Italy	Region Tuscany's plan 'From On-Demand to Proactive Primary Care' (for COPD from 2011)
		The Netherlands	National policy Lung Alliance Netherlands care standard COPD (2010), regional DMPs ( <i>provided example: Integrated COPD management 'De Kroonluchter', 2004</i> )
Spain		National policy Estrategia en EPOC del Sistema Nacional de Salud (2009)	
UK (England)		National strategy for COPD, including asthma (2005)	

DMP, disease management programme.

Source: Rijken & Bekkema<sup>31</sup>.

#### Horizontal attunement between single-disease DMPs

In the UK, National Service Frameworks (NSFs) and strategies have been developed by the National Health Service in collaboration with the health care and social care sector for several chronic diseases and patient groups. NSFs provide a systematic approach to manage a specific chronic disease or to manage care for specific patient groups. They incorporate evidence-based national quality standards of care, strategies to achieve these quality standards, implementation support and performance indicators. The NSF for diabetes is linked to the NSF for coronary heart disease and the National Stroke Strategy, but other NSFs are not linked.

In the Netherlands, some regional single-disease DMPs already started in the nineties. It lasted until 2008 before a national policy for a

'programmatic approach' of chronic diseases was introduced. This approach included the development and implementation of national standards of care. A care standard describes what is considered as quality care for a specific chronic condition and which components of care should be delivered in several phases of the disease process. It is used as a framework for the organization of the total care continuum and is also now adopted as a basis for 'integrated funding' of care for specific chronic conditions. Based on care standards local/regional DMPs are developed. In response to criticism that separate processes of developing care standards for specific diseases would lead to fragmentation and discordance, the ministry of Health has established a coordination platform. The main task of this platform is to improve concordance between disease-specific care standards by providing a 'meta-standard' as a model for existing and new care standards.<sup>32</sup> Several clinicians and



**Table 2** Management of multimorbidity\*, examples of DMPs covering COPD and/or diabetes

Diabetes	
Belgium <i>Care pathway diabetes type 2</i>	Not linked with other DMPs; no specific multimorbidity approach
Germany National policy, regional DMPs (diabetes type 2)	Not linked with other DMPs; multimorbidity is not considered
Italy <i>IGEA</i> (diabetes type 2) <i>Region Tuscany's Plan</i> (diabetes type 2)	Not linked with other DMPs; no specific multimorbidity approach This is a general reorganization of the regional health-care system, which applies disease management to five conditions: diabetes type 2, COPD, stroke, heart failure and hypertension. Patients who have more than one of these conditions are managed by one team
<i>Leonardo</i> (diabetes type 1 and 2)	Not linked with other DMPs. No specific multimorbidity approach, but the GPs and care managers have the competencies to address multimorbidity.
The Netherlands National policy, regional DMPs (example: <i>Diabetes Care System West-Friesland</i> ) (diabetes type 2)	Not linked with other DMPs. The Diabetes Care System West-Friesland is currently involved in an RCT on case management for diabetic patients with multimorbidity.
UK (England) <i>National Service Framework for Diabetes (diabetes unspecified)</i>	Linked with DMPs for coronary heart disease and stroke. In addition, universal care is provided under NHS.
COPD	
Germany National policy, regional DMPs	Linked with DMP for asthma. Patients can participate in several DMPs, but every single DMP is disease-specific.
Italy <i>Region Tuscany's Plan</i>	See above (diabetes)
The Netherlands National policy, regional DMPs (example: <i>De Kroonluchter</i> )	DMP 'De Kroonluchter' is currently developing an application to deal with prevalent comorbidities.
UK (England) <i>National Strategy for COPD 2005</i> , including asthma	Not linked with other DMPs, but universal care is provided under NHS.

DMP, disease management programme.

\*Information about the management of functional and participation problems as well as information about the support for self-management by European DMPs can be obtained from <http://www.nivel.nl/pdf/Rapport-chronic-disease-management-matrix-2010.pdf> (31).

