

REFLECTION PROCESS on CHRONIC DISEASES

INTERIM REPORT

A. INTRODUCTION

REFLECTION PROCESS

In conclusions adopted in March 2010, the Council called upon the Commission and Member States to launch a reflection process on chronic diseases. This reflection process would identify options to optimize the response to the challenges of chronic diseases, including proposed actions in health promotion, prevention and disease management. In its conclusions, the Council also asked for the active participation of all relevant stakeholders, including patients and people at risk.

This report builds upon the discussions in two meetings of the Working Party on Public Health at Senior Level (WPPHSL) on 10 October 2011 and 8 February 2012 and picks up key elements from the consultation among Member States, the EU Health Policy Forum, and a targeted consultation with about 80 stakeholders, representing industry, patient associations, and other interest groups. This report was prepared by a drafting group with representatives of the Commission and the current and future EU Trio-Presidencies (PL, DK, CY, IE, LT, EL) and the Council Secretariat. It has been prepared as an input for the WPPHSL discussion on 28 September 2012. It proposes EU actions in chronic diseases in two areas: Chronic disease prevention and health promotion and chronic disease management with an emphasis on patient empowerment.

Several questions at the end of the document seek to steer the discussion and pave the way for endorsement of the actions proposed.

CHRONIC DISEASES

Chronic diseases are diseases of long duration and generally slow progression¹. Overall, chronic diseases represent the major share of the burden of disease in Europe, which too often results in premature morbidity and loss of healthy life years. Increasing life expectancy contributes to the rising prevalence of chronic conditions, which calls for adequate prevention and sustainable disease management. Globally, Europe has the highest burden of chronic diseases which are responsible for 86% of all deaths². WHO considers the rise in chronic diseases an epidemic and estimates that this epidemic will claim the lives of 52 million people in the European Region by 2030³. Chronic diseases affect more than 80% of people over 65 in Europe. Moreover, in patients over 65, the presence of multiple conditions or co-morbidities is an additional quantitatively important element, which has a multiplier effect on health burden and management costs.

The growing burden of chronic disease therefore represents a major challenge for health systems across Europe and it also impacts on the wider social system and the economies in Member States. It is widely acknowledged that 70% to 80% of healthcare costs are spent on chronic diseases. This corresponds to €700 billion in the European Union and this number is expected to increase in the coming years⁴. About 97% of health budgets are presently spent on treatment, while 3% is invested in prevention⁵.

Although there are a significant number of different chronic diseases, they share common features such as risk factors and health determinants, and present common challenges to health systems.

The focus of the reflection process is to address these common features, rather than to address specific diseases.

¹ Chronic diseases also include a large number of relatively rare conditions. The EU has developed a common framework for addressing the challenge of rare diseases which are not the subject of this reflection – cf. Communication from the Commission to the Council, the European Parliament, the European Economic and Social Committee and the Committee of the Regions on "Rare Diseases: Europe's challenges" COM (2008) 679.

² WHO high level consultation <http://www.euro.who.int/en/what-we-do/event/regional-high-level-consultation-on-non-communicable-diseases>.

³ United Nations General Assembly 19 May 2011 Report by Secretary-General on the prevention and control of non-communicable diseases (A/66/83).

⁴ <http://www.oecd.org/dataoecd/43/9/48245231.pdf>

⁵ Together for Health: A strategic Approach for the EU 2008-2013, White Paper, European Commission, COM(2007) 630 final.

Socio-economic and demographic changes, progress in technology, medical practice and patient care have influenced the epidemiology of the major chronic diseases and, consequently the health and social response. Therefore, the challenge of chronic diseases must be addressed at all relevant levels – from communities to policy makers – and across policy fields.

THE ROLE OF THE EUROPEAN UNION

The European Union has a role to play in support of national and regional policies addressing chronic diseases. A European response must focus on added value through EU action, taking into account the EU role and competence in health as defined in Article 168 of the Treaty, economies of scale and the needs and requirements of Member States.

A specific EU initiative in this respect is the "European Innovation Partnership (EIP) on Active and Healthy Ageing", one of the flagship initiatives of the Europe 2020 strategy. This Partnership sets a target of increasing the healthy lifespan of EU citizens by 2 years by 2020, and aims to pursue a triple win for Europe by improving health and quality of life of older people, improving the sustainability and efficiency of care systems and creating growth and market opportunities for businesses. The EIP focuses on actions developed around 3 pillars: prevention, screening and early diagnosis; care and cure (integrated care); and active ageing and independent living.

