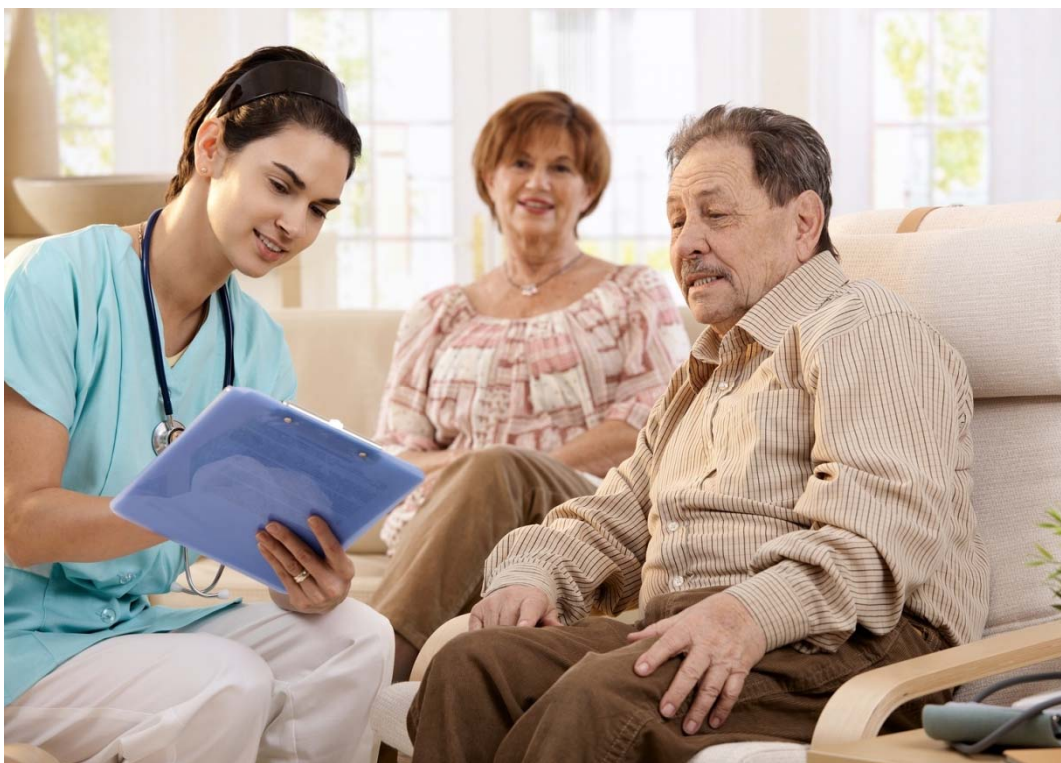


POSITION PAPER: ORGANISATION OF CARE FOR CHRONIC PATIENTS IN BELGIUM



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■ POSITION PAPER

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1. CHRONIC DISEASES: A CHALLENGE FOR THE HEALTH CARE SYSTEM

1.1. Chronic diseases remain a priority for the Belgian health authorities

In 2008, the Minister of Public Health & Social Affairs issued a national programme on "Priority to chronic patients!"¹ and a first inventory of its implementation took place in 2012².

This programme mainly focuses on five objectives:

- Improving the information for chronic patients and streamlining of administrative procedures to improve the access to the existing benefits and measures;
- Alleviating the financial burden for the chronically ill through a series of regulatory measures;
- Improving the day-to-day situation in terms of access to and quality of care for a long list of disease-specific target groups;
- Addressing the needs of patients with rare diseases;
- Initiating the setup of the Observatory for Chronic Diseases.

This position paper also mentions financial accessibility, administrative simplification and rare diseases but it will not go too closely into these matters as they have been addressed in the above mentioned plan.

If we want to improve the care for the chronically ill in a fundamental and sustainable way, we will have to address the care provision processes and the roles of and relationships between the different actors. First, the development of a comprehensive, long-term vision on how the healthcare system should evolve towards more integration and continuity of service provision to genuinely better serve the needs of the chronically ill.

A reflection process along these lines was pursued. In follow-up of the Ministerial Conference on Innovative Approaches for Chronic Illnesses in Public Health and Healthcare Systems and the EU Council Conclusion in December 2010³, the Minister commissioned the Belgian Health Care Knowledge Centre (KCE) to develop a position paper on the care of patients with chronic disease, in collaboration with the National Institute for Health and Disability Insurance (NIHDI/RIZIV/INAMI) and the Federal Public Health Services. The Regions and Communities contributed to the development of this position paper by the involvement of representative stakeholders in the steering group.

1.2. Chronic diseases: a challenge for all health care systems

1.2.1. Strategies proposed by international organisations

The international papers published by the United Nations, European Union and World Health Organization lay a basis for action in European countries⁴⁻¹⁴ (see scientific report, chapter 2.1). They emphasize:

- The importance of chronic diseases in terms of deaths and morbidity;
- The major role of social determinants and lifestyle factors, in particular tobacco, diet, alcohol and physical activity;
- The importance of multisectoral, cost-effective actions in the fields of health promotion and prevention;
- The need for strengthening health systems (national programmes, appropriate workforce, evidence-based actions);
- The major role of the first line of care, embedded in the community, offering a necessary link to more specialized health care services according to the patient's needs;
- The importance of data exchange systems;
- The need to develop integrated care models centred on the patient¹⁵. Some studies have shown the positive impact of their implementation in the community¹⁶⁻¹⁸.



1.2.2. Prevalence of chronic diseases in Europe

Chronic diseases have become the major cause of morbidity and mortality across the globe, accounting for 63% of deaths. Cardiovascular diseases (48% of deaths from non-communicable diseases), cancers (21% of deaths from non-communicable diseases), diabetes and chronic respiratory diseases are the most common causes of death in Europe⁹. However, a chronic disease has usually one or several risk factors in common with other diseases, and may have consequences on other systems (e.g. cardiovascular problems linked to diabetes). Consequently, the problem of chronic diseases is also a problem of frequent multimorbidity, as explained below¹⁹.

The growing prevalence of chronic diseases has an impact on the health care system and on society as a whole: chronic diseases impact on the home environment, family networks, social support services and workforce. In particular, vulnerable and socially disadvantaged groups carry a greater chronic disease burden. European governments are being challenged to integrate policies, budgets and service provision to suit the needs of the persons with a chronic condition^{20,21}.

1.3. Prevalence of chronic diseases in Belgium

The leading causes of death in our country are those of the European region: diseases of the circulatory system (33%) and tumours (27%)²².

The figures from the health interview survey²³ give an estimate of the prevalence of risk factors and self-reported chronic diseases in Belgium.

- A quarter (27,2 %) of the adult population reports at least one chronic condition; among the most frequent are low back pain (17,7%), allergy (13%), arthritis (12,7%), hypertension (12,7%), neck pain (9,4%), chronic headaches (8,1%), respiratory diseases (7.9%);
- Common mental disorders include chronic anxiety (4,6%), depression (4,9%) and 'serious psychological problems'(14%);
- Diabetes is reported by 3.4% of the respondents;
- Nearly half of the population reports pain (severe pain in 12%);
- Nearly one fifth (17,1%) of the population suffer from related functional limitations.

Risk factors for chronic diseases are more frequently reported by persons with a lower socio-economic status: overweight (47%), absence of physical activity (26%), smoking (a quarter of the population) and drinking ("overconsumption" in 10% of the men and 6% of the women).

1.4. Importance of multimorbidity

The challenge of chronic diseases is the co-occurrence of multiple diseases and medical conditions within one person, called "multimorbidity". Globally this prevalence increases with age in the general population²⁴ but other factors associated with a high risk of multimorbidity are a low level of education, obesity, tobacco and alcohol consumption^{25,26}. The lack of comparability between studies precludes from giving a unique estimate of the prevalence but as an illustration, the prevalence of at least 2 conditions in the general population ranges between 10% and 20% around 40 years and increases to 50-70 % in the population aged 70 years or more²⁷.

1.5. A burden for the frailest patients

Multimorbidity is synonym of an additional burden for the patient²⁸. Complex drug management and interactions with multiple care providers are aggravated by a monodisciplinary approach of the disease and a poor coordination between caregivers. A transition to less disruptive medicine calls for the identification of the patient's needs, the set up of priorities from his/her own perspective, coordination in clinical practice and the development of clinical evidence for multimorbidity.



1.6. Escalating costs of chronic diseases

The economic impact of chronic diseases extends well beyond the health care system²⁹: productivity losses for employers and indirect costs for the patients and their family are major consequences. They create vulnerabilities e.g. due to reduced (or in-)ability to work and the resulting loss of income and risk of poverty.

As illustrations, the European Union Policy Forum⁶ and Belgian studies cite the following figures on the costs for chronic diseases:

- Cardiovascular diseases cost the EU economy € 192 billion a year⁶. A Belgian study gave an approximation of € 3.5 billion for the year 2004, with the largest part (59%) being incurred by the National Institute for Health and Disability Insurance³⁰.
- Cancer treatment has financial implications for patients and families due to increased household costs, loss of income, use of savings for treatment. A Belgian study estimated that total average costs attributable to breast cancer amounted to € 107 456 for the society, over a period of 6 years (from 1 year before diagnosis to 5 years at follow-up)³¹. Productivity loss costs represented the major part of the total amount (89%).
- The 5 major respiratory diseases (asthma, lung cancer, chronic obstructive pulmonary disease, pneumonia and tuberculosis) cause a financial burden of over € 100 billion in Europe (health care costs and lost working days)⁶;
- Diabetes affects nearly 10% (52.8 million) of the adult population in the WHO Europe region with a cost of € 131 billion⁶.

Little is known about the costs of multimorbidity. Globally, about 70% to 80% of healthcare costs would be spent on chronic diseases⁶. This corresponds to € 700 billion in the European Union, a budget that is expected to rise in the coming years.

A recent review of the literature³² points out that there is uncertainty regarding to what extent the factors usually cited in the literature (demographic, health related, economic and social factors) contribute to increase health expenditures. Still a focus on promoting healthy ageing may reduce health care costs relating to a large elderly population. Moreover, making use of health technology assessment and increasing patient participation in decision process may improve efficient use of health resources³².



2. WHAT IS A CHRONIC DISEASE? FROM A DISEASE-ORIENTED TO A NEEDS-BASED CONCEPT

The diverse national and international initiatives and programmes set up to improve the care for the chronically ill, almost invariably address a disease-specific (or at least medically defined) target group. Examples are the care trajectories in Belgium, the 'affections de longue durée' in France³³. Policy interventions are often oriented towards patients with diabetes, chronic lung conditions or cardiovascular diseases. Yet, a WHO publication on health system research states that disease specific interventions are unlikely to bring about changes at the health care system level: they multiply investments in parallel programmes, focus on actions at the local level and jeopardize the implementation of long-term strategies³⁴.

The World Health Organization defines chronic diseases as "diseases of long duration and generally slow progression"¹⁰. This definition covers a wide range of health problems, mostly non-communicable diseases e.g. diabetes, cancer, musculoskeletal, respiratory, neurodegenerative, mental and cardiovascular diseases.

Beyond the concept of disease, there is an even more important concept for the organization of care, which is that a person with chronic disease(s) has needs that evolve according to the stage of the disease.

2.1. Multiplicity of patients' needs

The needs of the patient with long-term disease may be grouped along five main dimensions³⁵:

- **Biological needs:** mainly the relief of the physical symptoms, as pain;
- **Psychological needs** with two major components:
 - need for tailored information (e.g. on treatment options, evolution of the disease);
 - need for psychological support: to deal with emotions (fear, frustration, depression, distress) related to the chronic condition;
- **Health care services needs:** coordination of care provision and integration between the different settings;
- **Social needs:** can be a major concern for chronic patients, in particular issues in relation to their autonomy and social isolation,
- **Spiritual needs:** the search for meaning, which can go beyond religious beliefs.

A major characteristic of chronic care is that the evolution of the disease requires adapted interventions to respond to changing needs. Home care services play a major role most of the time but acute services are necessary in case of acute episodes whereas end-stage diseases call for accessible palliative care.

The conclusions of a KCE report are as follows³⁵:

- The care of a patient with long-term illness should be based on the patient's needs;
- Meeting a need depends on the individual perspective: a patient may assert that his/her need was met whilst (informal) caregivers disagree;
- Not all needs imply a professional intervention: the informal caregivers and the social network are often an invaluable help for the patient.



2.2. Needs-based approach for chronic care

The needs-based approach of the successful palliative support system that exists in our country can serve as an instructive example for the future of chronic care. Services are no longer vertically tailored along disciplines: they are rather developed (be it still vertically) and then integrated horizontally in a flexible way so as to adapt to the specific patient needs and to articulate with the locally available care and support structures. The future chronic care provision should adopt this integrative approach by placing the needs and expectations of the patient at the centre.

Consequently, in this position paper a patient with chronic disease is defined as a person with a set of needs:

- **along different dimensions (biological needs, psychological needs, etc.),**
- **in a more or less complex and individually specific combination,**
- **that are prolonged or permanent and evolving over time.**

The healthcare system has to develop new functions and skills, in order to address this multidimensional, prolonged and individually tailored nature of the needs. This entails a radical change from the classic acute-episode-oriented, biomedical, specific-expertise-driven functioning of our healthcare system.

