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**NOTE**

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| from: | General Secretariat of the Council |
| to: | Working Party on Public Health at Senior Level |
| Subject: | Reflection process: Innovative approaches for chronic diseases in public health and healthcare systems<br>- *Discussion* |

1. At its meeting on 6 June 2011 the Council (EPSCO) adopted conclusions "Innovative approaches for chronic diseases in public health and healthcare systems"[1], in which the Council invited Member States and the Commission *"to initiate a reflection process aiming to optimise the response to the challenges of chronic diseases"* (paragraph 9, first indent).

2. The Working Party on Public Health at Senior Level (WPPHSL) at its meeting on 10 October 2011 agreed the orientation, scope and timetable for the reflection process and decided that the Commission would consult the Member States to identify areas to be taken forward. Following that meeting, DG SANCO focused those consultations on the health promotion and the prevention of chronic diseases, i.e. the first area envisaged in paragraph 9 of the Council conclusions.

[1] OJ C 74, 8.3.2011, p. 4

3. At its meeting on 8 February 2012, the WPPHSL discussed the outcome of consultations mentioned in previous paragraph and established the "drafting group" led by the DG SANCO and with the participation of the two Trio Presidencies (PL/DK/CY and IE/LT/EL) to draft a report focusing on two areas: (a) health promotion and disease prevention and (b) chronic disease management and good practices exchange, including patient empowerment. The Member States had been consulted on that interim report before it was submitted to the WPPHSL meeting on 28 September 2012 .

4. At its meeting on 28 September 2012, the WPPHSL discussed the interim report[2] submitted by DG SANCO that focused on two areas mentioned above. The Member States expressed their readiness for exchange of good practices and gave concrete suggestions on areas to be covered by the work on chronic diseases. There was a broad support for developing a mechanism to validate good practice, building expertise from experiences addressing risk factors and future work on patient empowerment in chronic diseases management, including the mapping of patient empowerment initiatives across the EU Member States. The Commission (DG SANCO) has been invited to submit a final report.

5. The final report as set out in the Annex to this note is now submitted for the consideration and endorsement by the Working Party.

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[2] 13053/12

**ANNEX**

# REFLECTION PROCESS ON CHRONIC DISEASES

## FINAL REPORT

## 8 October 2013

Prepared by the Directorate General Health and Consumers, European Commission

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## A. INTRODUCTION

Chronic diseases are diseases of long duration and generally slow progression[3]. Major chronic diseases such as diabetes, cardiovascular diseases, cancer, neurodegenerative or mental illnesses, and musculoskeletal conditions often result in premature morbidity and loss of healthy life years. While positive developments in medicine and treatment of diseases, socio-economic changes and progress in technology, medical practice and patient care have led to a generally increasing life expectancy, this has has not been matched by a corresponding increase in healthy life years.

Chronic diseases represent the major share of the burden of disease in Europe and are responsible for 86% of all deaths[4] in the region. Chronic diseases affect more than 80% of people aged over 65 in Europe. Moreover, in patients over 65, the presence of multiple conditions or co-morbidities has a multiplier effect on the burden of disease and on management costs. This is particularly significant as current forecasts indicate that in the EU, the population aged 65 and above will rise from 87.5 million in 2010 to 152.6 million in 2060. The number of people aged 80 years and above is projected to almost triple from 23.7 million in 2010 to 62.4 million in 2060[5].

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3 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.

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

5 European Commission, The 2012 Ageing Report: Economic and budgetary projections for the 27 EU Member States (2010-2060), European Economy 2|2012 Available at: http://ec.europa.eu/economy_finance/publications/european_economy/2012/pdf/ee-2012-2_en.pdf

The growing burden of chronic disease represents a major challenge for health systems and economic and social development across Europe. It is widely acknowledged that 70% to 80% of healthcare costs are spent on chronic diseases. This corresponds to an estimated €700 billion in the European Union and this number is expected to increase in the coming years[6]. About 97% of health budgets are presently spent on treatment, whereas only 3% are invested in prevention[7]. Risk factors often contribute to the onset of chronic diseases and thus present considerable challenges to patients, health systems and society. Late diagnosis, late intervention and inadequate management are also relevant factors adding to the burden caused by chronic diseases. Healthy lifestyles, early diagnosis and timely intervention are therefore crucial in order to prevent or delay the onset of chronic diseases. Given the long progression of most chronic diseases and the consequent burden on individuals and on health systems, it is also essential to identify the most efficient and cost-effective ways of managing these diseases and their effects.