Source: Rijken & Bekkema<sup>31</sup>.

researchers still criticize this approach because it mainly addresses the additive effects of combinations of chronic diseases for the care that should be provided and neglects the possible adverse interactions between combinations of diseases and medicines as suggested by Boyd *et al.*<sup>20</sup> and others. Furthermore, it remains unclear how health-care providers should deal with the presence of comorbid conditions for which there are no standards of care, for instance osteoarthritis, which is highly prevalent among older persons and which may have a

huge impact on patients' quality of life and lifestyle (e.g. avoidance of activity because of pain<sup>33</sup>).

#### DMPs that address more than one chronic disease

In some European countries DMPs are developed that aim to address more than one chronic disease. An example is the plan 'From On-demand to Proactive Primary Care' that is developed in the Italian region of Tuscany.

Based on the Expanded Chronic Care Model,<sup>34</sup> a multidisciplinary programme embedded in primary care has been developed with much emphasis on self-management for patients and a large role for nurses as case managers. Since 2010 the programme is operational for patients with diabetes type 2 and heart failure. In 2011 the programme will be extended with the management of COPD, stroke and hypertension. This implicates that a patient with diabetes type 2 who also suffers from COPD will be treated by one multidisciplinary team for both conditions. As for the attunement of the (single-disease) DMPs in the UK and the Netherlands, it should be noticed that this approach is confined to some chronic conditions. The same holds for the German DMP for coronary heart disease, which has been extended with an extra module on heart failure.

DMPs that are specifically designed to address multimorbidity

The third approach we identified consists of DMPs specifically designed for people with multimorbidity. An example of this approach is the programme 'Polypatology', which is an experiment in the Spanish region of Andalusia. This programme started with the development of criteria for polypathology in order to define the target group. According to these criteria, patients are defined as polypathological when they have chronic diseases that belong to two or more (of eight) disease categories. In addition, the polypathological patient is defined 'by a special clinical susceptibility and frailty which entails a frequent demand for care at different levels that is difficult to plan and coordinate, as a result of exacerbations and the appearance of subsequent conditions that set the patient along a path of progressive physical and emotional decline, with gradual loss of autonomy and functional capacity'.<sup>35</sup> Subsequently, the Andalusian ministry of Health has designed an organizational process to manage the care of polypathological patients in collaboration with internal medicine specialists, family physicians and nurses. The aim of the programme is to improve continuity of care.

Therefore, it focuses on the professional roles, workflows and best clinical practices, supported by an integrated information system.<sup>35</sup> The Andalusian programme is not a classic DMP, because its starting point is not merely the presence of chronic disease(s). Therefore, this programme can be considered as a DMP blended with case management features.<sup>36</sup>

### Management of functional and participation problems

In order to get an impression whether European DMPs provide support for patients' needs related to their functional and participation problems, we consider several indications and describe our observations.

Components of the care continuum and disciplines involved

The first indication we wish to consider are the components of the chain of care that are addressed by the DMPs and the professional disciplines involved. Patients who experience functional or participation problems not only need medical interventions, nursing and lifestyle advice, but often also rehabilitation and reintegration support. Furthermore, these patients may have an increased need for psychosocial support. This implicates that in order to address the needs of patients with functional or participation problems, DMPs should cover rehabilitation, reintegration and psychosocial care as well.

Most DMPs for diabetes do not structurally provide rehabilitation and reintegration (except for the Tuscan DMP). The multidisciplinary team usually includes GPs, medical specialists, nurses and allied health-care professionals such as dieticians and podologists, and often also physiotherapists. In none of the reported DMPs for diabetes an occupational medical doctor, occupational therapist, psychologist, psychosocial nurse or social worker are participating on a structural basis.