In defining new areas of potential EU action, it is essential to ensure complementarity with the discussion and actions at international level. With their experience of addressing public health challenges, the EU and its Member States are key actors in the UN process on Non Communicable Diseases (NCD), and Europe can provide a steering role in the response to NCDs and other chronic conditions.

B. EU ACTION

1. CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION

Taking into consideration the long term nature and slow evolution of most chronic diseases, it is essential to take effective action on risk factors and health determinants, by putting an increased emphasis on **targeted** health promotion, prevention, and early detection to prevent or to delay the onset of diseases.

Four major risk factors to be tackled more effectively, both at EU and national levels have been identified in the UN High Level Meeting on NCDs: tobacco, alcohol, unhealthy diet and lack of physical activity. At EU level, there are already established policy strategies and approaches in place to tackle these risk factors such as tobacco legislation⁶ ⁷, EU strategies on nutrition and physical activity⁸ and alcohol-related harm⁹. Moreover, some major chronic conditions, such as types of cancer or HIV/AIDS, are linked to communicable agents, thus requiring integrated responses. Conditions in which people live and their lifestyles also influence their health and quality of life. There is a clear inequality in the burden of chronic diseases and in access to prevention and control¹⁰. Therefore, EU action on cancer¹¹, HIV/AIDS¹² health inequalities¹³, and mental health¹⁴ also contribute to address chronic diseases.

⁷ Directive 2001/37/EC of the European Parliament and of the Council of 5 June 2001 on "The approximation of the laws, regulations and administrative provisions of the Member States concerning the manufacture, presentation and sale of tobacco products".

⁷ Directive 2003/33/EC of the European Parliament and of the Council of 26 May 2003 on "The approximation of the laws, regulations and administrative provisions of the Member States relating to the advertising and sponsorship of tobacco products"

⁹ White Paper on a "Strategy for Europe on Nutrition, Overweight and Obesity related health issues" COM(2007) 279

¹⁰ Communication from the Commission to the Council, the European Parliament, the European Economic and Social Committee and the Committee of the Regions on "An EU strategy to support Member States in reducing alcohol related harm" COM(2006) 625

¹¹ http://www.un.org/ga/search/view_doc.asp?symbol=A/66/L.1

¹¹ Communication from the Commission to the Council, the European Parliament, the European Economic and Social Committee and the Committee of the Regions on "Action Against Cancer: European Partnership" COM(2009) 291/4

¹² Communication from the Commission to the Council, the European Parliament, the European Economic and Social Committee and the Committee of the Regions on "Combating HIV/AIDS in the European Union and neighbouring countries, 2009 -2013" COM(2009) 569

¹³ Communication from the Commission to the Council, the European Parliament, the European Economic and Social Committee and the Committee of the Regions on "Solidarity in Health: reducing health inequalities in the EU" COM(2009) 567

¹⁴ http://ec.europa.eu/health/mental_health/docs/mhpact_en.pdf

Despite all efforts to date, we have not been able to effectively achieve the health gain possible from tackling the common risk factors. The risk factor strategies outlined above need to be strengthened and integrated with disease management. The key challenge of the EU reflection process on chronic diseases is therefore to assess where EU action could help to promote effective, evidence-based and innovative actions, which, when applied in a systematic way, can make a real difference in health promotion and prevention towards reducing the burden of chronic diseases.

In this respect, the consultation with Member States and the targeted consultation with major stakeholders resulted in a wealth of proposals and inputs, some of which are set out in the table below.

Table 1. Elements to consider: inputs extracted from the consultation of Member States, EU Health Policy Forum (EUHPF) and other stakeholders

1. Recognize that prevention is essential in the response to chronic diseases:
✓ Adopt a cross-sectorial/ multi-stakeholders approach towards chronic diseases prevention: "health in all policies"/"health across administration" approach (integration of different sectors as health, education, energy, agriculture, sport, transport, communication, urban planning, infrastructure, environment, employment, industry and trade, finance, social and economic development)
✓ Develop models of integrated/evidence based/cost-effective/affordable/population-wide and multi-sectorial interventions
✓ Focus not only on primary prevention, but also on secondary and tertiary interventions to develop cost-efficient and high quality health policies
✓ Work toward a better integration between health promotion and disease prevention
✓ Mapping the fields in need of innovation and added value and monitoring the impact of new developed prevention tools
✓ Supporting studies on medical intervention as a mean of prevention (e.g. high dosage of vitamin D)
2. Tackle the risk factors:
✓ Continue working on common modifiable risk factors, namely tobacco, alcohol, unhealthy diet, lack of physical activity
✓ Further studies on "newly" identified risk factors, such as, stress and psychosocial factors, environment, genetic predisposition, unhealthy work environments
✓ Agree on common definition of risk factors, social and health determinants between the different European countries
✓ Facilitate and promote improved and healthy lifestyles choices at different levels: <ul style="list-style-type: none"> ➤ Encourage the development of policies to create health-promoting conditions that incentive patients, families, and communities to make healthy choices and live healthy lives ➤ Promote educational programmes for carers; inclusion/reinforcement of prevention and health promotion in medical curricula; improving training and mobility of health professionals and cross-border access to health records; strengthen role and responsibility of health professionals in prevention and in monitoring patients' compliance and response. In particular, frontline health professionals should ask about lifestyle behaviours and encourage positive action. ➤ Involve health insurance: incentives (including penalties) to undertake evidence-based health checks accompanied by measures to incentivise positive and healthy choices and lifestyles ➤ Involve employers in creating an appropriate environment for their employees; promotion of health at the workplace/occupational health, possibility to access training/physical exercises; proactive attitude by employers; ➤ Involve regional and national governments in improving the surrounding physical environment.