In order to address the burden of chronic diseases, both the health and social sectors need to develop more responsive and sustainable approaches. Given the often complex causes leading to the onset of chronic diseases, action should be taken at all relevant levels and across policy areas based on a strong commitment and involvement of public policy, the health community, citizens and patients, and wider stakeholders..

There is a need for a strong emphasis on prevention as well as on sustainable chronic disease management, and for a reorientation of budgets towards innovative approaches with an impact on the quality of life of people affected or at risk of chronic diseases. Prevention and strategies to delay the onset of chronic diseases along the life cycle need to be strengthened, making use of innovative concepts to avoid or reduce the need for health care interventions. This requires adaptations and changes in the systems, infrastructures, policies and legislation as well as incentives to support inclusive approaches and (behavioural) changes of people at risk.

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6 http://www.oecd.org/dataoecd/43/9/48245231.pdf

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

## B. EU ACTION ON CHRONIC DISEASES

The European Union supports Member States in addressing chronic diseases through a broad range of instruments and mechanisms. A major focus is put on initiatives related to risk factors and health determinants. European responses focus on added value through EU action, taking into account the EU competence in health as set out in Article 168 of the Treaty, the Health Strategy 2008 – 2013[8], and the needs and requirements of Member States. Another driver is the need for cost-containment and cost-efficient national health budgets.

At the same time, 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 should further steer the response to NCDs and other chronic conditions.

In this general context, the Council conclusions of 2010 on "innovative approaches for chronic diseases in public health and healthcare systems" invited Member States and the Commission to "initiate a reflection process aiming to identify options to optimise the response to the challenges of chronic diseases, the cooperation between Member States and summarise its outcomes in a reflection paper by 2012".

The mandate of the reflection process was to cover notably:

- *health promotion and prevention of chronic diseases*: to facilitate healthy choices in life for all citizens, to establish health promotion communication messages and interventions for all chronic diseases, to integrate health into education programmes; to further develop quantitative analysis of the cost effectiveness and health gains of health promotion and prevention; to explore, based on scientific evidence, the scope for early detection of relevant risk factors for chronic diseases; to strengthen prevention by applying the principles of health in all policies;

[8] Commission White Paper 'Together for Health: A Strategic Approach for the EU 2008-2013' COM(2007) 630 final, 23.10.2007

- *healthcare*: to identify and share good practices regarding ways to enable patients with chronic diseases to maximize their autonomy and quality of life; on effective, proactive early interventions; on secondary prevention; on the affordability and access of care for chronic diseases; on the implementation of innovative chronic care models, especially in primary and community health care, and on ways to reduce health inequalities in this field;
- *research* into chronic diseases: into how to base practical implementation of prevention, early interventions and care on existing scientific knowledge of chronic diseases, with the aim of improving strategies, technologies and support to allow active and healthy ageing;
- comparable *information* at European level on the incidence, the prevalence, the risk factors and the outcomes concerning chronic diseases, take account of different existing mechanisms such as the European Health Examination Survey, the development of morbidity statistics under Statistical Office of the European Communities, existing registries and other sources, to enable benchmarking and evidence-based policy.

The points on health information and research are addressed in separate discussions and processes. Health information is being taken forward in a separate discussion in the Working Party on Public Health at Senior Level. Future research priorities are being developed in the context of the Horizon 2020 preparations.

In parallel to this reflection process, the Commission and Member States carry out a reflection process on modern and sustainable health systems aiming to identify effective ways of investing in health, towards modern, responsive and sustainable health systems. Conclusions of the latter reflection process – some of which are also relevant to addressing chronic diseases - will also be presented to the Council´s Working Party on Public Health at Senior Level in October 2013.

## *1. THE REFLECTION PROCESS AND THE CONSULTATIONS*

A key question for the Reflection process was to assess whether EU action could help to promote effective, evidence-based and innovative actions, which, when applied in a systematic way, could contribute to a real difference towards reducing the burden of chronic diseases.