3. IMPORTANCE OF PATIENT EMPOWERMENT

The importance of patient empowerment is underlined by international papers³⁶, by the Belgian programme “Priority to chronic care patients!”¹ as well as by other national plans on chronic care (see scientific report chapter 2.3). Clearly, the old paternalistic image where the patient passively undergoes the treatment is far behind us. However, the stakeholders interviewed in this study pointed out that today limited effort is put into the empowerment of the informal caregivers and the patients themselves.

A systematic literature review on the techniques to foster patient's empowerment is detailed in chapter 6.1 of the scientific report. The adopted definition is mainly based on the work in this field by Bodenheimer et al. 2002³⁷ who defines self-empowerment as follows: “patients accept responsibility to manage their own conditions and are encouraged to solve their own problems with information, not orders, from professionals”. In the literature this concept of patient empowerment is closely related to other terms: patient self-efficacy, patient self-management and patient self-care (see definitions in section 6.3.1.1 of the scientific report).

The following interventions demonstrated (or not) their efficacy:

- Self-management programmes

These interventions are designed to improve patients' knowledge and skills to manage their chronic disease (e.g. educational sessions, written materials, motivational counseling). These interventions are usually successful for different chronic diseases: musculoskeletal pain, epilepsy, diabetes, mental health, hypertension, asthma³⁸⁻⁴⁴. Face-to-face interventions tailored to the patient are more effective, for example in the irritable bowel syndrome⁴⁵.

However other studies had inconclusive results in patients with chronic pulmonary disease⁴⁶⁻⁴⁸, heart failure⁴⁹⁻⁵¹, stroke⁵²⁻⁵⁴, kidney disease⁵⁵ and multiple sclerosis⁵⁶.



- Patient education with self-efficacy elements

Education including self-efficacy elements has usually a positive impact on symptoms and other patient outcomes (e.g. self-management). The programmes were provided in groups or on an individual basis for the following diseases: asthma⁵⁷, diabetes⁵⁸⁻⁶⁰, chronic obstructive pulmonary disease⁶¹, heart failure^{62, 63}, irritable bowel syndrome⁶⁴, kidney disease⁶⁵ and pain⁶⁶.

Two studies on rheumatoid arthritis⁶⁷ and diabetes⁵⁸ could not demonstrate the impact of these interventions.

- Psycho-educational interventions: their positive effects were demonstrated for fibromyalgia⁶⁸ and schizophrenia⁶⁹ but no conclusion can be drawn for angina⁷⁰ and asthma^{71, 72}.
- Interventions designed to meet the needs of specific cultural groups: they improved asthma symptoms⁷³ and diabetes' outcomes⁷⁴⁻⁷⁶.
- The effect of computer-based interventions was usually not demonstrated (hypertension⁷⁷, fatigue associated with neurological disease⁷⁸, chronic pain⁷⁹) except for children with asthma⁸⁰.

The scientific literature concludes that patient-empowering interventions are more likely to be successful when they are intensive, tailored to the patient's needs, using a wide range of approaches and multiple delivery strategies, and targeting also the informal caregivers.

4. SCOPE AND METHODS

4.1. Scope of the position paper: focus on chronic care and support delivered by the healthcare system

4.1.1. Importance of "health in all policies"

"Health in all policies" relates to the social determinants of health. The Commission on Social Determinants of health set up by the WHO⁸¹ expressed recommendations on this topic to tackle the problem of chronic diseases:

- Improving living conditions: education, nutrition, healthy places for living, working conditions, social protection, universal health care;
- Tackling the inequitable distribution of power, money and resources e.g. health equity in all policies, fair financing, gender equity, political empowerment of all groups in society;
- Measuring the problem and assessing the impact of action by monitoring and research on determinants of health.

The objective is to decrease the prevalence of risk factors and thereby the incidence of chronic diseases. However the action domains are multiple and require the involvement of policy-makers and actors from many sectors (housing, employment, fight against poverty) that go well beyond the health care system.

4.1.2. Scope of the position paper: focus on care and support delivered by the healthcare system

The partners involved in this project recognize the importance of "health in all policies" as well as the need for primary prevention. However they agreed to limit the scope of this position paper to the care (including the prevention of complications) provided by the healthcare system for patients suffering from chronic conditions.

On the one hand, addressing all different dimensions of the care for chronic patients, including primary prevention (screening, counselling, immunization and chemo-protection) and 'health & health equity in all policies' would demand to take into account a very wide and diverse set of interrelated factors that impact on health (housing, physical environment, lifestyle, and socioeconomic status). This was impossible to realize within



the timeframe imposed on this project but also went far beyond the competency domains of KCE.

On the other hand, the limited scope offers a meaningful framework to develop a coherent set of recommendations addressing a finite and well-identified target group of actors, who have the potential to substantially push forward a highly relevant part of the solutions.

4.2. Combination of methods

The proposals of this position paper rely on a combination of several approaches:

- A more theoretical, deductive approach⁸²: starting from (1) an analysis of the main international papers that advocate for national policies for chronic care, and from (2) a review of the (effectiveness of) policies for chronic care in four selected countries. The researchers started from these general proposals and applied them to a specific situation i.e. an ideal health care system oriented towards chronic care (with the activities required to bring that vision into practice);
- A more inductive approach (i.e. from facts to general situations)⁸² with the addition of data from:
 - previous KCE reports,
 - a systematic literature review on the techniques for patient self-empowerment,
 - an overview of new profiles and functions in the health care system, based on the situation in other countries;
 - a review of relevant initiatives in Belgium;
 - consultations of stakeholders on the strengths and weaknesses of the Belgian health care system for meeting the needs of the chronically ill, including also a critical look on the past initiatives regarding coordination structures in our country.

The draft report of the position paper has been submitted to several groups of stakeholders with different backgrounds: the project steering committee (mainly representatives from authorities and patient associations), two groups of experts with relevant experience fielding this domain and the scientific and the consultative committees of the newly installed “Observatory for Chronic Diseases”.

5. A VISION ON THE FUTURE ORGANISATION OF CHRONIC CARE IN BELGIUM

The paragraphs below describe:

- The vision of the organisation of chronic care in Belgium;
- The conceptual model developed to show how the system will realize its purpose.

5.1. Vision of the provision of chronic care in the Belgian health care system

5.1.1. Sources

The vision and conceptual model are based on insights that emerged from the analysis of:

- The Chronic Care Model published in the international literature⁸³ that lists the key features that determine chronic care of high quality:
 - Self-management support e.g. patient information, collaborative decision, guidelines for patients;
 - Decision support e.g. guidelines for health providers;
 - Delivery system design e.g. team practice, coordination of care;
 - Clinical information systems e.g. computerized information, registries;
 - Community resources and policies as for example physical activity programmes;
 - Health care organization e.g. leadership and definition of organization's goals.
- The reports from international organizations (United Nations, European Union and World Health Organisation) (see section 1.2.1);
- The policies for patients with chronic conditions in 4 countries (see scientific report chapter 2.3);
- The attributes of chronic care of high quality analysed in KCE reports^{84,85};



- Discussions with stakeholders and within the research team;
- A previous similar exercise for child and adolescent mental health care⁸⁶.

This vision refers to an idealized system: it will help to define further the requisite activities needed to support this idealized system.

5.1.2. Core vision

The health care system offers in terms of chronic care an array of services:

- **for and with people with chronic conditions, requiring ongoing management over a period of years or decades,**
 - **to help these people to improve their quality of life and to function better at home, at work/school, in the community and throughout life.**
- Beneficiaries: people with chronic conditions and their families/informal caregivers.
 - Delivering of services: the services are provided during the continuum of the chronic disease i.e. routine management, management of acute episodes and supportive care. These services extend beyond the boundaries of the healthcare system. As noted in section 4.1.2, health promotion, prevention, screening and early detection are of utmost importance but beyond the scope of this study.
 - Outcomes: the ultimate aim of the services is to help people to improve their quality of life and to function better in society - at home, at school, at work and in their communities. This requires a shift of paradigm, from problem-oriented to goal-oriented care⁸⁷. This vision of the ideal outcomes is in line with the vision of the International Classification of Functioning, Disability and Health (ICF)⁸⁸. As a matter of fact this classification based on a biopsychosocial model that integrates the medical but also the social consequences of disability.

5.1.3. Additional qualifications

This core of the vision is supplemented with additional qualifications: how is the purpose realized (modus operandi)? Who are the actors involved? Who 'owns' the system? What are crucial constraints in which the system has to operate?

5.1.3.1. Modus operandi

The following qualifiers specify how, ideally, a health care system oriented towards the delivery of chronic care should deliver services.

1. Co-ordinated: co-ordination is one key requirement of the chronic care model^{37,83}. Experiences in other countries showed a move towards a higher level of co-ordination between health services and also between health and social services.
2. Integrated care (closely related to the former concept): WHO defines it as "the management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system"¹⁵. In this document integrated care more specifically refers to a vertical integration between lines of care whilst the word "coordination" mentioned in the former point refers to multi-professional teams that work within the same level of care.
3. Person and goal-oriented: chronic care aims to assist individuals in achieving their maximum individual health potential in line with their individually defined goals in a planned way^{89,90}. One important determinant is the complexity of the care and social problems that will determine the complexity and coordination of the proposed solutions.
4. Sustainable: the system's capacity to provide and to maintain infrastructure such as workforce, facilities and equipment, whilst being innovative and responsive to emerging needs⁸⁴. The evaluation of the sustainability encompasses indicators on financial sustainability (e.g. healthcare expenditures), on workforce (for example the number and qualification of health professionals) and facilities (e.g. number of acute care beds).



5. Professionally supported: a human resource continuum, able to meet the range of needs of people with chronic conditions (from minimal personal assistance to daily total care), is essential to ensure that the right patients get the right type of care at the right time^{90, 91}. This professional network involves many different professionals and specialists working as teams.
6. Care of high quality, based on the best available evidence: safety, effectiveness, appropriateness (i.e. relevant to the clinical needs, given the current best available evidence), patient centeredness, timeliness, efficiency, equity, comprehensiveness⁹² and continuity of care are dimensions of high-quality care that have been described in previous KCE-reports^{84, 85, 93}.
7. Patient empowerment: “self-empowerment” places the patient in the centre of his/her care: empowered patients are more able to care for their health and for the interactions with health care professionals (cf. chapter 3).
8. Provide the care in the least complex environment that is clinically appropriate: whenever possible, (less complex) home-based or outpatient services will be provided instead of costly residential services.

5.1.3.2. *Actors*

Many actors contribute to the system e.g. GPs and primary care teams, community nurses, nurse practitioners, specialists, family caregivers, physiotherapists, speech and language therapists in different settings.

5.1.3.3. *Owner*

The Belgian (chronic) care system is for the largest part funded by public money, but private for profit and not-for-profit actors play a role in the provision of care as described in the profile of Belgium⁹⁴. Reforms need a shared ownership of the care providers and the authorities to implement successful changes.

5.1.3.4. *Constraints*

The available limited budget exerts an important influence on the health care system in general and on chronic care in particular. Moreover, the current professional and social/medical fragmentation in “pillars” (e.g. different sickness funds, private versus public institutions) might influence the implementation of the ideal organization of care for patients with chronic needs.

5.1.4. *Expanded vision of the provision of chronic care within the health care system*

In light of the qualifications added above, the vision can be formulated as follows:

The chronic care system offers a co-ordinated array of needs-based, personalized, goal-oriented, planned, professionally supported services for and with persons with chronic conditions requiring assistance over years or decades with the routine management of their condition as well as the management of acute care episodes. These services are provided in a high quality, efficient, sustainable, accessible, culturally competent and patient empowering manner in the least complex environment that is clinically appropriate. The objective is to improve the beneficiaries’ quality of life and to help them to function better at home, at school/work, in the community.



5.2. Conceptual model: activities to implement the vision of chronic care

Based on this vision, the conceptual model below shows the activities to be carried out to realize the purpose of a health care system oriented towards chronic care. This model is composed of 17 different activities, grouped in 6 functional modules (see scientific report, chapter 3).

5.2.1. Module 1: plan, provide and coordinate routine care

The 4 constituent activities are:

- To develop/revise individualized, needs-based plan of care with patient/family: this activity requires few resources when patients are in a steady stage of a single chronic condition. More effort is needed in case of multimorbidity and/or regular acute episodes;
- To provide services and support: in Belgium the routine care services (individual health promotion, preventive and curative care) are typically delivered by the GP and home nurse. They are also delivered at school/work or in residential facilities (e.g. psychiatric institutions, nursing homes);
- To monitor and evaluate progress: this monitoring gives professionals and patients/family a basis to decide on the nature and extent of the care pathway;
- To provide care coordination: this activity focuses on the coordination of daily routine care.

5.2.2. Module 2: provide acute episode response and specialized services

Acute episode response and specialized services are in a second module but a link is required with routine care. They play a role in case of

- need for more intensive care in acute situations (for example pneumonia with a significant decrease of the pulmonary function);
- need for more complex care when the chronic situation deteriorates and requires specialized care to reorient the treatment (for example a progressive evolution of the cardiac insufficiency that does not answer to ambulatory treatment).

There is a need for dedicated activities, tools, infrastructure and resources to provide a seamless transition between routine care and acute episodes response and specialized services (link between the first and the second modules).

5.2.3. Module 3: conduct early identification

This module encompasses 2 activities: the development of broad detection skills (i.e. in primary care workers, occupational healthcare workers) and the screening of target populations when appropriate.

5.2.4. Module 4: support patient/informal caregiver empowerment (including self-management)

The chronic care vision developed in this position paper resolutely puts the patient in the centre. In that way, helping the patient to take their own health and wellbeing in hands is just a concrete implementation of the ethical principle of autonomy^{95, 96}.