<ul style="list-style-type: none"> ➤ Support a "patient" centred prevention, social support and tailored educational programmes, "personalised prevention" ➤ Foster partnership and constructive dialogue between Government and civil society to support the provision of services for the prevention and control of chronic diseases
<ul style="list-style-type: none"> ➤ Improve communication in health: awareness raising, health education, responsible use of social networks and innovative communication technologies, improving health literacy, working towards a patient empowerment, recognizing the importance of education (theoretical as well as physical) from early age
<ul style="list-style-type: none"> ➤ Promote and adopt already existing measures to prevent or tackle risk factors: i.e. healthy diet, physical activity, vaccinations to prevent infections associated with cancers, the use of illicit drugs ➤ Improve awareness in the population. Improve surveillance and monitoring systems, including survey, monitoring exposure to risk factors, outcomes, social and economic determinants of health, and health system responses
<ul style="list-style-type: none"> ✓ Promote gender-based and age-based approaches for prevention and control of chronic diseases, to address the differences in the risks of morbidity and mortality between different populations ✓ Recognize the impact of inequality on prevention of chronic conditions and tackle this issue with specific measures
<p>3. Support targeted screening of risk groups and early detection/diagnosis</p> <ul style="list-style-type: none"> ✓ Improve diagnostic services in terms of affordability, accessibility and maintenance of diagnostic equipment and technologies ✓ Train health workers ✓ Create European registries on the different chronic conditions, develop a common framework of data collection and sharing of data and information on Chronic Disease Prevention and Health Promotion, including surveillance systems, within European countries, map the gaps in the data available and put efforts in reducing them ✓ Improve cooperation with civil society and NGOs to promote the provision of services for the treatment and care of non-communicable diseases

Reflecting upon these proposals by Member States and stakeholders, there is broad support for continuing action on risk factors and developing validated prevention approaches. Clearly, there is also a call for more to be done on targeted screening and secondary prevention. The stakeholder consultations identified a considerable number of aspects such as incentives to trigger behavioural changes of people at risk, more effective prevention linked to primary care, promotion of secondary prevention, regulatory and other measures to address major risk factors. Further proposals emphasised the importance of close interaction and effective communication among health care providers, regulators, insurances and targeted populations.

The importance of validated good practise

In the context of this reflection process, and in view of the discussions in the WPPHSL, it is proposed to emphasise the potential EU added value in triggering, coordinating and scaling up the exchange of good practice. A large pool of good practice exists across Member States. However, it is not always disseminated.

Therefore, we propose that good practices should be mapped and validated to facilitate their uptake in national/regional/cross-border programmes. This should ultimately help to identify common fields of actions at national and EU level across policies and sectors that contribute to positive health outcomes.

Focus for EU action

EU level action in this area should be ambitious and include a clear focus on social and technological innovation, new technologies, the use of social media, and make use of evidence from behavioural science.

A good practice mechanism at EU level could be established to identify, validate and disseminate good practice and information on policies, interventions and actions on chronic diseases, including the development of quality control instruments and examine barriers to the uptake of good practise. This would also provide at EU and national levels supporting evidence for cost-effective promotion and prevention activities, with a particular view on long-term benefits.

Once such a mechanism is in place, further steps could be taken, such as:

- (a) work towards scaling up validated good practices in pilot projects to demonstrate their usefulness on a European level.
- (b) intensify EU level cooperation regarding the exchange of good practice on early detection and screening for the most relevant areas of chronic diseases.