To this end, structured consultations were carried out with Member States and major stakeholders in 2011 and 2012, respectively. A first assessment of key elements of these consultations was presented in September 2012 in the interim report to the Council´s Working Party on Public Health at Senior Level. The working party discussed the interim report and has asked the Commission to further develop this paper into a final report describing new developments and further recommendations.

The consultations resulted in a wealth of proposals and inputs. In summary, Member States and stakeholders call for:

(i) continued action addressing risk factors;

(ii) developing validated prevention approaches; and

(iii) to concentrate more on targeted screening, early diagnosis and secondary prevention of diseases.

More specifically, the stakeholders focus on 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 and reduce major risk factors. Other proposals emphasised the importance of close interaction and more effective communication among health care providers, regulators, insurers and targeted populations.

In line with these recommendations, the final assessment of the stakeholder contributions includes the following conclusions:

- to apply a basic set of policy principles for health promotion and disease prevention
- focus on a broad set of chronic diseases with the highest medical and economic relevance
- to strengthen integrated action to combat major threats and risk factors with the potential to cause chronic diseases
- to pursue a health in all policies approach
- to improve the quality of treatment and healthcare
- to identify and follow-up opportunities for research
- to improve and scale-up early detection and prevention
- to work for a better coordination among all relevant parties

- to develop better data on health aspects for more efficient forecasting and planning
- Member States and EU must join forces with stakeholders including patients

Furthermore, stakeholders identified the following major gaps:

- Scientific collaborations sometimes lack a strategic framework in particular for transformation of basic science into applications and for creating links between different disciplines
- Availability and comparability of data on disease incidence and prevalence is still poor on EU and national levels.

EU level action should:

(i) be ambitious and focus on social and technological innovation, and take advantage of new technologies, the use of social media, and evidence from behavioural science

(ii) establish good practice exchange mechanisms at EU level 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 supporting evidence for cost-effective promotion and prevention activities at EU and national levels, with a particular view on long-term benefits.

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

(a) scaling up validated good practices in pilot projects to demonstrate their transferability and usefulness elsewhere

(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, the European Innovation Partnership on active and healthy ageing and stakeholder bodies such as the European Partnership for Action against Cancer or the European Mental Health pact are the appropriate fora for agreeing on joint approaches to address risk factors and actions towards reducing the burden of related chronic diseases.

Stakeholders mainly see a coordination role for the European Commission. In their view, the EU and Member States should closely collaborate with international organisations such as WHO or OECD in their efforts against non-communicable diseases. The EU should support Member States through promoting exchange of good practice and information and serve as a catalyst for action at national level towards improving chronic disease management. Member States should improve the availability and quality of data also to increase transparency and improve the quality of health care. Member States should focus on well-planned and strategic chronic disease programmes and should give prominence to comprehensive chronic disease management systems.

## *2. CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION*

Effective actions on risk factors and health determinants through targeted health promotion, prevention and early detection contribute to prevent or delay the onset of many chronic diseases.

The UN High Level Meeting on Non Communicable Diseases defined four major risk factors to be tackled more effectively: tobacco use, alcohol consumption, unhealthy diet and lack of physical activity. Established policy strategies and approaches are in place at EU level to tackle these risk factors: tobacco legislation, EU strategies on nutrition and physical activity[9] and alcohol-related harm[10]. The EU Platform for Nutrition and Physical Activity as well as the EU Alcohol and Health Forum already constitute effective platforms to boost actions in the EU. Furthermore, EU action on cancer[11], HIV/AIDS[12], health inequalities[13], and mental health[14] also contribute to address chronic diseases through established policies, instruments and structures. Some major chronic diseases, such as certain types of cancer or HIV/AIDS, are linked to communicable agents and require disease specific health approaches.

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

8 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 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

Living conditions and lifestyles influence public health and consequently the quality of life. There is a clear disparity in the burden of chronic diseases and in access to prevention and control[15] across Europe.

Despite all efforts to date, there is still much health gain to be achieved from work on common risk factors, labour and living conditions. Risk factor strategies need regular adaptations to take account of new developments and knowledge and should be more readily integrated with disease management.