As mentioned above (see 5.1.1 and 5.1.3.1), patient empowerment is an essential element of chronic care, including self-management and the support of informal caregivers. This module consists of 2 activities:

- To develop new provider skills and tools (e.g. patient diaries; guidelines/educational materials) for patient/caregiver empowerment;
- To provide empowerment services and support (information, coaching, peer support, training by formal and informal services).

5.2.5. Module 5: conduct health promotion and prevention activities

This module aims to prevent the onset of chronic illnesses and to postpone the age of onset. Despite its importance, it was agreed to keep this module outside this position paper (see 4.1). The prevention and health promotion module consists of 2 activities:

- To promote “Health in All Policies”, that addresses all policies such as transport, housing, the environment, education, fiscal policies, tax policies and economic policies. This activity requires multisectoral action for health, by all health authorities⁹⁷;
- To organize primary prevention activities targeting the main risk factors for chronic diseases.



5.2.6. Module 6: implement and follow-up a dynamic care model

The system must have the capacity to adapt itself and to refine the care model in the light of developments in society, in science, in the expectations of people with chronic conditions and in the economic reality.

The development and updating of a care module is an activity that incorporates four other activities:

- To base the model on societal values to reflect and respond to dominant trends in society;
- To assess the needs of people/ family with chronic conditions;
- To identify state-of-the-art practices, novel developments and techniques (e.g. the development of evidence based guidelines for the chronic care target population). Besides medical evidence, the knowledge base should include 'contextual' (i.e. what works in routine practice) and 'policy' (efficiency, equity on a national level) considerations.⁹⁸
- To incorporate budgetary/ resources constraints.

5.2.7. Requirements for the above mentioned activities

A set of 6 requirements need to be fulfilled for the successful implementation of each of the activities:

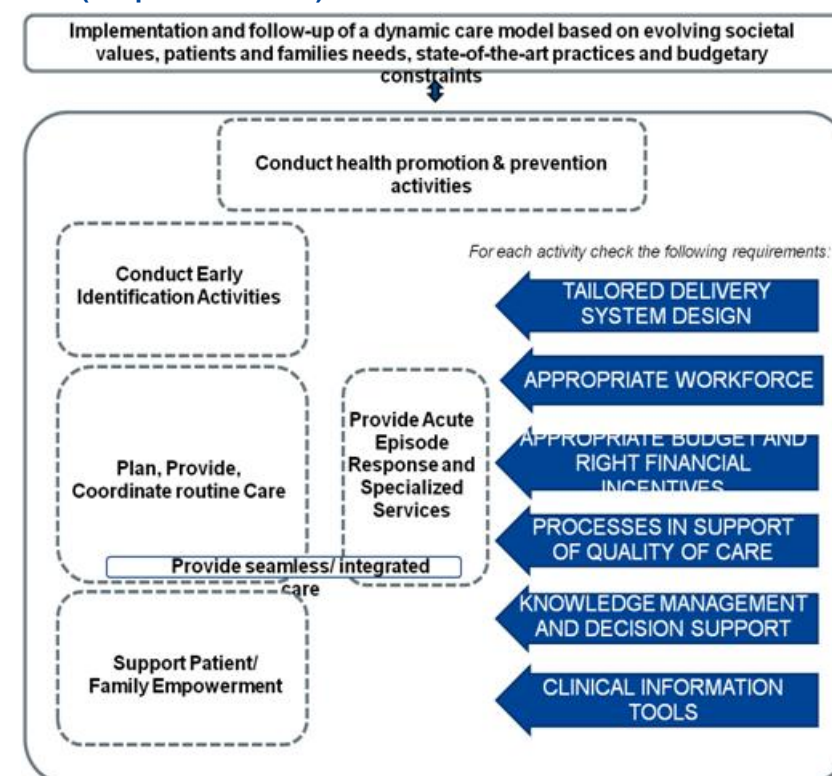
Tailored service design and organisation: with a shift from hospital-centred to primary care, as illustrated by examples in other countries^{90,91} (cf. scientific report chapter 2.3);

1. An appropriate workforce;
2. Appropriate budget and the right financial incentives;
3. Processes supporting quality assurance and improvement;
4. Knowledge management and decision support: clinical practice guidelines based on a review of the available evidence should be integrated into daily practice (including information for patients)³⁷;
5. Clinical information tools e.g. for the coordination, decision support, self-management, quality assurance mechanisms. These tools need to comply with the ethical principle of confidentiality^{95,96};

5.2.8. Overview of the conceptual model proposed for a health care system oriented towards chronic care

The figure below summarizes the proposed conceptual model. The interested readers will find the details of this figure in the scientific report (section 3.3.).

Conceptual model for a health care system oriented towards chronic care (simplified version)





5.3. From activity model to policy recommendations

The next study phase was the confrontation by the research team of the idealized conceptual model with the current Belgian situation (i.e. results of the SWOT-analysis and the critical analysis of the coordination structures – see scientific report chapters 7 and 8). The objective was double:

1. To identify the most important gaps between the conceptual model and the current system;
2. To formulate strategic recommendations to bridge these gaps.

The analysis of the current initiatives in Belgium as well as the interviews with stakeholders showed that the current health care system is predominantly disease-oriented and institution-driven, in contrast with the idealized health care system oriented towards chronic care. The current system is characterized by fragmented care delivery, both between and within lines of care. The problems call for fundamental changes in nearly all requirement dimensions (delivery system design, workforce, financial incentives, quality processes, knowledge management & decision support, and clinical information tools) for each of the functional modules of the conceptual model.

In the next section, we formulate twenty recommendations (and related action points) to reform the system into the desired direction.

6. POLICY RECOMMENDATIONS

These recommendations and related actions follow the same concentric structure as the conceptual activity model (described in 5.2.8). They start at the heart of the healthcare provision, i.e. in the primary care setting, the usual care environment of the patient with a chronic disease. The GP and the patient are the central actors, along with a multidisciplinary team, that offers planned, coordinated and integrated care. Next we will turn our attention to the seamless integration with other care levels and to the support for patient empowerment. Finally, we will place this set of activities in the broader context of the healthcare system, addressing the specific governance and organisational aspects needed to make the system run efficiently.

6.1. Plan, provide and coordinate routine care in the primary care setting

6.1.1. Individualized care plan

The care for an acute disease episode, punctual and reactive, differs from the care for people with one or several chronic conditions: chronic care needs to be planned and should be pro-actively oriented towards goals that have been defined in collaboration with the patient and caregivers involved. The care plan needs to rely on the evidence when available, taking into account the multimorbidity of the patient. Rather than being disease-oriented, these goals are spelled out in terms of quality of life and functioning in a long-term perspective. Moreover, this plan should guide the interventions of the whole primary care team and encompass the input of all professionals.

Yet, till recently, primary care workers were not formally trained for the implementation of a patient-centred, collaborative care plan, and they lacked effective tools to support them in this task. Moreover, the current system pays insufficient attention to psychological and social needs.

Another condition for the efficient development of a care plan is a sound knowledge of the available services that might be offered.



6.1.1.1. Recommendation 1

Develop and implement a multidisciplinary teamwork that shares a computer-based care plan and case management tool for chronic care, based on the current global medical record (Globaal medisch Dossier/Dossier Medical Global).

Action point 1.1: Develop teamwork around the patient

In Belgium, the (medical) care for the chronic patients was and still is predominantly the realm of the GP, and to a lesser extent, dependent on the pathology, of the medical specialists. Insofar as chronic care is frequently synonym of multiple conditions, the role of a primary care team is all the more important. This teamwork implies a.o. a common and agreed care plan, integration, coordination, delegation of tasks, patient empowerment to reach the targeted results in terms of health and quality of life. These requirements will be discussed in the following recommendations.

For highly complex medical situations (cystic fibrosis, serious renal failure), the specialist might also become a full member of this team, even for the routine care of the patient. This differs from the care provided during acute episodes, detailed in point 6.2.

Developing teamwork around the patient raised a number of questions during the development of this position paper. An important issue according to stakeholders is the fear that the patient would lose the legal right to choose his/her caregiver. However, the teamwork envisaged in this position paper is no rigid straightjacket but should be adapted to the patient's preferences. An illustration is the existing teamwork in hospital: the patient's satisfaction is the result of a positive perception of the quality of care provided by a team. Concretely the patient does not choose each physiotherapist or nurse but in case of problem shifts within the team are possible.

Requirements for developing multidisciplinary teamwork around the patient include:

- Training of health professionals (see recommendation 2)
- Sharing information through effective communication strategies, including meetings at the patient's bed (or teleconference),
- Using a common patient's record (see action point 1.2) including a chronic care module,
- Using common tools for needs assessment, planning, follow-up and evaluation of health and life goals (see action point 1.3)⁹⁹. The concept of "needs" refers to a global needs' assessment as described in 2.1 (including the needs for social support);

Action point 1.2: Develop and promote the use of a "chronic care module" within the global medical record to support the teamwork in primary care

Sharing information on the medical history and care plan is vital to ensure that all partners in the care would take coordinated their actions. For that purpose, a specific 'chronic care module' integrated into the global medical record (GMD/DMG) should have the following characteristics:

- Over and above being a classical medical record for storage of history, findings, results, etc;
- Including tools for needs assessment, planning and evaluation;
- Being shared between professionals, with levels of disclosure and access appropriate for each of them. The patient should have the right to determine who is entitled to consult/to write in his record;
- Conceived as to give to the patient an access to parts of the record¹⁰⁰. Typically, patients would insert notes, such as results of self-monitoring, or their will in relation to advanced care planning and euthanasia. This has been shown to contribute to better adherence to treatment and enhanced self-empowerment⁹⁶. Points requiring attention include privacy risks and the risk of "doing more harm than good" by needlessly exposing patients to worries or confusion⁹⁶.



- In this perspective, the use of a common module by health professionals can reduce their administrative workload a.o. by avoiding duplicate information input. The module could generate standardised information that allows the patient to benefit from specific services (for example reimbursement of diabetes medications).
- Consequently, it should mandatorily come under electronic format, easily accessible to all relevant parties, but with all required safeguards for the confidentiality of the data and the privacy of the patient. The current SUMEHR (Summarized Electronic Health Record) project is a first step in this direction. The summarized medical record under the responsibility of the GP is shared with other care providers through electronic platforms that fulfill security and confidentiality requirements.
- The module should be developed and extensively field-tested in close collaboration with the users.
- The existing care trajectories (currently for diabetes and renal insufficiency) and any future one should be fully integrated into the ccGMD/DMG.

In Belgium, developments should be fully integrated into the framework of eHealth and eCare¹⁰¹.

Two prerequisites for the efficient use of a shared record with ccGMD/DMG module are:

- That the patient is effectively informed about the advantages of having a GMD/DMG;
- That softwares used by the different health professionals are compatible to allow information exchange with the ccGMD/DMG. The eHealth platform has an important role to play in that respect by offering standard basic services to healthcare data exchange applications.

Action point 1.3: Promote the use of common evaluation tools to support the follow-up of the patient by the team.

The ultimate aim of health services for chronic patients is to help them to improve their quality of life and the way they can function in society, as stated in 5.1.2. The regular evaluation of the patient's functioning (including daily activities and social life) by means of standardised tools is important in that context.

WHO advocates the use of the International Classification of Functioning, Disability and Health (ICF)⁸⁸. In Belgium, there is some experience with the Resident Assessment Instrument (RAI), a tool for the evaluation and care planning of residents in institutions (see scientific report chapter 4.5, NIHDI initiatives). This registration of patient parameters with the so-called "BelRAI" online tool illustrates the feasibility of giving controlled access to a patient record to the professionals involved in the care of this patient.

6.1.1.2. Recommendation 2

Develop and implement mandatory training modules for needs assessment, for eliciting patient-defined life goals, for multidisciplinary work and implementation of a care plan.

The above-mentioned care plan should start from life goals defined by the patient (in collaboration with the GP and primary care team), to be followed by a needs assessment. However, the current training of health professionals is not tailored to this evolving role in chronic care:

- Academic curricula and clerkships for future physicians are oriented towards acute problems;
- The training of nurses is predominantly hospital-oriented, with little opportunities to specialize in chronic care (see also the concept of advanced practice nurse in action point 4.3) ;
- There is little training for specific competences, such as collaborating in multidisciplinary team.

For physicians, the training modules should be integrated into the academic curriculum. They could also be integrated into their continuing education ("accreditation/accrediting" system). Corresponding training should also be provided for the other health care professionals (for



example physiotherapists), during their initial education as well as by means of continuing education modules.

One way to implement this could be to dedicate specific sessions of continuing medical education (for example LOK/GLEMs) to multidisciplinary work (including the definition of roles and activities of the first and second lines of care), elaboration of care plans. These sessions should gather all health professionals from the local community (e.g. pharmacists, physiotherapists).

6.1.2. Provide routine care and support for the chronic patient

Reinforcing primary care is a prerequisite to foster comprehensive, appropriate and well-integrated care package, in the least complex environment that is clinically appropriate, at an affordable price. This is a challenge, in view of the increasing burden of chronic disease and the possible future GP shortage. Consequently, GPs will need support in several ways: help with the management of complex medical and social needs, delegation of routine clinical tasks to other caregivers, coaching from medical specialists, clinical decision support and training, and remuneration rewarding quality and cooperation.

The reinforcement of the primary care workforce implies in particular to think about the new roles and responsibilities of all primary care professionals.

6.1.2.1. Recommendation 3

Keep up the efforts to keep the GP and nurse professions attractive.