The DMPs for COPD show more examples of inclusion of rehabilitation and reintegration. For instance, the NSF for COPD in England provides

pulmonary rehabilitation group courses consisting of a package of exercise, education and support. The aim is to improve quality of life by strengthening the patients' feelings of control and empowerment (see <http://www.nhs.uk/NHSEngland/NSF/Pages/ChronicObstructivePulmonaryDisease.aspx>). The Dutch DMP 'De Kroonluchter' on COPD provides sports groups, a rehabilitation programme and psychosocial care on indication. With regard to the disciplines involved, occupational therapists, psychosocial nurses or medical psychologists occasionally participate in DMPs for COPD.

#### Patient-centredness

The responsiveness of DMPs to the functional and participation problems of patients may be reflected by the extent to which the individual patient's needs, preferences and abilities are taken into account in setting the goals of the patient's personal programme. For all DMPs mentioned in Table 1, the country-experts reported that goal-setting is a collaborative process between the patient and the central health-care provider. Patients' perceptions of illness are explored, personal targets are discussed, patients are made aware of the options they have, they are asked to explicitly express their consent regarding the programme goals they have agreed upon and the care plan that has been developed in collaboration between health-care providers and the patient.

It is not clear whether the goals of the individual programme are always laid down in a personalized care plan and whether patients always receive their plan on paper or have access to it in another way. In several countries the use of personalized care plans is encouraged, but not obliged. In 2006 the UK department of Health reported that half the people with long-term conditions did not have a personalized care plan covering health and social care. Therefore, a commitment was made that all people with long-term conditions would have such a plan by 2010.<sup>37,38</sup> A recent study in the Netherlands shows that many chronically ill patients do not know what a personalized care plan is or report

that they do not have a personalized care plan. This is also the case for patients with diabetes type 2, COPD or cardiovascular disease for whom most DMPs have been developed so far.<sup>24</sup>

#### Attention for social and cultural context

Another indication of the responsiveness of DMPs to patients' functional and participation problems is to what extent the social and cultural environment of the patient is taken into account. Country-experts report that the social and cultural context are taken into account when setting the patient's personal goals and developing the personalized care plan, but interventions tailored to the needs of specific social or cultural patient groups are not part of most DMPs. However, some attempts are made, for instance within the NSF for diabetes in England. In the Italian national DMP for diabetes type 2 (IGEA) equity indicators are collected to get insight into the need for specific interventions. Such assessments will probably also be made in other countries, but the question remains whether they have an appropriate care programme for patients with specific needs related to limited personal or social resources.

#### Assessment of quality of care from the patient perspective

The last indication we address is whether patients are asked to evaluate how well their condition is managed by the programme. Thus, do patients experience that their 'patient-defined' problems are reduced or solved by the programme? The survey shows that most often clinical parameters, hospital admissions and lifestyle changes are assessed to monitor and evaluate the individual patient's progress and the effectiveness of the total programme. In most DMPs reported in the survey, evaluation of the successfulness of the programme from the patient perspective is lacking. We assume that health-care providers do ask their patients whether the care they receive meets their needs, but this is not always carried out in a systematic way. Only a few DMPs presented in Table 1



monitor changes in patient satisfaction structurally: German DMPs, local programme 'Leonardo' and Dutch DMPs. In Germany, structured surveys on patient satisfaction in 10%-samples of participants are an obligatory part of the legally required DMP evaluation. The Dutch DMPs make use of validated instruments such as Consumer Quality indices<sup>39</sup> or the older Quote-instruments.<sup>40</sup>

### Support for self-management

The last challenge we address is whether European DMPs promote self-management, thus whether these programmes structurally address the many components of self-management and whether they are equipped to strengthen patient activation and empowerment in general.