***EU action***

**(i) The exchange of good practices**

A large pool of chronic diseases prevention and health promotion good practices exists across the EU. However, this wealth of information and knowledge is not always disseminated and accessible to the best possible extent. There is therefore a need to map good practices systematically and, ideally, to validate them to facilitate their uptake in regional/national/cross-border programmes. This measure would help to identify common fields of actions across policies and sectors that contribute to positive health outcomes at national and EU level.

To this end, the Joint Action on addressing chronic diseases and promoting healthy ageing which should become operational in 2014 includes the development of a mapping of good practices – with a focus on prevention. With a total budget of almost € 10 million, the joint action brings together health authorities from Member States and stakeholders with the Commission and helps to improve the cooperation and networking of relevant entities dealing with chronic disease prevention and management across Europe, with the aim to scale up and transfer good practices and innovative approaches to other regions and settings. The Joint Action will address chronic diseases through the following elements:

(i) A Platform for knowledge exchange. (ii) Good practices in health promotion and prevention on chronicity: review existing policies and practices and identify needs and gaps. (iii) Common Guidance for care pathways for multi-morbidity. (iv) A Diabetes case study to map good practices for detection of high risk people for diabetes, primary prevention, secondary prevention and management, non-pharmacologic interventions, patient empowerment, and national policies.

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

**(ii) The European Innovation Partnership on Active and Healthy Ageing**

A specific EU initiative 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.

The EIP is delivery-focused and aiming at combining health objectives with that of systems' sustainability and growth and jobs. All EIP actions support the idea of shifting the approach from reactive episodic care to a patient centred approach. This shift is to be brought about through innovative, coordinated and comprehensive community based prevention, assessment and integrated case management systems delivered within an integrated health and care and social system. They relate to either prevention of chronic diseases or the management and long-term care of chronically ill patients, and focus on support of implementation of actions locally, regionally and nationally, by:

- Developing support tools for better prevention of falls and frailty, notably through identification of complex interventions in frail co-morbid old people
- Strengthening the role of patients, namely through better adherence to treatment and scaling-up of personal remote monitoring and self-care solutions
- Supporting the implementation of integrated care models in regions through providing practical toolkits and guidelines on integrated care models for better integration of prevention and management of chronic patients
- Validating the evidence and verifying the feasibility of good practices for identification of successful practices for wider dissemination and implementation

- Working in focused areas, such as empowering patients, using ICT tools for seamless care or presenting risk stratification methodologies and risk management models for addressing the population's health
- Brokering joint stakeholders initiatives to facilitate implementation of innovative approaches across typical competence lines
- State of the art innovations and scientifically sound knowledge on how those innovations can be safely and effectively used in new concepts of care and care related prevention in the elderly, and, as a whole, implemented in daily life and care practice.

The actions associated with the European Innovation Partnership on Active and Healthy Ageing will be useful in taking forward comprehensive strategies to address chronic diseases. The Partnership's delivery-focused actions provide a feasibility check and real life examples that motivate other actors and inspire policy makers.

The work on frailty under the Partnership illustrates the necessary policy interventions to shift the approach from reactive disease management to screening, triage, anticipatory care and prevention of functional decline. Though there are no proven strategies to reverse frailty, evidence suggests that only complex interventions are likely to be effective. Addressing and identifying frailty dynamics and tipping points (generic early warning signals; older age self-monitoring; clinical frailty monitoring; prediction and prevention tipping points) will give clues on how to structure services. Because frail older adults require a proactive, multimodal, coordinated multi-disciplinary and multiagency approach, preferably delivered in an integrated health and care system, the Partnership's work will help identify and develop innovative organisational approaches and technical solutions that target frail older people for evidence on proven interventions that could achieve a more efficient use of resources and increase the sustainability of health and care systems. In particular, the EIP is looking at the application of ICT and e-health to services that are expected to be effective in the prevention and treatment of frailty and functional/cognitive decline. This will also result in better quality of life and a reduction in the use of health care services due to increased independent living.

On Adherence, the Partnership's work is looking at healthcare interventions (also including the role of pharmacists) not just in the frame of follow-up of pharmacological treatments, but more broadly in terms of linkage to more comprehensive care plans that will empower individuals to track their own main risk factors, to take small steps towards achieving well-being goals and to be remotely monitored by a health team, leading to higher compliance and significant cost savings.