Action point 3.1: Further establish general practice as a fully-fledged specialty in medical faculties

The attractiveness of general practice implies that it is positioned as a fully-fledged specialty within the medical faculties¹⁰², which in some cases means no less than a major culture shift. What is needed is:

- an accurate image of the profession from early on in the curriculum;
- clerkships of high quality in various primary care settings for all medical students;
- courses on the specific problems of general practice organisation, so as to better prepare the future general practitioners for their task.

Action point 3.2: Improve the working conditions of general practitioners

Fostering good working conditions (including financial ones) is one of the key elements to improve the attractiveness of the GP profession. The KCE report on the attraction of the profession recommended to¹⁰²:

- favour the work in teams or within networks, in order to improve the working conditions of the GPs;
- develop well-organized out-of-hours services to diminish the professional stress while guaranteeing the continuity of care (see also the recent KCE report on the subject¹⁰³, with proposals for various scenarios);
- create possibilities for a better balance between private and professional life, e.g. opportunities for career breaks (including maternity leaves), or part-time work;
- improve the image of the profession by offering new career perspectives to GPs (e.g. research, quality initiatives);
- extend the current initiatives i.e. administrative and ICT support for primary care practices.

Some recent initiatives are fully in line with these recommendations, such as the Impulse III Funds that supports (a.o.) the single-handed practices.

Action point 3.3: Maintain and reinforce the measures to increase the attraction of the nurse profession

Since 2008, a number of new measures were taken to increase the attractiveness of the nursing profession in hospitals¹⁰⁴: reduction of workload and stress, new qualifications, better remuneration and more involvement in decision making. A similar move is needed for nurses in ambulatory care.



6.1.2.2. Recommendation 4

Develop and recognize new functions and roles in primary care

As a complement to the measures suggested in the previous action points, the content of the primary care work itself must also evolve (see two KCE reports on the subject^{105,106}):

- delegation of clerical and coordination tasks to other professionals, e.g. social workers;
- delegation of clinical tasks to other health professionals (from GP to nurse, from nurse to nursing aid);
- differentiation of the nursing profession to increase the attractiveness of the profession for the nurses with a Master diploma;

Action point 4.1: Develop and support the possibility for the GP to delegate routine clinical tasks to other health professionals

Sharing tasks with other health professionals may decrease the workload of the GP, whilst improving the attractiveness of the professions involved (those that delegate and the ones that receive more responsibilities).

In a number of countries, advanced practice nurses, with a specific training at an academic level, are taking up tasks that previously were performed by the GP. This function does currently not exist in Belgium, but the curriculum of nurses could be diversified, including an option oriented towards this new function (see action point 4.3).

More examples of other health professionals taking up tasks previously restricted to physicians can be found in chapter 6.2 of the scientific report e.g. the new roles of community pharmacists in the UK and Canada^{107,108}.

In Belgium, the concept of integrated primary care practice, where providers from different backgrounds (GPs, nurse practitioners, clerical staff, dieticians, psychologists) work together is quite uncommon (apart from the '*wijkgezondheidscentra / maisons médicales*'). Many GPs work in small-scale practices, within an informal network of local care providers. These practices often lack the critical mass to employ other collaborators besides clerical staff. The professional who usually takes up delegated clinical tasks is a home nurse.

The models of integrated care and care networks that were developed for patients with psychiatric conditions offer a good illustration of how effective task sharing between members of a multidisciplinary team can operate¹⁰⁹.

Requirements for task delegation

- The development of protocols of agreement between different health professionals, specifying mutual roles, responsibilities and other collaboration modalities;
- A stable and trustful working relationship between the care provider who delegates and the professional who takes up new tasks;
- Common agreed care protocols adapted to this delegation of clinical tasks;
- The set up of training (or adaptation of the current one) in the nursing schools and academic centers (see action point 4.3); the first step is to reach agreement on the competences and specific requirements for nurses to take on this new role;
- A specific training of health professionals oriented towards task sharing and chronic disease management in multidisciplinary teams;
- Official recognition of the existing and the new specific nursing trainings (see scientific report 6.2), in particular the specific professional titles;
- The shared use of a 'chronic care module' in the electronic medical record (cf. first recommendation) by physicians, nurses and other (health) professionals. Till now, the electronic medical records and corresponding softwares have been developed independently for the different health professions, with little attention for the data sharing;
- The set up of quality assurance mechanisms, including structure criteria (required competences and training, equipment, infrastructure), process and outcome measures, with indicators preferably derived from the routine electronic medical record;
- A reform of the remuneration system, away from the current fee-for-service model, so as to create incentives for task delegation, communication and shared responsibility (see recommendation 18);
- Legal reforms, to broaden the competences of the non-physician health professionals, and specifying liability issues;



In the same vein, clinical pharmacists can assist and participate more in all stages of the medication management, e.g. in nursing homes¹¹⁰;

Action point 4.2: Develop and support the possibility for nursing tasks to be delegated to less qualified professionals

In the same way, tasks currently still very often performed by nurses, can be delegated to nursing aids or other health professionals, to informal caregivers or even to the patient him/herself. Nurses indeed carry out many tasks (administrative, clerical tasks, support of the activities of daily life) that do not require their level of education. This applies both to the institutional setting¹⁰⁵ and to home care¹⁰⁶.

The evaluation of the recent pilot projects on the new roles for nursing aids in home care nursing led to the recommendation to further develop and embed the role of nursing aids, taking into account the same set of requirements as for action point 4.1¹¹¹:

- Organisational models;
- Availability of common agreed care protocols;
- Training, including for multidisciplinary work;
- Information exchange;
- Quality assurance mechanisms;
- Official recognition and adapted financing;
- Legal framework defining new competences for nurse aids, to perform additional tasks under the supervision of a nurse.

The implementation of task delegation also implies to consider the following points:

- Right balance between training requirements and quality standards on the one hand, and feasibility, cost and workforce availability on the other hand: if the threshold is too high, this might well be counterproductive; if it is too low, the patient may be exposed to unjustifiable risk.
- Revolution in the culture of the professionals: the experts identified the culture of the professions as a major obstacle for task delegation, as some health professionals are reluctant to delegate their tasks to

others. This emphasizes the need to define these new roles and competences in close agreement with the stakeholders.

- Choice of a team versus choice of an individual health professional: patients should accept to opt for a team of professionals (see recommendation 1) instead of choosing individual care providers who are not necessarily used to work together. The objective is to guarantee a higher quality of care through collaboration between professionals. In all cases, they should have the right to express and discuss their preferences and keep privileged relationships with one/a few professional(s).
- Shift from informal professional networks to more structured teamwork to improve efficiency (e.g. the set up of care plans; interdisciplinary meetings to discuss common cases).
- In case of complex situations, the risk of multiplying the number of health professionals and having fragmented care increases. The intervention of a case manager should therefore be considered (see action point 7.1).
- Consideration for the potential shortage of nurses in institutional care induced by the creation of new attractive roles in the home setting; reforms should be gradual and take all dimensions into account in a concerted way.

Action Point 4.3: Develop training for the role of advanced practice nurse and recognize this qualification

Advanced practice nurses are specifically trained nurses, capable of taking up a number of tasks of the GP. Currently, in Belgium, nurses can also obtain extra qualifications/specific titles, allowing them to work with a specific group of patients (e.g. geriatry, oncology). However many of these qualifications are not legally recognized whilst other ones do not offer financial advantages. Furthermore, specialties are mostly disease-specific, whereas the patients' health conditions call for an advanced practice nurse who can care for multimorbidities.

Chapter 6.2 of the scientific report analyzes the potential role of an advanced practice nurse in the care of the chronic patients. Two broad categories of nurses are^{112, 113}:



- Nurse practitioners: substituting the physician for some clinical activities, including prescription of drugs and medical tests, diagnosis, screening, health promotion and prevention, monitoring of patients with chronic diseases, care coordination¹¹³;
- Clinical nurse specialists: whose main function is to support and to improve the quality of nursing care in a specialised area of practice defined according to the patients' age (e.g. paediatrics), the setting (e.g. emergency room), the disease (e.g. asthma or cardiovascular disease), the type of care (e.g. psychiatric or palliative care) or the health need (e.g. pain management)^{113, 114}.

Main requirements are:

- A basic curriculum of nurses that emphasizes also the work in other settings than the hospital.
- The development of specific training for advanced practice nurse, integrated in the curricula of the nursing schools and academic centers. A possibility could be to complete the current curricula for nurses who already obtained a complementary qualification.
- A training that encompasses multimorbidity so that advanced practice nurses are competent to care for the chronic patient in a holistic way.
- The official recognition of this title and related competences by the legislation and by the Belgian health care system.
- The set up of a program of continuing education.

6.1.2.3. Recommendation 5

Provide the care in the least complex environment that is clinically appropriate

The previous sections underlined the need to link the care plan with life goals and they described by whom this care will be provided. This section deals with the optimal setting where the care should be provided, in particular when the patient's health status severely gets worse. Most persons with chronic condition(s) are indeed very well looked after at home. However very old persons and patients at an advanced stage of illness may experience at a moment major difficulties in relation to their care needs or social needs.

Even if these cases admission into an institution should only be a fatality: it will be considered when all alternative solutions to keep the persons in their own home environment have been exhausted. These outpatient services are to be preferred when multidisciplinary, well-coordinated and accessible (primary care) services are available 24 hours a day.

Action point 5.1: Develop policies to encourage the persons with chronic needs to stay at home

The KCE report on residential care for the older persons formulated concrete recommendations, including: more stringent access criteria to residential facilities; support for informal caregivers, a.o. by granting them an appropriate administrative and financial status; promotion and support of innovative initiatives for home care for the older persons¹¹⁵.

Effective coordination of care, tailored to the individual patient, and an adapted living environment are important contributing factors. For the latter, a proactive municipal policy should foster physical accessibility, safety and the availability of supportive services (for example "meals on wheels"). The local coordinating structures for health care and social care (see Action Point 7.2) should strive to articulate caregivers and services with the other actors of the community: municipal authorities and services, police, local shopkeepers and service providers (cleaning services, hairdressers,...), local volunteer organizations, etc. so as to improve the daily environment.

There are a number of recent initiatives in Belgium to encourage people to stay in their living environment, even with chronic needs. The transformation of psychiatric hospital beds to alternative structures of mental care can serve as an example of efforts invested towards the care of the patient in his/her environment¹⁰⁹. Another illustration is the project on alternative forms of care for older persons (known as 'Protocol 3')¹¹⁶: it will be an opportunity to identify the most promising models.



Action Point 5.2: Support the informal caregivers to improve their quality of life, so as to allow the patients to stay in their life environment as long as possible.

Many patients wish they would live at home as long as possible rather than to be admitted in a residential structure. Consequently, the support of the informal giver is of utmost importance, as is illustrated by the KCE report on care for dementia¹¹⁷. Providing them information and training, financial incentives, and technical, psychological and logistic support (such as respite care) can contribute to their quality of life and their capacity to care for the patient in his living environment. One of the objectives is to delay (or obviate) the need for institutionalisation. Concretely, this means additional capacity of financially accessible respite care and day centres, to alleviate the burden of the informal caregivers.

Easily available and comprehensive information on these initiatives (from health professionals, patient organizations, sickness funds) is a condition sine qua non for their use by the target population.

Action point 5.3: Increase the availability of financially accessible alternatives to hospitals and to nursing homes

- **Alternatives to the hospital for patients with complex needs**

Some patients with an advanced chronic disease can no longer stay at home, given their physical and / or psychological status. Ready-for-use solutions may be admission to a hospital or institution. Still, in Belgium, a number of recent initiatives for patients with complex problems: centres for patients with multiple sclerosis, amyotrophic lateral sclerosis and Huntington disease have been created to avoid admission in acute hospitals. These specialized centres originate from collaboration between hospitals and residential care. Patients receive specific care, families receive support, the personnel have the required competences and there is a link between the centre and the hospital for complex situations. At present these structures are developed for specific patient populations but these initiatives could be a source of inspiration for other patients with complex needs who cannot stay at home but do not require acute care.

The need for alternative care settings is frequent for patients with severe mental disease. The recommendation for switching from hospital to adapted care settings implies the development of models of alternative

care, adapted to different levels of autonomy. Integration in the society is important as well as a multidisciplinary follow-up of these patients¹¹⁸.

- **Alternatives to nursing homes for the older persons**

The KCE report on future needs of residential care for the older persons¹¹⁵ concluded that a substantial increase in the number of available beds will be needed in the coming decades. In parallel, the stakeholders interviewed in this study pointed out the need to develop alternatives close to the patient's environment. Some of them could help solving transitional situations and could be less expensive than institutionalisation. Illustrations are day care centres, respite care, social support at home, service flats, kangaroo-homes and other intergenerational solutions (mixed neighbourhoods) and telematic support.

6.1.3. Monitor and evaluate progress and quality of care

Quality improvement initiatives and quality assurance procedures are necessary to ensure that care for the chronic patient is provided in the most efficient way.

Quality initiatives in other countries (see scientific report chapter 2.3.) generally appear to focus on a few medical conditions.

Effective quality improvement procedures invariably calls for standardised data collection, analysis and feedback, leading to corrective measures. The development of sets of clinical quality indicators and the implementation of a quality system in Belgium were studied in a KCE report of 2006⁸⁵. In 2008, there was a study on quality in general practice¹¹⁹, which identified a number of key elements for the elaboration of a successful quality system. Meanwhile, the KCE study on medication use in rest/nursing homes¹¹⁰ had shown large variability in the quality of the medication management systems, and also made a number of recommendations to improve the prescription quality.