#### Components of self-management addressed

All reported DMPs on diabetes pay attention to symptom management by patients and self-care and lifestyle changes, as components of self-management most directly related to compliance with medical instructions. In most DMPs self-monitoring of blood glucose levels is also practised, although we have no information about the percentages of participating patients who perform self-monitoring techniques. Furthermore, nearly all country-experts report that attention is paid to coping with the psychosocial consequences of having diabetes. A component that is not often addressed is involving the social network of the patient (e.g. partner, employer) in the self-management process. Active involvement of the family or others in the programme of the diabetic patient has only been reported for the Belgian care pathway for patients with diabetes type 2 and the UK NSF for diabetes. The results of the DMPs for COPD are very much alike. Again, the absence of efforts to involve the patient's social environment in the self-management process is striking. This finding is consistent with the generally low attention for the impact of the social and cultural context of the patient on the programme (s)he is offered as we noticed earlier.

#### Decision support for patients

Patient activation and empowerment starts with increasing patients' knowledge and facilitating them to play their part in disease management. To increase knowledge, patient education is a basic component of all DMPs for diabetes and COPD. Besides verbal education, the DMPs offer education material specifically designed for patient (sub)groups. However, to take an active role in decision making, patients may also need more personalized/individualized information, for instance about their clinical parameters and the treatment options that apply to them. Professional guidelines and personal data from clinical information systems can be made accessible by a patient portal. Patient portals are not common yet, but nice examples exist. To date, the DMPs for diabetes and COPD considered here do not provide direct access for patients to their own clinical data, except for the Dutch example for COPD 'De Kroonluchter', which offers a patient portal linked to the clinical information system. In the Belgian care pathway for diabetes type 2 clinical information systems with patient portals will be developed in the near future. In Belgium and in Germany (example region North-Rhine) a diabetes passport is used, which is carried by the patient through the chain of care.

### Discussion

This article provides some insights into the responsiveness of current European DMPs to patients' needs defined in terms of multimorbidity, functional and participation problems and self-management.

#### Goal-oriented care

Generally speaking, we conclude that the European DMPs we considered have several characteristics that make them more suitable to respond to particular patients' needs than traditional problem-oriented care. This especially holds for the process of collaborative goal-setting. In this process the personal targets of the

patient are discussed, while taking into account the individual patient's needs, preferences and abilities. This goal-oriented approach provides the opportunity to prioritize goals that really matter to the patient, for instance in the social domain of life. Nevertheless, all DMPs have their programme objectives and considering the indicators that are most often used to measure programme effectiveness (clinical parameters, hospital admissions and lifestyle changes), the issue of goal attainment from the patient perspective is not considered a decisive outcome at the moment. An additional problem in this respect is that a valid system to register patient priorities in clinical practice does not exist. It may be worthwhile to explore whether the International Classification of Functioning, Disability and Health (ICF<sup>41</sup>) can be used as a basis for the development of a clinical registration system that covers both patient priorities and patient relevant outcomes. Regarding prioritizing goals and care for people with multimorbidity, it may also be worthwhile to incorporate cross-disease or 'universal health outcomes'<sup>42</sup> in patients' assessments. Tinetti and colleagues recently demonstrated that disease-specific symptoms and impairments, which are the usual targets of treatment, account for much of the significant associations between several chronic diseases that are common in older adults and universal health outcomes such as self-rated health, activities of daily living (ADL) functioning and survival.<sup>42</sup> Knowing the contribution of disease-specific symptoms and impairments to universal health outcomes for people with multimorbidity will allow clinicians to consider treatment effectiveness across diseases, hence facilitating clinical decision making.