The partnership actions on prescription and adherence will therefore contribute to the sustainability and efficiency of the health system (e.g. reducing medicines waste) and will support the development of new models of communication between health professionals and patients, and among health professionals. The work of the EIP will contribute to address at a broader level the issue of innovation in the delivery of health and care in a more holistic way, in particular the design and validation of effective intervention strategies, the improvement in the measurement of adherence behaviour, and for ensuring that changes in health outcomes can be attributed to the recommended regimen, the improvement of our understanding of the effects of health care teams and system-related factors on adherence and the definition and development of tools for prescription systems, including e-prescription issues.

The Integrated Care Action Group focuses on delivering care that is coordinated vertically across the levels of health care (primary, hospital, specialist) and horizontally across health and social care. The partners are committed to create a critical mass to reduce avoidable/unnecessary hospitalisation of older people with chronic conditions, through the effective implementation of integrated care programmes and chronic disease management models, including tele-monitoring solutions. These innovative practices can give inspiration and evidence to relevant policy initiatives, such as the Joint Action on Chronic Diseases, or the Reflection Process on Modern, Responsive and Sustainable Health Systems. Moreover, the Action Group provides a framework for a growing network of committed professionals, for bottom-up innovative solutions to grow in scale and for better market opportunities for European businesses. Ultimately, by improving the quality and efficiency of care and by reducing unnecessary hospitalisations, integrated care solutions can contribute to better and more sustainable health systems.

Finally, seventy-one good practices submitted by the Reference Sites provide the necessary evidence based inspiration for the re-design of health and care systems.

**(iii) Addressing risk factors: tobacco, alcohol, nutrition strategies**

There is a clear need to intensify efforts towards the prevention of risks factors. In particular, the Commission will take forward work on tobacco control, and, building on the results of the external evaluations of the strategies related to nutrition, overweight and obesity health related issues and on alcohol related harm, where a Joint action will be implemented from 2014. The Commission will cooperate with the Member States to consolidate or develop new activities on nutrition and physical activity and alcohol related harm to take account of the evaluation recommendations.

It is well established that smoking causes a large number of chronic diseases, including various forms of cancer as well as stroke, blindness, cataracts, periodontitis, coronary heart disease, pneumonia, chronic obstructive pulmonary disease, asthma, and reduced fertility. The action at EU level against smoking currently includes product regulation (e.g. health warnings on tobacco packs, setting limits for tar, nicotine and carbon monoxide), advertising bans, harmonisation of excise duties, measures to support smoke free environments and anti-smoking campaigns. The measures put forward in the recent Commission proposal to revise the Tobacco Products Directive include, inter alia, improved information on health effects of smoking, notably through large mandatory pictorial health warnings and the ban on tobacco products with characterizing flavours. These measures are expected to reduce smoking, in particular by young people, and as such contribute to reducing the burden of chronic diseases in the long run.Full implementation of the Council Recommendation on smoke free environments will also be elementary in protecting people from the negative impacts of tobacco smoke.

**(iv) Disease prevention**

While the focus of EU action has been on addressing risk factors, there has also been considerable activity on preventing major diseases. Over the years, the EU has put emphasis on cooperation on **cancer,** based most recently on the Commission communication on "Action Against Cancer: European Partnership" (COM (2009) 291 final)**.** The Commission's priorities included improving cancer information, providing advice through the European Code Against Cancer and developing guidelines for cancer screening.

To take a further example, as regards **diabetes**, a series of projects have been supported under the health programme. The Joint action on addressing chronic diseases and promoting healthy ageing across the lifecycle includes a work package on managing chronic diseases, taking diabetes as an example.

**(v) Data collection and indicators on chronic diseases**

Using appropriate, comparable and reliable data and indicators for chronic diseases prevention and management serves the purposes of policy monitoring and facilitates policy-making based on evidence. These are the leading objectives for Eurostat data collection and the European Core Health Indicators (ECHI). However, there is a need to improve the utilisation and analysis of data and information already available and to ensure its sustainable, policy-oriented further development. As far as possible, the relevant indicators from the ECHI list should be used. New data collection should be launched only when existing data cannot cover long-term policy needs. The well-established cooperation with OECD, WHO and ESTAT will be continued.