All these recommendations are applicable to the provision of chronic care and will not be repeated in detail here (see scientific report chapter 5).



6.1.3.1. Recommendation 6

Develop and implement a continuous quality improvement programme for chronic care

A quality system needs to arise from two complementary dynamics: a genuine quest for quality on the part of the providers and a strong impetus and leadership on the part of the health authorities (see section 6.6).

Authorities play a major role in particular in the domain of quality improvement⁸⁵: development of a quality policy, legislation, creation of a quality platform, standardisation of IT systems. They have also the responsibility to define the right balance between summative and formative assessment. While summative assessment has external consequences (for example financial), formative assessment leads to personal improvement through feedback.

The development of a system for the measurement of quality requires⁸⁵:

- The definition of clear objectives and consequences of the measurement;
- The definition of the scope of the measurement, with indicators that cover specific aspects of the disease but also generic components of the care (e.g. coordination, efficiency)¹²⁰;
- The set up of a valid data collection system that makes maximal use of existing databases;
- The feedback to all participating care providers.

The ongoing evaluation of the care trajectories should yield a number of insights on how to improve the system so as to better respond to the various needs and goals (e.g. for patients with multimorbidity).

Action point 6.1: Clarify the objectives and consequences of the quality system

As long as the objectives and consequences of the data collection and analysis have not been explicitly spelled out and agreed upon, confusion and mistrust may persist on the field, hampering the introduction and functioning of the quality improvement system. Different, sometimes conflicting objectives are indeed possible; they may be as varied as:

- External quality control or benchmarking, with or without public or peer disclosure of the results, with or without sanctions or rewards (such as accreditation, certification or licensing; financial consequences);
- Auto-evaluation and quality improvement, with or without disclosure of the results to the authorities, the peers or the public, but without sanctions; benchmarking and feedback are often part of these systems;
- Clinical epidemiology research; if this objective is included, it may lead to an increase in the number of data items to be collected, with the risk of 'registration fatigue' and the failure of the QI objective;
- Monitoring of health care resources utilization for control or for planning of health care services and resources;

To start up the quality system, the second option should be preferred. All stakeholders should be involved in the design of the quality system, including the patients, to make sure that their perception of what is good quality chronic care is taken into account. Rather than exclusively focusing on disease-linked indicators, the quality system should also focus on the degree to which the care satisfies patient-defined needs and goals and meets integration and continuity standards.

Action point 6.2: Search and select meaningful quality indicators in collaboration with the specialists of the domain

Examples of quality indicator development, based on the available evidence in the published literature and the input of clinical experts can be found in the KCE reports on the monitoring and evaluation of quality of care for type 2 diabetes patients¹²¹, the treatment of testis cancer¹²², the treatment of breast cancer¹²³, the organisation of stroke units¹²⁴ and a framework for quality assurance in general practice¹¹⁹.

A similar process could lead to the selection of quality indicators that relate to other above-mentioned relevant dimensions of chronic care, including those related to patient satisfaction and empowerment.

Specific quality indicators are furthermore required to monitor the quality in institutions (e.g. nursing homes, institutions for persons with a chronic mental disease).



Whereas quality indicators with a robust evidence-base remain scarce, one can tap into a growing body of international work. Major sources include:

- The Global Monitoring Framework of the World Health Organisation, working on the development of a set of voluntary global targets for the prevention and monitoring of NCDs ¹⁴.
- The Organisation for Economic Co-operation and Development (OECD) Health Care Quality Indicators project, aimed at the measurement and comparison of the quality of health service provision in the different countries ¹²⁵. Areas of interest include patient safety, patient experiences and primary care.
- National initiatives in other countries, such as the list of indicators for chronic diseases, recently developed in Québec ¹²⁰.

Action point 6.3: Set up a system of data registration, maximally reusing existing data

The burden of data registration is an often-mentioned barrier experienced by the care providers. The 'chronic care module' included in the medical record mentioned in recommendation 1 should allow easy data extraction, analysis and export for evaluation purposes. It should become the backbone of the quality indicators data collection, and maximally reuse the data routinely stored in the medical record. Data collection in nursing homes and alternative care settings (for example mental care) are important as well.

Data export for centralised analysis, benchmarking and feedback should use the eHealth services, and fully make use of the framework offered by the eCare platform.

Agreements should be made between GPs and other caregivers, the health authorities and the software providers on semantic and data exchange standards, for maximum data exchange possibilities between the different software packages on the market. Only packages meeting the agreed requirements should receive the official label giving access to the use (and remuneration) of the chronic care GMD/DMG module.

In a second phase, ad hoc linkage with routine hospital discharge data, sickness fund reimbursement data and the Personal Health Record of the

patient could be envisaged, so as to include information on the whole spectrum of care.

Action point 6.4: Provide feedback to all professionals involved in the integrated care of chronic patients

Data analysis, benchmarking and feedback should be entrusted to an independent, publicly funded research team under the scientific supervision of the stakeholders. Ideally, practices with a substandard level of performance should benefit from counselling by coaches, if needed with the collaboration of scientific societies (GPs, specialists, nurses, physiotherapists). This feedback should be provided regularly and should include clear targets and an action plan ¹²⁶.

The following requirements are necessary for the successful implementation of a quality system

- Watertight confidentiality and privacy protection considerations guarantees are of utmost importance before initiating data collection.
- Previous experiences showed that data validity problems and especially the problem of missing data seriously diminish the value of a feedback system. Hence the need for periodic auditing of data quality and exhaustiveness.
- The quality system needs its own stable budget to make sure that the system is built and run in a professional and user-friendly way.
- The implementation of systematic data collection and feedback demands a professional culture shift: substantial resources should be invested in the user-friendliness and the positive image building of the quality improvement system.



6.1.4. Provide care coordination

6.1.4.1. Recommendation 7

Support the GP in the management of complex cases

Once long-term goals and a care plan have been established, they need to be implemented and followed up. This entails also orchestrating the input of all health professionals and others who intervene in the support and care of this patient. This is no medical but a managerial task, which not necessarily needs to be performed by a health professional. It includes planning, monitoring and anticipating changes in health, nursing and social needs, and coordinating the care across all parts of the health and social care system.

The evolution of technologies (cf. “Mobile eHealth” in action point 14.1), http://www.who.int/goe/mobile_health/en/ can facilitate the organization of meetings between care providers. However the management role goes far beyond that and the appointment of a specific professional may be of great value.

Action point 7.1: Develop the role of case manager for the coordination of care of patients with complex needs (micro level)

The primary care team should in principle be able to deal with the routine care of most chronic patients. However, patients with complex needs might benefit from the intervention of a case manager^a. In delicate transition periods, e.g. early after diagnosis, after hospital discharge, after an acute episode, multidisciplinary consultation^b and establishment or revision of a care plan might be needed (see Action point 7.2 and recommendation 10). A positive effect from case management on the outcome has been demonstrated, e.g. for older persons and persons who suffer from dementia^{18, 127}.

^a The term “case manager” is internationally used, named “zorgbegeleiding” in the Flemish context;

^b A multidisciplinary consultation during delicate transition periods is named “zorgbemiddeling” in the Flemish context (SEL) and (“concertation multidisciplinaire” in the French-speaking context (SISD - see <http://public.guidesocial.be/associations/sisd-bruxelles-asbl.157242.html>)

Ideally, the GP calls on resources available at the level of his/her practice, but this is seldom the case. Alternatively, home nurses (or other (health) professionals such as social care workers, community workers from CPAS/OCMW (Centre Public d'Aide Sociale/Openbaar Centrum voor Maatschappelijk Welzijn) can take up this role of case manager, in agreement with the patient and the GP. The requirements are, by and large, similar as for delegation of clinical tasks (see action point 4.1). Both clinical and social tasks could, for that matter, be integrated into a single contract or agreement between GP and the case manager if the latter is a healthcare worker trained for that task. More specifically, the requirements for a successful case management integrated in a primary care team include:

- A trustful relation with the patient, and effective support from the GP who will recognize the role and the importance of this new partner in the fulfilment of the care plan;
- Structural shifts: new organisational models need to be developed, defining the respective roles, responsibilities and other collaboration modalities;
- Training of the healthcare professionals involved to help them to acquire a set of required skills, also for multidisciplinary work;
- All required case management competences and skills should also be integrated into the existing or new curricula leading towards this role;
- A good knowledge of all locally available resources and services is also an important prerequisite;
- The shared use of an adapted electronic medical record (see also recommendation 1 on the ‘chronic care module’);
- Quality assurance procedures, with special reference to the level of realisation of the patient goals;
- Official recognition of this role and financing mechanisms offering incentives to collaborate and share responsibilities;
- A legal framework defining competences and responsibilities.



For the most complex cases, the primary care team can call on the existing local support or network structures (see action point 7.2). The latter can, in any case, offer various types of assistance and support to the patient, the family and the primary care team. This point, including an additional number of requirements, will be developed under action point 7.2.

When implementing case management in daily practice, the following points deserve particular attention:

- Risk of overburden: case managers are at risk of getting overburdened, in particular in case of a high demand for problematic social coordination issues.
- Professional culture barriers: some GPs, especially in single-handed practices, might experience delegating tasks to a case manager as a profound culture shift, even if the patient is still keeping a trustful relationship with the GP.
- The practicalities of coordination meetings: GPs often have difficulties to attend coordination meetings where they have a central role to play: attending meetings is time consuming, in particular when there is long additional travel time. Modern telematics could be of help, provided their access is facilitated and streamlined.
- Profile of the case manager: for some stakeholders, the case manager should be a health professional to coordinate biomedical as well as non-medical care (ideally a nurse with training in community health). For others, the case manager could be a social worker for the coordination of non-biomedical services. When a nurse performs medical tasks, it might be more efficient to combine this work with case management, rather than to involve yet another new actor.
- New interactions for the patient: he/she should be prepared to start a relationship with a new professional, perhaps not involved previously in the primary care team.
- Case management versus disease management: there is a risk that care coordination would be mainly or exclusively disease-oriented (cf. care trajectories): this might be a threat for the quality of care in case of multimorbidity (e.g. redundancy of tests, conflicting prescriptions).

Action point 7.2: Further develop and streamline local coordination structures and networks to support care providers in the coordination of care of patient with (very) complex needs (meso level)

Experiences in other countries have shown that the integration of services within the community setting yields positive outcomes. As an illustration, the SIPA project in Québec, offering a full range of coordinated health and social services, appeared to reduce hospital and nursing home utilization without increasing costs¹⁶.

- Coordination structures in Belgium: an intricate tangle

Case management activities linked to an individual patient, i.e. operating at the micro-level, also require more general support structures at a community level. In Belgium they were predominantly set up by the federal and regional health authorities, by sickness funds or by OCMW/CPAS (Centre Public d'Aide Sociale/Openbaar Centrum voor Maatschappelijk Welzijn). The accumulation of several waves of reform, at different jurisdiction levels, in different sectors and of additional private initiatives resulted in an intricate tangle of structures with limited articulation between them (see chapter 8 in the scientific report): GDT/SISD (Geïntegreerde Diensten Thuiszorg/Services Intégrés de Soins à Domicile), SEL (Samenwerkingsinitiatief EersteLijns gezondheidszorg), CCSSD (Centres de Coordination de Soins et Services à Domicile), CPAS/OCMW, RML/LMN (Réseaux Multidisciplinaires Locaux/ Lokale Multidisciplinaire Netwerken), ONE/ K&G (Office de la Naissance et de l'Enfance/ Kind en Gezin).

- An opportunity for effective support

Even so, coordination structures can offer effective support to members of primary care teams and thereby increase the efficiency of care. Coordination structures can be an encounter platform where different disciplines meet, may benefit from supervision and share resources for effective care coordination. They are the place where information about all available services and their access conditions can be found. For (very) complex cases, they can offer case coordination assistance, by orienting patients and caregivers towards the most appropriate services. They can help in the development of local multidisciplinary networks and offer professional help in the elaboration of collaboration agreements. They can



also become a pole of training and continuous education. One illustration is the recent establishment of 'Health Houses' ("Huis voor Gezondheid"^{128,c}), where provider organisations can find local administrative support and share premises and meeting facilities. Through this proximity, learn to know each other and collaborate more effectively.

In parallel, these structures can also offer direct information and advice to the patient and her family, helping them to find the best suited health professionals and services for their needs.

The effective implementation of coordination structures depends on the following points:

- Of paramount importance is that they bridge the gap between the medical and the social sector, and between primary care and the institutional and second-line care levels.
- A clear definition of roles and responsibilities.
- Dedicated professionals (typically nurses with a specific training in community health or social care workers) and structural funding should ensure that they offer stable professionalised support, well anchored in the local context.
- The definition of the population covered: depending on the level of staffing, these structures typically serve a population of a few thousand to some 15 000 inhabitants. On one hand this is at an operational meso-level above the micro-level of the individual practice, On the other hand these structures are embedded into a higher, more strategic meso-level of the GDT/SISD (with often also an intermediate sub-GDT/SISD level at the small-town-scale – see Recommendation 16), and should articulate, and eventually be integrated with the LMN/RML. Reaching a 'critical mass' is of importance to enable a service that offers reliable quality.

6.2. Provide acute episode response and specialised services

The quality and in particular the continuity and efficiency of health care services provided to a population depend upon the quality of the primary care teams but also upon the network of other, specialized services, including hospitals³⁶. The primary care team is a bridge between the community services and the other actors of the health system, helping people navigate in this system in the most appropriate way.