#### Patient perceived quality of care: process and outcomes

Structural assessment of patient perceived quality of care should be part of every DMP. To assess the quality of care from the patient perspective, several instruments are available such as CQ indices and the PACIC.<sup>43</sup> The PACIC (Patient Assessment of Chronic Illness Care) questionnaire

assesses whether, according to the patient, the care (s)he receives is patient-centred and proactive and incorporates collaborative goal-setting, problem-solving and follow-up support. The PACIC is based on CCM; it has been validated for several groups of chronic patients<sup>44,45</sup> and is now available in several languages. It should be noted however that this instrument as well as CQ indices assess patients' perceptions of the quality of the care process rather than patient perceived outcomes. Regarding patient perceived outcomes, it is important that we do not only assess outcomes 'from the patient perspective' (e.g. patient-rated health), but also outcomes outside the medical domain, which are considered particularly relevant or that are prioritized by individual patients, for instance being able to maintain social contacts, to participate in the labour market, to visit a theatre, to do the shopping, to ride a bicycle or to drive a car, or to experience autonomy in general. As mentioned above, the ICF-model may be useful to develop a comprehensive set of goal-oriented 'patient relevant outcomes'.

#### Development of support programmes for specific target groups

Another issue that needs further attention is the availability of appropriate programmes (within or linked to current DMPs) for chronic patients with limited functional or social resources and for patients with other cultural backgrounds. A prerequisite is that within existing DMPs equity indicators are collected. Moreover, the support needs of patient groups with lower access or worse health outcomes need to be studied in-depth in close collaboration with target patient groups. To improve current DMPs we also suggest to strengthen relationships with social care and community services. Greß *et al.*<sup>18</sup> already concluded that the link between health-care services and community resources and policies, as proposed in CCM, is often missing. Our observations tend to support this conclusion. Some developments towards more integration are visible (e.g. England, Tuscany) and may provide valuable information for other DMPs as well.

### Alternative models to manage multimorbidity

Judging from our survey we conclude that most European DMPs do not have a solid answer yet to the problem of multimorbidity. In many European countries disease management is of a very recent date and methods of linking DMPs or dealing with multimorbidity have to be developed yet. Some country-experts report the development of applications within DMPs to deal with prevalent comorbidities. Others report experiments with case management for patients with multiple conditions within or linked to existing DMPs.

Without trivializing the potential of DMPs to improve the quality of chronic illness care, disease management may not be the full answer to the challenges of ageing populations with multimorbidity. Therefore we suggest to reflect fundamentally on a different approach to address the needs of people with multiple chronic conditions. To respond adequately to the combined physical, functional, mental and social needs of these people, we believe that patient-centredness and goal-oriented care should be the key elements of such an approach as these allow crossing boundaries of individual diseases. Recently, a generic comprehensive model of goal-oriented care based within primary care has been proposed.<sup>46</sup> Primary care is ideally suited to the management of multimorbidity, as it puts the patient, his values and his social context at the centre of the care process rather than specific diseases. Hence, to implement such generic comprehensive models of care a strong primary care system is necessary.<sup>47</sup> This is not to say that primary care is the only type of care that should be involved. We believe that chronic illness care could benefit from strong relationships with social care and community facilities. Naturally, specialized medical care may be necessary in some phases of the illness process as well.

We suggest some components of the proposed generic care model that should be taken into account in the management of multimorbidity:

1. shared-decision making with patients (and their families) to prioritize goals and care options from the patient perspective;

2. assessing the feasibility and acceptability of non-medical treatment and preventive behaviours for patients, and exploring their self-efficacy and health beliefs;
3. consider possible harm of medical interventions, e.g. being attentive to possible interference of medicines and side-effects (principle of 'primum non nocere');
4. assessing the feasibility and acceptability for patients of medication intake in case of polypharmacy and exploring patients' medication concerns;
5. assessing the total burden of treatment (not only drug management, but also patients' efforts to organize and coordinate care and to gain knowledge and abilities to share in decision making) for individual patients and to tailor their care to patients' daily lives (call for 'minimally disruptive medicine'<sup>48</sup>);
6. closely monitoring of the development and impact of functional limitations and impairments;
7. increasing the 'social capital' through the establishment of intersectoral relationships with community services and organizations to prevent or reduce participation problems (e.g. social isolation, being housebound, unemployment).