At EU level the concept of establishing a European health information research infrastructure consortium (ERIC) is currently being explored. The ERIC is a tool designed for high-profile research infrastructures with a European dimension. It is a legal entity recognised in all EU Member States. Its basic internal structure is very flexible, leaving its members to define by way of internal regulations and statutes, case by case, membership rights and obligations, the bodies of ERIC and their competences. The creation of an ERIC on health information would offer a comprehensive and sustainable response, and would benefit Member States, their public health institutes, researchers and experts. Such a sustainable infrastructure, complementing the work done by Eurostat, could be used by Member States with the support of the Commission and in coordination with OECD and WHO to improve the availability and comparability of data and relevant ECHI indicators on chronic diseases at national and EU level.

**(vi) EU funds and programmes**

Funding for research related to chronic diseases is important to drive developments in basic, translational and applied research. Besides the Health programme, the EU has several funding instruments in place towards improving prevention, treatment and care of chronic diseases.

The framework programmes for research and technological development (FPs) fund research at a transnational level in order to structure and integrate Europe-wide research. In relation to chronic diseases the Seventh Framework Programme (FP7, 2007-2013) invested substantial sums into brain research and related diseases, research on human development and ageing, major diseases and disorders, including cancer, cardiovascular diseases, diabetes and obesity, rare diseases, and severe chronic diseases. The future research programme "Horizon 2020" foresees continued support for research in these areas, with health and demographic change identified as one of the main societal challenges addressed by the programme.

In addition, structural EU funds offer a wide variety of co-funding to projects and programmes with an impact on addressing chronic diseases. To this end, subgroup 2 of the reflection process on sustainable healthcare systems will present a detailed report on funding directions and possibilities.

## *3. 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. This has implications for education and training of providers and requires adjustments of medical training curricula to define new skills to meet needs of patients with chronic conditions and for healthcare providers to review organisational arrangements.

While the organisation and financing of health care is in the responsibility of the Member States, there are 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 seek to 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 a large number of relevant topics to be considered in improving the management of chronic diseases. .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, which presents a separate report with recommendations. Also within the European Partnership on Active and Healthy Ageing, an action group on integrated care has been established, which can provide evidence on the integration of health and care systems, including areas such as patient empowerment and ICT.
Against that background, the informal meeting of the EU Health Ministers in April 2012 suggested to start with the exchange of experiences and the identification of the advantages and barriers for implementing patient empowerment practices.

***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.

Although there exists a variety of definitions of patient empowerment, most of them agree about consequent steps towards patient empowerment: from providing information to patients about treatment, through collecting feedback from patients about treatment, to informed patient's choices regarding treatment options and active participation in the treatment.
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 thereby would reduce drug and treatment costs and hospital utilisation.

***EU action***

The provisions of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare clarify the rights of patients to be reimbursed when they choose to receive their healthcare outside their home Member State. It thereby gives all patients the possibility of greater choice of healthcare provider. In addition the Directive sets out the minimum guarantees that should apply to all patients and all healthcare within the EU with regard to patient rights: the right to information on quality and safety standards; the right to a copy of a medical record; the right to access complaints procedures; the need for all providers to be covered by liability insurance or a similar guarantee. The Directive also requires all Member States to create at least one National Contact Point to assist patients in using their rights and getting the information they need.

Although focused on reimbursement for treatment received abroad, the Directive is underpinned by the notion of patient empowerment when it comes to decisions about choice of healthcare provider and system. There is a strong emphasis on the provision of information to patients to enable them to make informed choices. The information to be provided will be potentially useful to all patients, not only those who choose to seek healthcare abroad. The Directive provides that clear information should be given to all patients: about their entitlements; about quality and safety standards and their operation in practice; about the available treatment options , and about their rights as a patient. In the immediate future, it is therefore necessary for Member States to ensure that they meet their obligations under the Directive (which has a transposition deadline of 25 October 2013).

Regarding future action on patient empowerment, two options were proposed to the Working Party on Public Health at Senior Level in the Interim report:

(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.