6.2.1.1. Recommendation 8

Ambulatory and inpatient specialized services should play a major role in the care of chronic patients, in particular at critical moments such as at initial diagnosis or at the occurrence of exacerbations, complications or new comorbidities; they should operate in a continuum with the first line of care.

Complementary investigations in relation to the diagnosis or complications often require interventions of specialists, possibly entailing a (day) hospital stay. Hospital admission is not only an unsettling experience for the patient, but it often also is disruptive for the continuity of care – an issue extensively discussed in the KCE report on seamless care¹²⁹.

The coordination mentioned in 6.1.4. is also a must within the walls of the hospital in order to share a common vision on the patient's care plan, and to prevent care fragmentation. There is a need for multidisciplinary consultations around the chronic patient, in whatever unit he is admitted.

When the situation of the patient does not require acute care anymore, the transition to ambulatory care calls for strong collaboration between the hospital and the subsequent setting (see action points 5.3^{118,130} and 11.3).

^c Not to be confused with 'Maison médicale / Wijkgezondheidscentrum'



6.2.1.2. Recommendation 9

Specialists involved in the care of chronic patients should also support the primary care team, in particular through knowledge sharing (based on the best available scientific data)

This role was highlighted in the KCE report on diabetes care¹²¹ and the ones on rehabilitation^{131,132}. This task is currently already provided for in the care trajectories, but for specific diseases only. The ongoing evaluation of these care trajectories should give directions on how to apply this assignment to multimorbidity and should suggest corresponding reforms in its procedures and financing.

The basis for a concerted action at patient level should be a co-designed and commonly agreed and shared care protocol, adapted to the patient's individual care plan, and serving as the guiding principle for the GP, the specialists and other members of the primary care team.

The support by specialists is not a one-way, hierarchical process; all care providers are supposed to benefit from the expertise from other team members. A possible format could be that specialists take part to ad hoc continuing education meetings gathering members of the primary care team with whom they habitually collaborate.

Task sharing among GPs and specialists implies the same implementation points as the ones developed in recommendation 4 (incl. the definition of roles and responsibilities).

6.2.1.3. Recommendation 10

Specialists called in for diagnosis, work-up or acute episode management of chronic patients should take the full spectrum of medical and other patient needs into account and integrate their intervention into the care plan.

Specialist services are by definition oriented towards a specific body system or type of pathology, and, hence, less likely to consider the chronic patient, who has often multiple conditions and needs, as a whole.

Whenever a chronic patient who has a chronic care module within his/her record is referred to a specialist, this physician should have access to this module, so as to be informed on all health problems, on the medication scheme and the care needs/plan. Furthermore, the specialist should have the possibility to add new information and treatment options, to be integrated into the record, after discussion with the GP.

6.2.1.4. Recommendation 11

Transition between primary care and other care levels should not disrupt the continuity of care along the lines of the individual care plan of the patient

In the conceptual model used in this position paper, the provision of seamless/integrated care is on the interface between module 1 (plan, provide, coordinate routine care) and 2 (provide acute episode response and specialised services). The WHO definition of integrated care has been mentioned in chapter 2.1.4 of the scientific report: "the management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system"¹⁵.

The delivery of integrated care was a common leitmotiv of the national plans "chronic disease" found in the four other countries (regions) studied. In Belgium, many initiatives from the RIZIV/INAMI aim at the development of new models of integrated care (see scientific report chapter 4.5, section on care coordination). The geriatric care programme¹³³ mentioned in the action point below (11.3) can serve as an example of a type of programme that potentially could be extended to other patients with chronic disease(s).



In 2010, KCE dedicated a study to the issue of seamless care with regard to drug treatment continuity at hospital admission and discharge¹²⁹. Among other things, this report made recommendations for the use of practice guidelines and shared procedures for seamless care and for the exchange and sharing of electronic patient data^{95,96}.

Action point 11.1: Develop and promote the use of shared protocols across lines of care, in particular for defining the procedures in case of admission and discharge

Shorter hospital stays go along with an increasing burden on primary care when the patient returns home. Additional risks are linked to the transition between settings: 20% to 60% of hospitalized patients would experience problems linked to medication changes during these transitions¹²⁹. This asks for procedures shared between the different levels of care to ensure seamless, continuous care, with special reference to non-disrupted drug treatment¹²⁹. Pharmacists have a major role to play in this context:

Action point 11.2: Share an electronic medical record between lines of care.

The chronic care module within the medical record (see Recommendation 1), should become the key vehicle of information exchange while respecting the rules of safety and confidentiality¹²⁹.

Action point 11.3: Appoint a discharge manager for smooth transition between hospital and primary care for patients with complex medical and/or social needs

The action point 7.1. highlighted the value of a case manager for the coordination of care in case of complex chronic situations. This function is of particular importance during acute episodes, at admission and discharge from hospital.

In the same way, the discharge manager will ensure a smooth transition when the patient returns home, through a close collaboration between the patient and the primary care team (including the usual case manager if any). Discharge management is especially relevant in a context where a growing number of very old people need seamless care when returning home, in order to prevent readmission or institutionalization.

“Liaison nursing” has been developed in a number of countries to improve the continuity of care between different settings (hospitals, rehabilitation centres etc.). Liaison nurses assess the patient’s needs and plan the care, mainly at admission or discharge. They also provide support and patient education.

In Belgium, the geriatric care programme¹³³ includes an internal liaison function for geriatric patients hospitalized in non-geriatric nursing units as well as an external liaison service. The latter means that a social worker or nurse acts as a discharge manager to guarantee the continuity of care and makes formal arrangements with the primary care team, home services or residential facility. This organisational model could be generalised to all patients with complex needs who require coordinated services when returning home.

The function of discharge manager requires an official endorsement and recognition including a profile description, and adequate funding to enhance cooperation between lines of care. The requirements to professionalize this function are similar to the ones described for the case manager (see 6.1.4).

6.3. Conduct early identification

One module of the conceptual model of chronic care encompasses two activities: the development of broad detection skills and the screening of target populations. The second one is out of the scope of this position paper (see .

Insofar as the care for a chronic patient is different from the care for an acute disease episode, there must be a moment the GP decides that this person will from now on be considered as a chronic patient, who will henceforth benefit from a specific ‘chronic care management’ approach. The GP is in the best position to diagnose them as well as to assess their related needs. Other healthcare workers (for example the pharmacist, the occupational physician) can also act as signalling agents.



6.3.1.1. Recommendation 12

GPs and other healthcare workers should have broad detection skills for early identification of chronic conditions.

The WHO described the role of the primary care team as a help for the patient to navigate between the community and the most appropriate actors of the health system (including preventive and specialized services)³⁶. In particular GPs have to encourage eligible patients to participate in population-based organised screening programmes.

Moreover, GPs and occupational physicians should in their routine work be attentive to early symptoms or signs of chronic conditions. The existing prevention module in the Global Medical Record ('GMD/DMG plus') is a good basis and the list of topics should be regularly updated on the basis of the last published evidence.

A potential pitfall is the risk of over diagnosis, with subsequent overtreatment and eventually, harm to the patient. Hence, only evidence-based screening early detection efforts should be offered i.e. only when earlier detection and treatment have been shown to effectively contribute to a more favourable outcome. These aspects should be dealt with in depth in the educational programmes.

6.4. Support patient and informal caregiver empowerment

6.4.1. Develop provider skills and tools for patient empowerment

Engaging and empowering consumers are part of the ideal vision on chronic care, as found in the national plans for chronic diseases in other countries (see section 5.1. above and chapter 2.3. of the scientific report). Patient empowerment also features as a key issue in the models put forward by international organisations (UN, EU, WHO³⁶) and in the Belgian programme "Priority to chronic patients!"¹.

Chapter 3 of the scientific report underlines the importance of patient's involvement and chapter 6 looks at the most efficient techniques to reach this objective. The patient has to define his/her own goals with the active commitment of the GP and other healthcare professionals (see recommendations 1 and 2). The definition of goals is based on the patient's life values, after careful information on the disease(s), treatment options and consequences. One illustration is the importance to inform the

patient when opting (or not) for a treatment in prostate cancer: the patient should be aware of the side effects of an operation as well as the risks when choosing for watchful surveillance.

The care providers must consider the patient and informal caregivers as competent, resourceful partners in the care process itself.

6.4.1.1. Recommendation 13

Make the health professionals more sensitive to the role of patients/informal caregivers as partners, and foster the development of appropriate skills, intervention programmes and tools**Action point 13.1: Develop specific educational and training programmes on patient empowerment and include this topic in the curricula for physicians, nurses and other healthcare professionals**

Patient empowerment requires the caregivers to develop their competences in this domain, which should come from theoretical insights, but also from exposure to success stories, making the concept more tangible. Concomitantly, they will have to develop a number of skills to identify and implement opportunities: giving self-confidence, active listening, alleviating anxiety, conveying information in a comprehensible and well-balanced way and motivating for better compliance.

Patient associations can provide highly useful expertise to these programmes by sharing first-hand experiences and perceptions with care providers.



Action point 13.2: Develop intervention programmes and tools for the empowerment of the patient

Characteristics of successful interventions

As stated above, much more is required than just giving the correct information to the patient. The review of patient-empowering programmes described in the literature (see chapter 3 above and chapter 6.1 of the scientific report) has shown that interventions are more likely to be successful if they are:

- Tailored to the specific needs of each patient, also taking into account his/her cultural background;
- Comprehensive, i.e. using a wide range of self-management approaches; e.g. for asthma, successful interventions consisted of patient education, self-monitoring, regular medical review and a written asthma plan⁴⁰⁻⁴²;
- Using multiple delivery strategies; e.g. face to face sessions with follow-up phone calls or additional educational materials^{40-42,61};
- Involving not only the patient, but also the caregivers and family¹¹⁷; this is particularly relevant in the case of children with chronic conditions^{41,57};
- Intensive: including for example intensive education or actual skills training^{50,60,74};
- Self-monitoring

Scientific organisations of healthcare providers and patient organisations should collaborate to develop and introduce models of patient self-monitoring or self-management with appropriate coaching. See, as an example, the KCE report on long term self-monitoring of anticoagulation therapy: the conclusions drew the attention on the fact that not all patients are eligible for self-monitoring without risk for the quality of care¹³⁴.

Requirements for successful programmes to develop patient empowerment

- Professional caregivers should receive training and supervision to acquire the necessary knowledge and skills for their new roles;
- The training and supervision of the patient and family could be delegated to the advanced practice nurse or case manager, under the supervision of the physician;
- The remuneration schemes for the management of complex chronic conditions should adequately compensate for these training and supervision tasks;
- Periodic evaluations should allow to refine the interventions and increase their impact on the outcome parameters;
- If the intervention also relies on computer-based tools (e.g. automated monitoring tools, shared diaries, shared access to the medical record), these technical components should have been tested before launching the programme, including important aspects as user-friendliness and ergonomics.

The existing tools usually target one specific disease; the challenge is to conceive programmes in a more transversal way, addressing common needs across different chronic conditions. Patient education, motivation and training of self-management skills taps into the same pedagogical and psychological competences, whether is for diabetes, COPD or any other disease.



6.4.2. *Provide patient empowerment services and support*

6.4.2.1. *Recommendation 14*

Integrate patient-empowering attitudes and actions in routine care for chronic patients

Action point 14.1: Provide timely, accurate and comprehensible information on the treatment, the evolution of the disease, and the availability of services and support (financial, material)

The GP (and other adequately trained primary healthcare professionals) are in the front line to provide information to the patient. The pharmacist for example can provide information in relation to the best therapeutic options (including referral to the GP) as far as this opinion is based on the best available evidence, without any other competing interest. Information by the GP on the advantages of a GMD/DMG is also highly relevant in this context.

The discussion with the patient on the goals of the care plan cannot be successful before the patient and informal caregivers have obtained all relevant information on the treatment, the evolution of the disease, the availability of services and of financial and other support. Giving access to the patient to his/her record can be an important element in this process of full information.

The national programme “Priority for chronic patients!” also emphasizes the role of the sickness funds for providing access to centralized information, e.g. on reimbursements and benefits or availability of care services². Suitable information channels include web services and call centres, reachable via a single call number.

Patient organisations bring a definite added value in this area: they can support the patients and informal caregivers, and offer an opportunity for sharing experiences between peers.

Finally, the evolution of health technologies, such as “Mobile eHealth” brings new opportunities for patient participation in health care¹³⁵. Mobile technologies improve the exchange of information to and from the patient, resulting in a higher quality of care, in particular in remote places. Although it is currently not yet a reality, certainly not in geriatric populations, it well might become highly relevant within a few years.

Requirements

- ‘Hands-on’ training in the skills for conveying complex information to lay persons, possibly with a low level of education, should be offered to healthcare workers;
- Adequate information tools (leaflets, websites,..) covering the most frequent conditions and information needs should be developed in collaboration with patient groups and communication specialists;
- Specific provisions for foreign language users and specific cultural groups should further be elaborated and made widely accessible;
- The integration of patient-generated information into the electronic medical record should be made possible (see action point 1.2).
- The remuneration schemes for the management of complex chronic conditions should compensate for this time-consuming but essential episode in the care plan.

Action point 14.2: Integrate patient and informal caregiver empowerment in routine care

Not only the patient but also informal caregivers can benefit from getting more empowerment. Yet, empowerment cannot be imposed, nor have all patients the required intellectual capacity, even with adapted information. In these cases, the GP, in collaboration with other members of the primary care team, is in the best position to identify family members who can potentially participate to decisions.