This latter component asks for structural investment in building strong relationships with social care and local community services. In addition, research is needed to help clinicians gain knowledge and skills to address these components in daily practice and to make changes in health-care systems to support patient-centredness and goal-oriented care. In order to increase the quality of chronic illness care, it is important that universal health outcomes and outcomes that address patients' goals are assessed in DMPs and other care programmes as well.

### Acknowledgements

We wish to thank the following country-experts for their substantial efforts to provide data about disease management programmes in their country: Caroline Baan PhD (RIVM, the Netherlands), Yann Bourgueil MD (Irdes,

France), Assoc. Prof. Niels H. Chavannes MD PhD (Dept Public Health and Primary Care, Leiden University Medical Center, the Netherlands), Toni Dedeu MD (Barcelona Research Institute of Health and Social Services Assessment, Spain), Antje Erler MD MPH (Goethe-University Frankfurt, Germany), Prof. Stefan Greß MD PhD (University of Applied Sciences Fulda, Germany), Stephanie Heineman MPH (University of Applied Sciences Fulda, Germany), Claire Janssens MD (NIDHI, Belgium), Luc Maroy (NIDHI, Belgium), prof. A. Niroshan Siriwardena MB MMedSci PhD (University of Lincoln, UK), Luca Valerio MD (European Public Health Association/Catholic University of the Sacred Heart, Rome, Italy).

### Source of funding

The writing of this article was funded by NIHDI, the Belgian federal institute for health and disability insurance. The survey we report upon in this article was initiated by the European Forum for Primary Care and financed by NIHDI.

### Conflict of interest

None.

### References

- 1 TNS Opinion & Social. Health in the European Union, Special Eurobarometer 272e. Brussels: European Commission, 2007.
- 2 European Statistics of Income and Living Conditions. Eurostat (Statistical database of the European Union), 2009.
- 3 van Weel C, Schellevis FG. Comorbidity and guidelines: conflicting interests [Comment]. *Lancet*, 2006; **367**: 550–551.
- 4 Caughey GE, Vitry AI, Gilbert AL, Roughead EE. Prevalence of comorbidity of chronic diseases in Australia. *BMC Public Health*, 2008; **8**: 221.
- 5 Rijken M, van Kerkhof M, Dekker J, Schellevis FG. Comorbidity of chronic diseases. Effects of disease pairs on physical and mental functioning. *Quality of Life Research*, 2005; **14**: 45–55.
- 6 Hoeymans N, Schellevis FG, Wolters I. Hoeveel mensen hebben één of meer chronische ziekten? In: *Volksgezondheid Toekomst Verkenning, Nationaal Kompas Volksgezondheid*. The Netherlands, Bilthoven: 2008.
- 7 Nolte E, McKee M, Knai C (eds). Managing chronic conditions: an introduction to the experience in eight countries. In: *Managing chronic conditions. Experience in eight countries*. Observatory Studies Series no 15. European Observatory on Health Systems and Policies, 2008.
- 8 Mold JW, Blake GH, Becker LA. Goal-oriented medical care. *Family Medicine*, 1991; **23**: 46–51.
- 9 Boeckxstaens P, Bekaert S, De Sutter A, De Maeseeneer J. Translational research and multimorbidity: a need for a paradigm-shift. *International Public Health Journal*, 2011; **3**: 207–214.
- 10 Wagner EH, Austin BT, Von Korff M. Organizing Care for Patients with Chronic Illness. *Milbank Quarterly*, 1996; **74**: 511–544.
- 11 Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A. Improving chronic illness care: translating evidence into action. *Health Affairs*, 2001; **20**: 64–78.
- 12 Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness. *JAMA*, 2002; **288**: 1775–1779.
- 13 Zitter M. A new paradigm in health care delivery: disease management. In: Todd WE, Nash D (eds) *Disease Management: A Systems Approach to Improving Patient Outcomes*. Chicago: American Hospital Association, 1997: 1–25.
- 14 Weingarten SR, Henning JM, Badamgarav E *et al.* Interventions used in disease management programmes for patients with chronic illness – which ones work? Meta-analysis of published reports *British Medical Journal*, 2002; **325**: 925.
- 15 Faxon DP, Schwamm LH, Pasternak RC *et al.* Improving quality of care through disease management: principles and recommendations from the American Heart Association's Expert Panel on Disease Management. *Circulation*, 2004; **109**: 2651–2654.
- 16 DMAA: The Care Continuum Alliance. DMAA Definition of Disease Management, 2006. Available from: [http://www.dmaa.org/dm\\_definition.asp](http://www.dmaa.org/dm_definition.asp), accessed 24 June 2010.
- 17 Schrijvers G. Disease management: a proposal for a new definition. *International Journal of Integrated Care*, 2009; **9**: 1–3.
- 18 Greß S, Baan CA, Calnan M *et al.* Co-ordination and management of chronic conditions in Europe: the role of primary care – position paper of the European Forum for Primary Care. *Quality in Primary Care*, 2009; **17**: 75–86.
- 19 Ritchie C. Health care quality and multimorbidity. The jury is still out. *Medical Care*, 2007; **45**: 477–479.
- 20 Boyd CM, Darer J, Boulton L, Fried LP, Boulton L, Wu AW. Clinical practice guidelines and quality of care