During the discussion in September 2012, there was no clear preference between the two options but it was clear that even if a specific disease was taken as a starting point, the results should be relevant and applied to other diseases. Consequently, the Commission initiated a study "Empowering patients in the management of chronic diseases" which is a mapping of patient empowerment initiatives in Member States which seeks to help understand the concept of patient empowerment – meaning a principle of patients making informed choices - as a prerequisite to exercise patient rights. It aims at identifying inherent advantages and barriers to empowering patients. The study is expected to further propose a method to validate transferability of good practices, between management models of different chronic diseases in different health systems and to develop scenarios of EU future collaboration on this subject.

The work will 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. The results are expected in summer 2014.

Patient empowerment was also recognised as a priority by the European Parliament which allocated resources to the European Commission in form of a pilot project for developing work on promotion of self-care and patient empowerment in the European Union as a means to support the cost-effective utilisation of healthcare systems. The requested work, though not exclusively focused on patient empowerment in chronic diseases, will complement the work proposed in this paper.

Moreover, as set out in the Action Plan for the EU health workforce[16], the management of chronic conditions means new competencies and roles for health professionals programmes with consequent implications for medical and nurse training programmes to incorporate information and communication skills to ensure more patient involvement. European research[17] is underway to evaluate the impact of new professional roles on practice, outcome and costs, drawing on evidence from a chronic disease pathway.

Also, other Commission and Member States initiatives take into account patient empowerment in chronic disease management, such as on ehealth, in the context of the European Innovation Partnership on Active and Healthy Ageing and the Joint Action on addressing chronic diseases and promoting healthy ageing, in particular the work on multi-morbidity and poly-pharmacy.

## C. CONCLUSIONS AND THE NEXT STEPS

Addressing the burden of chronic disease is a central priority for the European Union and its Member States. We cannot ensure sustainable health systems without addressing the underlying economics of behaviour and chronic diseases. There is a need for sustainable and coordinated approaches which fully explore the potential of prevention and build upon the identification and dissemination of good practice. While it will be for Member States to adapt their health and social systems, there is scope for increased action at EU level particularly to transfer proven interventions and strategies..

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16 Action Plan for the EU health workforce, Commission Staff Working document, SWD (2012) 93 final of 18 April 2012

17 FP7 project MUNROS, Healthcare Reform: the impact on practice, outcomes and costs of new roles for health professionals.

**Risk factors**: The Commission will continue to give priority to the four key risk factors for chronic diseases - tobacco, nutrition, physical activity and alcohol. The Commission proposal to revise the current Tobacco Products Directive is under discussion in the Parliament and the Council. On nutrition and physical activity, in response to the call of the Irish EU Presidency, the Commission intends to contribute to the preparation of an action plan on childhood obesity for 2014–2020 within the EU High Level Group on Nutrition and physical activity. On alcohol, an action plan is currently being considered, and a joint action with Member States is due to be launched in 2014 . In all domains, action will seek to help reduce health inequalities.

**Prevention**: Member States and the Commission will look at **targeted prevention** including new innovative actions in the field of social media, behavioural science and new technologies as well as the more traditional activities on the risk factors in the new Joint Action on addressing chronic diseases and promoting healthy ageing across the lifecycle. The Joint Action is intended to examine the barriers to uptake of prevention, targeted screening of risk groups, and treatment of major chronic diseases (taking diabetes as an example), and look in more detail at how to address multi-morbidity and other complex issues in the framework of chronic diseases.

**Cooperation on cancer** is considered to be a model of EU added value focused on a major group of chronic diseases. In 2014, a new Joint Action on Comprehensive Cancer Control is due to be launched, and work is underway to revise the breast cancer screening guidelines and to develop a set of minimum quality standards for breast cancer services..

**Health information:** Sustainability of data collection is necessary in order to improve the availability of comparable data for evidence-based policy. Such sustainability cannot be achieved without long-term commitment and is preferred to temporary and project-based approaches. A possible solution in this respect would be the establishment of a European health information research infrastructure consortium (ERIC) to support the collection and analysis of measurable and comparable health data and information for research and evidence-based development, for implementation and evaluation of action for health within Member States and at EU level.