In parallel, structures such as the High Level Group on nutrition and physical activity, the Committee on National Alcohol policy and Action and broader stakeholder bodies such as the EU Platform for Nutrition and Physical Activity, the EU Alcohol and Health Forum, the European Partnership for Action against Cancer and the European Mental Health pact are the appropriate fora for agreeing on joint approaches to address risk factors but also on actions towards reducing the burden of major chronic diseases.

The actions associated with the European Innovation Partnership on Active and Healthy Ageing will also be taken into account. In particular, the outcomes from actions on better prescription and adherence to treatment, on prevention of functional decline and frailty and addressing multi-morbidity.

In the framework of the European Health Information System, there is a need to improve the utilisation and analysis of data and information and to strengthen the already existing cooperation with OECD, WHO and ESTAT. New data collection should however be launched only when existing data cannot cover the needs. As far as possible, the relevant indicators from the European Community Health Indicators (ECHI) list should be used.

2. MANAGEMENT OF CHRONIC DISEASES

Healthcare systems and social care structures in EU Member States are faced with an increasing demand for the care of chronically ill patients and the need to ensure high quality and safe healthcare, within an efficient and sustainable healthcare system. Major challenges for health systems include the continuous care needs of chronic disease patients and the occurrence of multiple diseases (co-morbidity), especially in older patients. Thus, optimal management of chronic diseases is one key factor for patients, their relatives and for the sustainability of healthcare and social systems. A successful management of chronic diseases will also require a motivated and highly skilled workforce, not only in terms of numbers, but also in terms of roles, tasks and responsibilities.

While the organisation and financing of health care is in the responsibility of the Member States, there may be areas of EU added value action. The challenges to the respective health systems are common across most EU Member States, and activities at EU level may facilitate the national development of chronic disease management.

In this respect, the consultation with Member States and a targeted consultation with major stakeholders, involving patient organisations, resulted in the following list of topics to be considered in improving the management of chronic diseases:

Table 2. Elements to consider: inputs extracted from the consultation of Member States, EU Health Policy Forum (EUHPF) and other stakeholders

1. Map and implement existing good practices
✓ Map existing examples of good practices across EU and at a more global level (for examples: telecare trial in UK as an example of considerable savings for healthcare system and beneficial for patients)
✓ Promote and sustain the sharing/exchange of good practices
✓ Strengthen synergies between existing structures, resources, network to optimise the efficiency of chronic disease management
✓ Favour more coherence and coordination between different existing programmes at the national level
✓ Reflect on lessons learnt from the arrangements for communicable diseases at the European level; e.g. shared risk assessment, coordination of surveillance across EU
2. Develop innovative approaches
✓ Recognise that chronic diseases are often characterized by multi-morbidity and thus needs a cross-sectorial/ multi-stakeholders approach towards their management
✓ Involve health professionals along with teachers, Human resources staff and other professional groups in the development of innovative approaches
✓ Implement innovative chronic disease management programmes, in particular in the setting of primary and community health care systems
✓ Improve the access to treatment, care and management to vulnerable groups
✓ Take into consideration the importance of gender, age, mental health, horizontal issues (such as health literacy) while developing innovative approaches towards chronic disease management
3. Promote e-health and create common frameworks of operation
✓ Develop common framework of data collection and sharing on chronic disease promotion/prevention/management programmes within the different European countries
✓ Development of European guidance of legal issues concerning data protection, reliability and transparency of sources of information
✓ Agreement on languages and terminology in health related issues for data analysis in order to facilitate cooperation between Member States and/or regions to address common legal and organizational challenges in primary care and e-health
✓ Promote awareness actions for e-health and telemedicine and other innovative solutions towards citizens, patients and health carers
4 Address cross cutting issues
✓ From a patient perspective: patient empowerment (linked to the conclusions of the informal Council), i.e. by e-health tools, patient education programmes, self-treatment programmes, patient centred care - involvement of relatives. Networking. Tackling inequalities and underlying societal parameters of chronic conditions
✓ From a system perspective: coherent and high quality management and care. Strengthen primary health care structures and partnerships for integration of prevention and care: health promotion, prevention, treatment and rehabilitation at local level – close to the citizens. Assess and promote continuity and coordination across sectors within the health care system and between sectors. Invest into Secondary prevention and timely treatment to prevent a chronic onset of diseases

The results of the consultations summarised in the table above show a wide range of topics to be potentially addressed within chronic disease management. In general terms, there is support for the integration of care, the use of disease management models, the exchange of good practices, and strengthening the role of patients, for example by using eHealth and tele-medicine solutions.

Some of these issues are already addressed in other initiatives. The reflection process on the sustainability of health systems is looking into how to foster modern, responsive and sustainable health systems, and has a working group dedicated to integrated care. Also within the European Partnership on Active and Healthy Ageing an action group on integrated care has been established.