Requirements to achieve a successful implementation of patient empowerment are:

- The development of adequate strategies adapted to the patient’s situation, in particular for more vulnerable groups (for example other cultures, mental disease);
- A regular revision of the therapeutic goals and of the care plan, in partnership with the patient.



6.5. Conduct health promotion and primary prevention activities

This point was deliberately left out of the scope of this position paper as explained in point 4.1.2.

6.6. Implementation and follow-up of a dynamic care model

At the level of the health care system, relevant know-how should be built up for the further elaboration and implementation of the above-described vision on chronic care. Healthcare is in constant evolution, and so is the societal context in which it operates. Policy makers need to develop their capacity to continuously adapt and improve the system.

The conceptual model identified four activities aimed at the development and regular update of the care model: (1) Base the model on societal values to reflect and respond to dominant trends in society and (2) on the needs of patients and their families; (3) Keep an eye on state-of-the-art practices, and (4) incorporate the budgetary and resource constraints into the reflection.

A first round of these activities has been initiated in this research project but there is a need for an ongoing effort to follow up the actions that were launched, to identify new needs and implement the corresponding measures. High-level leadership and pro-active management should get things moving in the right direction, with adapted macro- and meso-level structures coming in support of the local networks.

Implementation and follow-up of a dynamic care model are synonymous with the existence of an effective information system that relies on key performance indicators to support all stakeholders (patients, caregivers, care institutions and policy makers) in reaching the goals set out in this position paper. The objective is follow-up through the use of key performance indicators, screening and reporting. It is of utmost importance to consider the ergonomics of the information system to invest little energy for the best possible yield. Suggestions from the Institute of Medicine¹³⁶ include e.g. a user-friendly registration process, collection of valuable information that is also relevant for the patient, priority for minimal sets of core elements that provide timely and essential information, pro-active re-use of data, strategies of results integration across the several facets of the health system.

6.6.1.1. Recommendation 15

Develop and maintain scientific know-how at the macro level, to ensure the implementation and follow-up of a comprehensive and integrated system oriented towards the chronic patient

Action Point 15.1: Support the development and implementation of guidelines adapted to the complexity of the chronic diseases

Chronic care is in essence complex, a.o. due to the frequent occurrence of multimorbidity (see 1.4). However most research – and the guidelines resulting from it – focus on one disease only, with little consideration for coexisting conditions. As a consequence, a treatment targeting one condition might trigger new problems in patients who suffer from other chronic conditions. One illustration is the risk of gastric ulcer in patients with a chronic pulmonary disease receiving glucocorticoids whilst taking at the same time anti-inflammatory drugs for osteoarticular pain. Ideally, clinical trials should include old people and examine the effectiveness of treatment in patients with comorbidities¹³⁷.

However, the clinicians involved as experts in this study pointed out that there is sketchy evidence applicable to specific patient populations. For patients with multimorbidity, in particular, there is scarce evidence about the effectiveness of treatments and care models. Yet, evidence based practice defined as “the integration of best research evidence with clinical expertise and patient values”¹³⁸ does not undermine this potential for innovation. In this context, a structured consultation of experts and patient preferences could usefully complete the available scientific literature.

One concrete initiative to share common protocols between health professionals is the development of care pathways¹³⁹ (“zorgpaden/itinéraires cliniques”). Care pathways aim to standardize practice and to enhance coordination of care “for a well-defined group of patients during a well-defined period”. This concept is promising but in practice most pathways are restricted to inpatient care. Only recently integrated care pathways covering inpatient and outpatient care (“transmural”) were introduced. In this case they are predominantly initiated by teams in hospitals: in a next step they should be more frequently initiated by the primary care teams¹³⁹.

**Action Point 15.2: Set up a strategic cell for further development of the care model for chronic diseases**

In May 2012, the Observatory of chronic diseases (Observatoire des maladies chroniques – Observatorium voor chronische ziekten) was set up with a.o. the task to identify the needs and define the optimal care for the chronically ill. Besides the scientific and consultative sections of the Observatorium, both populated by experts and stakeholders, there is a need for a small scientific research office: this should keep track of the mainstream international evolutions in the field of chronic diseases, scrutinizes the domain for new developments, and commissions the development of specific guidelines or studies, a.o. on evolving needs, innovative approaches or complex conditions. It should integrate and bundle this information, craft preparatory documents and draft specific measures or reforms, to be subsequently validated by the respective sections of the Observatory.

The objective is to get more harmonization in the policies and decisions taken at various institutional levels. The Interministerial Conference on Health and the Institute announced in the governmental declaration of December 2011, could play an important interfacing role to foster the collaboration between institutions.

Requirements

- The Observatory should get access to all relevant epidemiological data e.g. from the care trajectories or from the Health interview survey;
- The Observatory should also have a strong articulation with the Cancer centre, with the National Council for Quality Promotion (NRKP – CNPQ), with the academic research centres and with the relevant authorities at regional and community level.

Action Point 15.3: Create an operational competence pool for the design and implementation of new chronic healthcare processes

Our healthcare governance model is mainly based on negotiations between the providers and the sickness funds: many decisions and reforms emanate from groups composed of specialists in the specific clinical disciplines (medicine, nursing, pharmacy...) and experts in health insurance. The result is that reforms are often funded in knowledgeable and valid insights, but, from a practical, operational point of view, they are poorly designed and implemented and hence, miss much of their potential impact.

Expertise from people with other backgrounds may bring new insights in these discussions on how to implement successful changes. Professionals specialised in management, business process design and (re-) engineering, occupational ergonomics and communication, could help to bridge the gap between the conception of a solution and its successful implementation in the field.

A team of professionals with the above-cited organizational competences should have the remit to optimize the implementation of the recommendations from the Observatory. More specifically, it should strive to maximize ergonomics, user-friendliness and (administrative) simplicity of the proposed changes, whilst integrating as much as possible existing data sources, procedures, services. This team should also, whenever appropriate, elicit stakeholder input, with special reference to the patients.

6.6.1.2. Recommendation 16**Optimize the existing coordination structures at meso and macro level or develop new ones where needed**

Health systems operate at and across, the macro, meso and micro levels as explained in a WHO publication on health policy and system research³⁴. At macro level system, the main roles include developing policies and regulations, balancing policies, strategies, resource allocation and health worker reward systems in line with overall system goals and coordinating delivery activities and interventions.

The meso level comprises both the local health system and the organizational level, such as hospitals. The main roles are (1) provision of health services and wider health promoting activities adapted to local



needs and circumstances; (2) coordination among actors; (3) management of health services and activities; (4) supervision and training of service providers; (5) adaptation of national policy and guidelines to local circumstances. Experience abroad shows that leadership as well as the inclusion of hospitals within this meso level are requirements for a successful implementation of changes.

Finally, the micro level includes the citizens, local providers and services, local authorities and the interactions between them.

Action point 16.1: Optimize the coordination structures at meso level

- **Operational meso level:** platforms for exchange between care providers

Insofar as good chronic care is coordinated and planned, there is a need for platforms where individual caregivers can meet and forge partnerships, find specific support and help (e.g. like is the case from the palliative care networks) or discuss local issues. Action Point 7.2. referred to this level as the operational meso-level. These structures should also help to make the link between the care for the individual patient and the structures at a larger scale level (cf. GDT/SISD).

- **Strategic meso level:** coordination platforms for exchange between the representatives of the different providers and other actors active in chronic care

Many structures and platforms already exist, both in the medical domain and in the social care domain, but they often overlap, each with its own players, providing its own services. The result is that providers and patients often fail to obtain the help in theory available (see scientific report chapter 7).

One can anticipate barriers for the implementation of these reforms as for example: vested interests and territorial reflexes of actors who today fulfil (some of these) coordination tasks; division of the target population following the traditional pillars; co-existing (if not competing) structures; division between federal and regional/community competences, the huge divide between the healthcare and social sectors.

In the meantime, efforts should be oriented towards creating places and opportunities where the respective partners can collaborate in a continuous and efficient way.

Requirements

- Complete coverage of the territory with one operational coordination platform at small-town level (or large municipality) and one cupula platform at the large-town or province level. The boundaries of the former should never cross those of the latter.
- Reliance on existing structures and organisations whenever possible with a pursuit of more coherence between all geographical levels, by appropriate recognition and/or financial incentives for those willing to reorganize according to the blueprint of the neatly subdivided territory described above.
- Communication tools and data sharing to put the information at all interested stakeholders' disposal.

Action point 16.2: Create a strategic coordination cell at the highest strategic level

The least one can say is that for the health and social care sector, the successive state reforms have not resulted in a transparent and easy to manage system. As long as competences are scattered over different decision levels, there will be a need for coordination and agreements, in particular between the federal and the regional levels.

The Interministerial conference for health is the platform where coordination between decision levels happens. Besides, the governmental declaration of December 2011 mentions that an Institute will be set up to give concerted solutions to the future challenges of the healthcare system. Without any doubt, setting up an effective chronic care plan is one of the most important challenges, and the Institute should become the place where the different competence levels meet and collaborate, working towards a harmonious and efficient integration of the structures at the different levels. At the very least, this strategic coordination cell should watch over the decisions taken at the different levels and prevent these from being overlapping, let alone contradictory. Ideally, it should become a



credible and visionary common think tank with the backing of all relevant political levels.

6.6.1.3. Recommendation 17

Ensure the accessibility and the equity for the chronically ill

In the international papers, the accessibility of services is considered as a priority for people who suffer from chronic disease. A white paper published by the EU Commission in 2007 restates the fundamental principles for EU action on health²⁰ a.o. a strategy based on shared health values: universal access to good quality care, equity and solidarity. Likewise, the UN General Assembly Declaration on the Prevention and control of Non-communicable diseases of September 2010⁸ urges the member states to reduce health disparities and adopt universal health coverage.

In Belgium, the accessibility of care, and in particular the financial accessibility, was the main theme of the national programme "Priorité aux maladies chroniques!" (see 1.1)¹. The long list of decisions to improve the (financial) accessibility in general and the reimbursements for specific target groups in particular, will not be repeated in this position paper.

However, during the SWOT analysis, the stakeholders pointed out a number of evolutions threatening the accessibility of care and these issues need to be addressed:

- An increasing number of specialists work in private practice: the consequences are increasing delays for consultations in hospitals, in particular in rural areas;
- Waiting lists for older persons who need institutional care and admission policies not always targeting those most in need.
- Limited access to respite care (in particular due to financial barriers and lack of information for the interested persons);
- Legal and reimbursement criteria excluding patient groups on the basis of their disease profile for example.
- Geographical barriers to accessibility as for example in cardiac rehabilitation: officially recognized centres are not evenly distributed in

Belgium, leading to poor accessibility in rural areas and/or in case of transport problems¹³¹.

6.6.1.4. Recommendation 18

Let the current payment systems evolve to become more supportive of high-quality, integrated, multidisciplinary and patient-empowering chronic care, with special attention for ambulatory care

Action point 18.1: Gradually move from a predominantly fee-for-service payment system towards more mixed forms of payment

The vast majority of stakeholders and experts consulted in the course of this study project underlined the incompatibility between the current financing system and the provision of multidisciplinary chronic care based on patient-defined needs (see chapter 7 in the scientific report). Fundamentally, in a fee-for-service system, the financial incentives are not well aligned with the imperatives of chronic care:

- a number of crucial but time-consuming tasks, like priority setting, coordination and patient education are undervalued;
- the system creates disincentives for delegation of tasks and multidisciplinary work: for a self-employed providers as sharing budgets with other care providers may be problematic;
- the system may induce underuse for more vulnerable groups.

The problem is not limited to the remuneration of medical doctors. The KCE report on home nursing also pointed out a number of similar problems¹⁴⁰: the obsolete and complex list of billing acts; the lack of fee differentiation by qualification level; the lack of incentives for coordination between the first and second line of care; the inadequacy of a purely fee-for-service system for the follow-up of chronic conditions, in particular in the long-term care context.

In addition to the current predominantly fee-for-service system of payment, a number of other existing forms of payment should continue to be developed, and new ones could be added. Current alternatives for the fee-for-service system are:



- The current remuneration for the Global Medical record (GMD/DMG) is a 'light' form of capitation, with corresponding co-payment reductions for the patient. The financing mechanisms applied in the care trajectories follow the same principle: a yearly flat rate fee for the coordination tasks of the GP and the specialist; waved co-payments for the patient. Still, in both cases the flat rate is far from covering the entire cost of care, and the fees for each individual contact remain the main source of income for the physician;
- At the other end of the spectrum, the full capitation system of the integrated primary healthcare practices ("wijkgezondheidscentra / maisons médicales") functions with a per capita rate, adjusted for care needs, covering not only the care provided by the GP, but also by nurses, and other healthcare professionals incl. physiotherapists, speech therapists, social workers etc. This system is more supportive for multidisciplinary collaboration and task delegation.
- The financing reform in palliative care can serve as instructive examples for further reforms of the financing of chronic care.

Reward quality

The current system has its own valuable dynamics, mainly oriented at the satisfaction of the patient and interaction with the individual provider. Yet, it has very few, if any, mechanisms formally linking remuneration to measured achievement of quality goals. Although such approaches were shown not to be invariably successful or recommendable, a progressive introduction of mechanisms rewarding the achievement of quality targets could be envisaged¹⁴¹. But the quality measures have to be supported by evidence whenever possible, and based on accurate, validated and readily available data (see recommendation 6). Such a system should allow for individualised feedback to the health professionals, but it should also monitor its own overall impact, effectiveness, cost-effectiveness and potential unintended consequences.