**Chronic disease management:** Within this reflection process, focus was given to patient empowerment. Broader EU action related to the sustainability of health systems – and the outcome of the health systems reflection process – will also have to take account of the needs related to the management of chronic diseases

As noted above, the implementation of the Directive on patients' rights in cross-border healthcare will clarify the rights of patients to be reimbursed when they seek treatment abroad. Furthermore, the Directive should lead to an increase in the amount of information available to patients to enable them to make informed choices. In connection with the Directive, the Commission will publish detailed information on patient rights via the "Your Europe" website. It will also be producing information for patients in the form of leaflets and a video, to help inform patients of their rights. The National Contact Points which Member States must set up under the Directive will also have a crucial role to play in the provision of information to patients.

On **patient empowerment**, as a next step, DG Health and Consumers is currently considering setting up a dedicated expert group nominated by Member States. The group would examine the results of the mapping exercise and the EU initiatives related to patient empowerment and put forward ideas for policy actions to be taken forward to create favourable conditions and develop guidance for patient empowerment.

It is clear that the EU has limited legal powers to legislate on patients' rights as such within EU Member States. Nevertheless, patients benefit from several EU actions, including the possibility to report any adverse reaction to medicinal products either directly to national authorities or to the respective health care provider. Another important step is laying down provisions on recognition of prescriptions. Chronic disease patients are often dependent on their medicines and will now have greater certainty of having a prescription recognised in another country.

The development of **European Reference Networks** within the framework of the Directive on patients' rights in cross-border healthcare is also a potentially significant step. These Networks will bring together centres of expertise across the EU with the aim of helping knowledge to move between health systems. The overall aim will be to improve the capacity of all health systems to diagnose and treat those diseases which the Networks cover.

The **European Innovation Partnership on Active and Healthy Ageing** goals combine the health and care objectives with that of financial sustainability and fostering of innovation. As such the Partnership aims at providing the scheme for successful system redesign. On the individual level it seeks to re-focus the health and care systems on the continuum of care, delay the onset of disease, and counteract the progression of frailty, but also promote the active living and independence of older people. There is growing awareness that better care and sustainability will come from the reconfiguration of the provider level, not only from more financing. This requires identifying new approaches to encourage health care professionals' engagement with the changes. As for health and care systems, the Partnership advocates more integration of care, eventually leading to reduction of unnecessary hospitalisation and better use of resources.

The Partnership's work within Action Groups includes activities on priorities such as adherence to treatment, frailty and integrated care. It has already entered the implementation phase and will provide the first results from year 2014 on. This includes the actions undertaken by more than 600 partners individually, as well as common initiatives, such as development of standards, guidelines and practical toolkits to facilitate the deployment of good practices on the large scale.

The Partnership uses different tools. Despite the active stakeholders' leadership of the development and implementation process it nonetheless requires the Commission's effective support. As far as Reference Sites are concerned, it will include developing and constantly expanding a repository of good practices; optimising an active exchange and coaching mechanism allowing more efficient transfer of knowledge from the leading regions to the ones in need; promoting the use of the existing European and other funding sources, including the structural funds.

**Funding:** Within Member States, there is an urgent need to change the imbalance between prevention and care in health budgets. Investing in prevention will help to avoid paying for treatment in the future. Therefore, reshaping available funds into more effective means of prevention, encouraging innovative approaches and making full use of the new insights provided by behavioural science, should be regarded as priority in effectively addressing chronic diseases.

There are a number of EU programmes in place which can provide support to addressing chronic diseases and support Member States in the process of changing priorities. This includes the Research programmes and structural funds, but also the health programme which underpins EU health policy and already provides financial support towards addressing chronic diseases, for example to the joint actions mentioned above.

There is also clear scope for an improved use of EU funding to optimise chronic disease management, such as by identifying and scaling up the use of promising technologies that could help patients and professionals manage chronic conditions outside of hospital settings, as well as in better understanding and managing the complexities of chronic diseases, such as polymorbidity and the best approaches to be adopted in managing the various stages of chronic diseases.

**Taking the discussion forward:** In order to continue the discussion on where further EU action might add value, DG Health and Consumers intends to organise an **EU summit on chronic diseases** in 2014. The summit would review action to date and provide a forum for participants from Member States and stakeholder organisations on future needs.

The Senior Level Working party may wish to review progress on these and other initiatives to address chronic diseases at a later stage.