- for older patients with multiple comorbid diseases. Implications for pay for performance. *JAMA*, 2005; **294**: 716–724.
- 21 De Maeseeneer JM, van Driel ML, Green LA, van Weel C. The need for research in primary care. *The Lancet*, 2003; **362**: 1314–1319.
  - 22 Leys M. *A Social Science Perspective on Care for Chronically Ill People. Relevance for Public Health and Healthcare Policy Making*. Brussels: Vrije Universiteit Brussel, October 2010.
  - 23 de Klerk M. Aantal mensen met beperkingen en/of chronische ziekten. [Number of people with disability and/or chronic conditions.] In: Klerk MMY de. Rapportage gehandicapten 2000. Arbeidsmarktpositie en financiële situatie van mensen met beperkingen en/of chronische ziekten. [Report on disabled people 2000. Labour market position and financial situation of people with disability and/or chronic conditions.] The Hague: Netherlands institute for social research, 2000.
  - 24 Heijmans M, Spreeuwenberg P, Rijken M. *Ontwikkelingen in de zorg voor chronisch zieken. Rapportage 2010 [Developments in chronic care. Report 2010]*. Utrecht: NIVEL, 2010.
  - 25 Von Korff M, Gruman J, Schaefer J, Curry SJ, Wagner EH. Collaborative management of chronic illness. *Annals of Internal Medicine*, 1997; **127**: 1097–1102.
  - 26 Heijmans M, Foets M, Rijken M, Schreurs K, de Ridder D, Bensing J. Stress in chronic disease: do the perceptions of patients and their general practitioners match? *British Journal of Health Psychology*, 2001; **6**: 229–242.
  - 27 Lorig K. Self-management of chronic illness: a model for the future. *Generations*, 1993; **17**: 11–14.
  - 28 Lorig K, Holman H. Arthritis self-management studies: a twelve-year review. *Health Education Quarterly*, 1993; **20**: 17–28.
  - 29 Rijken M, Jones M, Heijmans M, Dixon A. Supporting self-management. In: Nolte E, McKee M (eds) *Caring for People with Chronic Conditions. A Health System Perspective. European Observatory on Health Systems and Policies Series*. Berkshire, UK: Open University Press, 2008: 116–142.
  - 30 National Primary Care Research and Development Centre. WISE. Whole System Informing Self-management Engagement. NPCRDC, University of Manchester, 2008.
  - 31 Rijken M, Bekkema N. *Chronic Disease Management Matrix 2010. Results of a Survey in Ten European Countries*. Utrecht, The Netherlands: NIVEL, 2011.
  - 32 van Schilfgaarde R. Implementation of the ‘Standard of diabetes care’: the approach in The Netherlands. Presentation at the Health Executive Summit in Paris, May 19–21, 2010 (presentation can be downloaded from <http://www.zonmw.nl>, programme disease management, accessed 14 December 2010).
  - 33 Steultjens MP, Dekker J, Bijlsma JW. Avoidance of activity and disability in patients with osteoarthritis of the knee: the mediating role of muscle strength. *Rheumatoid Arthritis*, 2002; **46**: 1784–1788.