Therefore, in the context of this reflection process on chronic diseases, we propose to tackle the management of chronic diseases by starting with the role of patient empowerment. This is in line with the debate at the informal meeting of the EU Health Ministers in Horsens (Denmark) in April 2012, in which patient empowerment was considered a cornerstone for chronic disease management.

The role of patient empowerment in chronic disease management

Disease management is a patient-centred approach in which care delivery is optimised. In most definitions of chronic disease management, the following characteristics can be identified: optimal cooperation between multiple healthcare professionals with the right skills, from different disciplines, and different institutions. Furthermore, patients are actively involved in their care process and manage the disease within their competence for an optimal result (patient empowerment).

The role of the patient is central to chronic disease management. Patient empowerment integrates multiple concepts that enable a person to effectively self-manage their disease. Many chronically ill people are not hospitalised and are still functioning actively in all aspects of society and therefore self-care and care in the home setting are important. For this to work effectively, patients need to be empowered to make decisions about their healthcare in close collaboration with the healthcare providers.

In general, patient empowerment is considered an important and promising element of chronic disease management. It is however not obvious which practices are most effective for specific target groups. There are different models that can be applied.

Evidence suggests that self-management, especially for people with long-term conditions, can be effective through behavioural change and self-efficacy (for example for diabetes patients) and may reduce drug and treatment costs and hospital utilisation.

Focus for EU action

Actions should aim at improving patient empowerment as a cornerstone of the EU approach to chronic diseases. Suggested areas for special attention are the exchange of experiences and the identification of the advantages and barriers for implementing patient empowerment practices (as proposed by the informal meeting of the EU Health Ministers in April 2012).

It is therefore proposed, as a first step, to address the patient empowerment aspects of chronic disease management. As a starting point, the Commission intends to carry out a mapping of patient empowerment initiatives in Member States. This mapping should help to define the scope of patient empowerment and to identify advantages of and barriers to patient empowerment, such as limited financial and human resources. The mapping should not only include patient empowerment initiatives targeted at a specific disease, but also initiatives targeted at patients with multiple morbidities, as this requires a different approach towards the organisation of health systems.

For further work, two options are possible:

- (a) Exchange of good practice on patient empowerment in chronic diseases management without focusing on specific diseases.
- (b) Taking well established good practices as starting point, e.g. for the empowerment of patients in the management of diabetes, and exploring whether these practices can be transferred to other chronic diseases.

At a later stage, guidance on patient empowerment could be developed, e.g. in the form of Commission or Council Recommendations, or supporting the development of consensus statements by professionals organisations.

This work will take into account the other initiatives such as the Commission work on e-Health, the Reflection Process on the sustainability of health systems and the European Innovation Partnership on Active and Healthy Ageing, in particular the actions on integrated care. It should also take into account how best practices can be implemented, i.e. how resistance to necessary changes in the health system can be overcome.

C. THE WAY FORWARD

There appears to be general consensus about the need for increased EU action regarding the identification and dissemination of good practice in addressing **chronic disease prevention**. A basic initial infrastructure in this respect making use of new technologies could be developed and tested through a Joint Action on chronic diseases under the Health Programme.

The Joint Action would start by looking at targeted prevention including new innovative actions in the field of social media, behavioural science and new technologies as well as the more traditional actions on the risk factors. The Joint Action could also examine the barriers to uptake for prevention, targeted screening of risk groups, and treatment of major chronic diseases (taking diabetes as an example) and could look in more detail at how to address multi-morbidity and other complex issues in the framework of chronic diseases. This work could over time lead to a more structured mechanism at EU level, however, this would require further discussion.

On **disease management**, work would focus initially on a mapping of patient empowerment initiatives in the Member States. This mapping would include: an analysis of advantages and barriers to patient empowerment; a selection of good practices and definition of their success factors; the methodology of their transferability and the analysis of their cost-effectiveness (where possible).

At a later stage, guidance on patient empowerment could be developed, e.g. in the form of Commission or Council Recommendations.

D. QUESTIONS FOR DISCUSSION

1. On chronic disease prevention, do you agree with the proposal to develop a mechanism to validate good practice? Would your Member State be interested in taking part in the Joint Action described above?
 2. Are there experiences in addressing the risk factors described above at national and EU level which you think we can build on?
 3. On chronic disease management, do you agree with the proposal to first provide a mapping of patient empowerment initiatives? Which of the follow-up options would you prefer; exchange good practice on general aspects of chronic disease management or to take specific diseases as a starting point?
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