Need for gradual implementation and pilot testing

A shift from fee-for-service system towards financing based on needs requires a close follow-up of new financing models, so as to optimize the system gradually. This would also include a monitoring of the quality and efficiency of care and of the equity and accessibility.

Moreover, the stakeholders also mentioned the administrative complexity resulting from multiple payment mechanisms, in particular in case of multimorbidity.

By all means, a thorough examination of these payment mechanisms is needed, and new models of payment will require thorough preparatory work, incl. development and testing of operational procedures and financial agreements for multidisciplinary collaboration (see recommendation 4). The input from expertise as advocated in Action Point 15.3 is essential.

Action point 18.2: Invest in primary care

The propositions suggested in 6.1 imply investment in primary care: multidisciplinary teamwork, the development of specific ICT applications, the attraction of primary healthcare professions, the official recognition of new functions, (in particular the case manager), a performant quality system, alternative settings for the care of persons with complex needs imply specific budgets. In the same way, fostering patient empowerment (see recommendations 13 and 14) also requires specific investment for providers' education and the development of adapted tools.



6.6.1.5. Recommendation 19

Plan and monitor at the highest level the health professionals requirements

Accessibility of care has also to do with the availability of an adequate workforce to respond to the patients' needs.

In Belgium there is a need to improve the coordination and harmonization of routine data collection on the 'stock and flows' of healthcare workers and of GPs in particular (i.e. head count and demographic characteristics, actual level of activity, attrition or migration rate, complementary information on practice arrangements and workload)¹⁴².

A workforce planning framework should be developed, that is taking into account the anticipated and planned changes in the healthcare delivery system, including new functions and roles and the projected evolution of the healthcare needs in an evolving demographic context.

6.6.1.6. Recommendation 20

Transform the recommendations and action points of this position paper into an operational chronic care plan, and evaluate their implementation through the development and subsequent measurement of action-specific indicators

All recommendations and action points proposed in this position paper should be transformed into a concrete chronic care plan. The Observatory for chronic diseases should be fully involved a.o. to prioritize concrete actions. In Belgium, decision making traditionally relies on bilateral agreements between specific stakeholders groups and sickness funds. Yet, the multidisciplinary and collaborative nature of chronic care that transpires throughout this position paper obviously asks for decisional mechanisms that resolutely put the patient at the centre with other stakeholders' interests relegated to a position of secondary importance.

However profound, the reforms advocated for in this position paper should whenever possible be built upon existing structures, rather than create new ones. A health care system should be seen as a "complex adaptive system"^{143,144} where individuals act "in ways that are not always totally

predictable, and whose actions are interconnected so that one agent's actions changes the context". Clearly new initiatives will inevitably change the current steady state of the health care system and give rise to new situations where the actors play a different role that influences the equilibrium. The challenge is to thoughtfully modify the incentives in order to make the existing structures and actors gradually adapt to the new, more integrated configuration of the care system, better tailored to the long-term needs of the chronic patient.

Finally, in the years to follow, the degree of implementation of each component of the plan should be evaluated by means of a set of indicators corresponding to each specific action. These indicators could be developed by the Observatory for Chronic Diseases. They should maximally reuse existing data. More specifically, the authorities should invest in an effective, user friendly and safe automated mechanism of data extraction and transfer from the electronic patient file, as the cornerstone of the future evaluation system.



7. REFERENCES OF THE POSITION PAPER

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■ APPENDIX OF THE POSITION PAPER

APPENDIX 1. RECAPITULATIVE INVENTORY OF THE MAIN ACTION FIELDS AND OF THE ACTORS INVOLVED

The implementation of the recommendations of the position paper requires initiatives in different domains:

- Education;
- Development of protocols and tools for communication;
- Development of ICT technologies;
- Quality improvement initiatives;
- Empowerment of the patient and informal caregiver;
- Manpower;
- Organizational reforms.

The following sections analyze who are the main actors to be involved for each of these seven domains.

Appendix 1.1. Education

Appendix 1.1.1. Academic institutions and high schools

Academic institutions and high schools are in front for the implementation of the following recommendations:

- Action point 3.1: attraction of the GP profession;
- Action point 4.2: training for advanced practice nurses;
- Action point 7.1: new function of case manager;
- Recommendation 12: development of detection skills;
- Action point 13.1: provider skills for patient empowerment.

Appendix 1.1.2. Professional organisations

Conversely, professional organisations have the responsibility to include the following points in their programmes of continuing education:

- Recommendation 2: training modules for needs assessment and elaboration of a care plan;



- Action point 7.1: development of an education programme to develop case management competences;
- Action point 11.3: development of a training module for discharge management;
- Recommendation 12: continuing education to maintain/improve detection skills.

Appendix 1.2. Development of protocols and tools for communication

Appendix 1.2.1. Professional organisations

The professional organisations have the main responsibility in the development of the tools referred to in the following action points:

- Action point 1.2: development and use of a chronic care module in the medical record;
- Recommendation 12: tools for facilitating early detection;
- Action point 13.2: tools for patient empowerment;

Appendix 1.2.2. Patient Organizations

- Action point 13.2 (tools for patient empowerment) also requires the active involvement of patient organizations.

Appendix 1.2.3. Comité de l'assurance/Verzekeringscomité

- Action point 1.3: endorsement of a standard evaluation tool to assess patient needs.

Appendix 1.3. Development of Information and Communication Technology applications

Appendix 1.3.1. eHealth

Many recommendations and action points of the position paper require specific Information and Communication technology (ICT) applications for their successful implementation. The implementation of new ICT applications mainly falls under the responsibility of eHealth:

- Action point 1.2: development and use of a 'module chronic care' in the medical record in collaboration with the professionals;

- Action point 6.3: data collection for the measurement of quality indicators;
- Action point 13.2: development of tools for patient empowerment in collaboration with the patient associations and the health professionals;
- Action point 14.4: implementation of a health care system oriented towards chronic care, based a.o. on data collected at different levels.

Appendix 1.3.2. Comité de l'assurance / Verzekeringscomité

- Action point 1.2: development and use of a chronic care module in the medical record.

Appendix 1.4. Quality improvement initiatives

Quality improvement initiatives require the know-how and collaboration of different actors:

Appendix 1.4.1. Federal authorities and federated entities

- Action point 6.1: definition of clear objectives and consequences of the quality system in collaboration with the stakeholders;
- Action point 11.3: need for appointing a discharge manager for complex cases (cf. geriatric care programme).

Appendix 1.4.2. Professional organisations

- Action point 6.1: definition of clear objectives and consequences of the quality system in collaboration with the stakeholders;
- Action point 6.2: search for quality indicators;
- Action point 6.4: feedback to the professionals;
- Action point 11.1: development of shared protocols between lines of care;
- Action point 15.1: development of clinical guidelines including comorbidities.

Appendix 1.4.3. Patient Organizations

- Action point 6.1: definition of clear objectives and consequences of the quality system in collaboration with the stakeholders;



- Action point 6.2: search for quality indicators.

Appendix 1.4.4. eHealth

- Action point 6.3: data collection for the measurement of quality indicators.

Appendix 1.4.5. Conseil National pour la Promotion de la Qualité / Nationale Raad voor KwaliteitsPromotie

- Action point 6.1: definition of clear objectives and consequences of the quality system in collaboration with the stakeholders;
- Action point 6.2: search for quality indicators;
- Action point 11.1: development of shared protocols between lines of care

Appendix 1.4.6. Comité de l'assurance/Verzekeringscomité

- Recommendation 6: support of a continuous quality improvement programme for chronic care, including the 4 action points mentioned above

Appendix 1.4.7. Legislation

- Action points 6.1, 6.3, legal framework and conditions for data collection;
- Action point 11.3: need for appointing a discharge manager for complex cases (cf. geriatric care programme).

Appendix 1.5. Empowerment

Empowerment calls for a strong collaboration between the patient and the health professional.

Appendix 1.5.1. Patient Organizations

- Action point 5.2: support of the informal caregiver to allow the patient to stay at home as long as possible and desired;
- Action point 13.2: development of tools for patient empowerment;
- Action point 14.1: provision of timely and accurate information;
- Action point 14.2: foster patient empowerment in routine care.

Appendix 1.5.2. Academic institutions and high schools

- Action point 13.1: providers skills for patient empowerment.

Appendix 1.5.3. Professional organisations

- Action point 13.1: providers skills for patient empowerment;
- Action point 13.2: development of tools for patient empowerment.

Appendix 1.5.4. Sickness Funds

- Action point 5.2: support of the informal caregiver to allow the patient to stay at home as long as possible and desired;
- Action point 14.1: provision of timely and accurate information;
- Action point 14.2: foster patient empowerment in routine care.

Appendix 1.6. Manpower

Appendix 1.6.1. Federal authorities

- Recommendation 19: planning manpower whilst taking into account new roles and functions in primary care.

Appendix 1.6.2. Professional organisations

- Action point 3.2: working conditions of general practitioners.

Appendix 1.6.3. Comité de l'assurance / Verzekeringscomité

- Action point 3.2: working conditions of general practitioners;
- Action points 4.1 and 4.2: delegation of tasks from GPs to other professionals and from nurses to less qualified health professionals;
- Action point 7.1: case manager function.

Appendix 1.6.4. Legislation

- Action point 3.2: working conditions in the first line of care (GPs);
- Action point 4.1 and 4.2: delegation of tasks from GPs to other professionals and from nurses to less qualified health professionals;
- Action points 4.3: recognition of new qualifications for nurses;
- Action point 7.1: recognition of case manager function.



Appendix 1.7. Organizational reforms

Appendix 1.7.1. *Observatorium for chronic diseases*

- Action point 15.1: follow-up of relevant scientific development and data on chronic care/patients;
- Action point 20: translate this position paper into an operational plan and evaluate its implementation.

Appendix 1.7.2. *Federated entities*

- Action points 5.1, 5.2 and 5.3: care in the least complex environment: policies, support of informal caregiver, development of alternatives to institutions;
- Action point 15.1: follow-up of relevant scientific development and data on chronic care/patients;
- Action point 16.1: optimize coordination structures at meso level;
- Recommendation 17: accessibility and equity for all chronic patients e.g. respite care, waiting lists for institutional care.

Appendix 1.7.3. *Interministerial conference*

- Action point 5.1: policies to encourage patients with chronic disease to stay at home;
- Action point 7.2: streamlining of coordination networks;
- Action point 16.1: optimize coordination structures at meso level;
- Action point 20: translate this position paper into an operational plan and evaluate its implementation.

Appendix 1.7.4. *Future Institute for concerted solutions to the challenges*

- Action point 7.2: streamlining of coordination networks;
- Action point 16.1: optimize coordination structures at meso level;
- Action point 16.2: strategic coordination cell at the highest level;
- Action point 20: translate this position paper into an operational plan and evaluate its implementation.

Appendix 1.7.5. *INAMI/RIZIV*

- Action point 15.1: follow-up of relevant scientific development and data on chronic care/patients;
- Action point 15.2: operational competence pool for implementation of reforms.

Appendix 1.7.6. *Comité de l'assurance / Verzekeringscomité*

- Action points 5.1, 5.2 and 5.3: care in the least complex environment: policies, support of informal caregiver, development of alternatives to institutions;
- Recommendation 16: optimize existing coordination structures;
- Recommendation 17: accessibility and equity for all chronic patients;
- Recommendation 18: mix of payment mechanisms and budget for ambulatory care.

Appendix 1.7.7. *Legislation*

- Action point 5.1,: policies to encourage patients with chronic disease to stay at home.



Main actors involved in the implementation of the action points and recommendations

	Universities/ High Schools	Professional Organizations	Patients organizations	Com.assur./ Verzek.Com.	eHealth	Federal Authorities	Federated Entities	CNPQ NRKP	Minister (law)	Sickness Funds
Education	AP.3.1 AP.4.2 AP 7.1 Rec 12 AP 13.1	Rec 2 AP 7.1 AP 11.3 Rec 12								
Development of Protocols and tools for communication		AP 1.2 Rec 12 AP 13.2	AP 13.2							
Development of ICT applications				AP 1.2	AP 1.2 AP 6.3 AP 13.2 AP 14.4					
Quality improvement initiatives		AP 6.1 AP 6.2 AP 6.4 AP 11.1 AP 15.1	AP 6.1 AP 6.2	Rec 6	AP 6.3	AP 6.1 AP 11.3	AP 6.1	AP 6.1 AP 6.2 AP15. 1	AP 6.1 AP 6.3 AP 11.3	
Empowerment	AP 13.1	AP 13.1 AP 13.2	AP.5.2 AP.13.2 AP 14.1 AP 14.2							AP.5.2 AP 14.1 AP 14.2
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	Observatorium for chronic diseases	Institute concerted solutions	for Interministerial Conference	Comité Assurance/ Verzekeringscomité	Federated Entities	INAMI RIZIV	/ Minister (law)
Organizational changes	AP 15.1	AP 7.2	AP 5.1	AP 5.1	AP 5.1	AP 15.1	AP 5.1
	AP 20	AP 16.1	AP 7.2	AP 5.2	AP 5.2	AP 15.2	
		AP 16.2	AP 16.1	AP 5.3	AP 5.3		
		AP 20	AP 20	Rec 16	AP 15.1		
				Rec 17	AP 16.1		
				Rec 18	Rec 17		



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Finally, this report has been approved by common assent by the Executive Board.

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