  - 34 Barr VJ, Robinson S, Marin-Link B *et al.* The Expanded Chronic Care Model: an integration of concepts and strategies from population health promotion and the Chronic Care Model. *Hospital Quarterly*, 2003; **7**: 73–82.
  - 35 Jadad AR, Cabrera A, Lyons RF, Martos F, Smith R (eds) *When People Live with Multiple Chronic Diseases: A Collaborative Approach to an Emerging Global Challenge*. Granada: Escuela Andaluze de Salud Pública (Andalusian School of Public Health), 2010.
  - 36 Chen A, Brown R, Archival N, Aliotta S, Fox PD. *Best Practices and Coordinated Care*. Princeton, NJ: Mathematica Policy Research, 2000.
  - 37 Department of Health. Our health, our care, our say: a new direction for community services. White paper. UK department of Health, January 2006.
  - 38 National Health Service. *High Quality Care for All. NHS Next Stage Review – Final Report*. London: NHS, 2008.
  - 39 Damman OC, Stubbe JH, Triemstra AHM, Spreeuwenberg P, Delnoij DMJ. Comparative health care information: consumer quality index (CQI) information on differences between providers. *European Journal of Public Health*, 2007; **17** (2 Suppl): 34.
  - 40 Kerssens JJ, Groenewegen PP, Sixma HJ, Boerma WGW, van der Eijk I. Exploration of patient evaluations of health care quality in 12 different European countries in relation to health system performance. *European Journal of Public Health*, 2003; **13** (4 Suppl): 77.
  - 41 World Health Organization. *International Classification of Functioning, Disability and Health: ICF*. Geneva: WHO, 2001.
  - 42 Tinetti ME, McAvay G, Chang SS *et al.* Effect of chronic disease-related symptoms and impairments on universal health outcomes in older adults. *Journal of the American Geriatrics Society*, 2011; **59**: 1618–1627.
  - 43 Glasgow RE, Wagner EH, Schaefer J, Mahoney LD, Reid RJ, Greene SM. Development and validation of the Patient Assessment of Chronic Illness Care (PACIC). *Medical Care*, 2005; **43**: 436–444.
  - 44 Aragones A, Schaefer EW, Stevens D, Gourevitch MN, Glasgow RE, Shah NR. Validation of the Spanish translation of the Patient Assessment of Chronic Illness Care survey. *Preventing Chronic Disease Public Health Research, Practice and Policy*, 2008; **5**: 1–10.



- 45 Wensing M, van Lieshout J, Jung HP, Hermsen J, Rosemann T. The Patients Assessment Chronic Illness Care (PACIC) questionnaire in the Netherlands: a validation study in rural general practice. *BMC Health Services Research*, 2008; **1**: 182.
- 46 De Maesener J, Roberts RG, Demarzo M *et al.* Tackling NCDs: a different approach is needed. *The Lancet*, 2011; DOI: 10.1016/S0140-6736(11)61135-5.
- 47 World Health Organization. The World Health Report 2008. Primary Health Care Now more than ever. Geneva, Switzerland: WHO, 2008. Available from: [http://www.who.int/whr/2008/whr08\\_en.pdf](http://www.who.int/whr/2008/whr08_en.pdf), accessed 8 September 2011.
- 48 May C, Montori V, Mair F. We need minimally disruptive medicine. *British Medical Journal*, 2009; **339**: 485–487.