



EU REFLECTION ON CHRONIC DISEASE

EPF consultation response

10 May 2012

The European Patients' Forum welcomes the opportunity to contribute to the European Commissions' stakeholder consultation on the reflection process on chronic diseases. EPF is a not-for-profit, independent organisation and umbrella representative body for patient organisations throughout Europe. We advocate for high-quality, patient-centred, equitable healthcare for all patients across Europe.

EPF currently represents 54 patient organisations, which are national patients' platforms and chronic disease-specific patient organisations at EU level. Together they reflect the voice of an estimated 150 million patients affected by various chronic diseases. EPF focuses on issues that are common to all patients, across diseases areas and EU countries.

Patients' perspective on chronic diseases is unique: patients live with their disease, learn to manage it, and to navigate the health system to get the right care. In addition, chronic diseases impact many areas of patients' lives, including the workplace, family and social interactions. This is why we believe patients play a key role in identifying service needs and ensuring that strategies to address chronic disease are effective in fostering high quality and sustainability of healthcare, and improved quality of life.

While EPF already has contributed to this reflection process through the European Health Policy Forum¹, our response below reflects the specific perspective of patients and develops some of the key messages and recommendations of the EUHPF response.

This response is based on a consultation of EPF's European-wide membership: a draft response was developed and sent to EPF's members for comments and feedback. We then developed this final response, integrating the input and comments received from our members.

This response is also available online on EPF's website, www.eu-patient.eu.

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¹ http://ec.europa.eu/health/interest_groups/docs/euhpf_answer_consultation_jan2012_en.pdf

I. The current situation regarding chronic disease in the EU

Question 1.1: What further information and evidence (in addition to that provided in the Commission paper) should be taken into account by national governments and the EU regarding the chronic disease situation?

Definition of chronic disease

EPF believes the term “chronic disease” is preferred over “non-communicable disease” used by the United Nations,² as the latter only encompasses a restricted list of chronic diseases. Some chronic diseases are communicable (e.g. hepatitis, HIV/AIDS, tuberculosis); furthermore, mental disorders form a significant portion of chronic disease.

It may be helpful to include a common definition of chronic disease in the EU strategy, as long as the above-mentioned factors are taken into account. The World Health Organization report “Innovative Care for Chronic Conditions” (2002) favoured the term “chronic conditions” stating that chronic conditions are “health problems that require ongoing management over a period of years or decades” and pointing to several common aspects shared by chronic conditions.³

EPF recommends that a definition for the purposes of the EU Strategy on chronic diseases should be developed in collaboration with patients: defining chronic diseases also means defining persons encompassed by this definition, and their rights.

Burden of disease

In a time of economic crisis, Member States and the European Union are looking at cost savings; but these should not be the main criteria for evaluating specific strategies in chronic disease management. The ultimate goal of an EU strategy on chronic diseases must be to improve the health and quality of life of European citizens, including persons at risk of or affected by chronic diseases. This strategy should be based on the common European values of universality, access to good quality care, equity and solidarity.⁴ It should adopt a holistic approach to health that encompasses both physical and mental health and social integration. Health, after all, is not only a state of physical but also mental well-being, not merely the absence of disease.⁵

When assessing the burden of chronic diseases, the *burden on individuals and their families*, as well as their burden on wider society need to be taken into account. In this respect, it is important to mention that chronic diseases affect people of all ages: older persons, but also children and teenagers, and a large proportion of adults of working age.

The effects of illness are not only physical, but also psychological, emotional and social. Illness impact people’s quality of life, education, employment and integration into society. The disease burden is compounded by specific vulnerabilities that patients and their families face due to illness: dependence on timely access to safe, high quality healthcare and the needed support services; reduced or inability to work and the resulting loss of income and risk of poverty; the direct and indirect costs of illness; and social discrimination and stigma. Chronic disease is often a direct cause of health inequalities for patients and their families.

While recognising the heavy burden of the “big” chronic diseases – such as cardiovascular, diabetes, respiratory diseases and cancer, EPF stresses the significant burden of all chronic diseases

² “Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases”, September 2011.

³ World Health Organization 2002, *Innovative care for chronic conditions: building blocks for action: global report*, p 11. http://www.who.int/chp/knowledge/publications/iccc_ch1.pdf

⁴ Council Conclusions on “Common values and principles in European Union Health Systems” (2006/C 146/01)

⁵ As defined by the World Health Organization, “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” (Preamble to the Constitution of the World Health Organization, 1948).

individually and collectively, on patients, their families and society. Some figures from other disease-areas serve to illustrate this point:

- *Alzheimer's and dementias*: the annual direct and indirect costs of Alzheimer's and other dementia diseases are around €130 billion in the EU27 (€21,000 per patient).⁶ Over half of these costs (56%) are borne by informal care.⁷ The UN Political Declaration on NCD recognises dementias as a major chronic disease.⁸
- *Mental health*: The Operational Plan of the European Innovation Partnership on Active and Healthy Ageing states that depression affects 1 in 5 of older people living in the community and 2 in 5 living in care homes. Furthermore, mental health problems are often linked to physical chronic disorders, and they have a major negative impact not only on quality of life, but also on the costs of healthcare as well as costs to society outside the health sector.⁹
- *Parkinson's disease*: There are more than 1.2 million people living with Parkinson's in Europe¹⁰ and the incidence is forecast to double by 2030,¹¹ primarily as a result of the ageing population. The estimated annual total cost of Parkinson's disease is €13.9 billion.¹²
- *Musculo-skeletal disorders*: Chronic diseases such as rheumatoid arthritis and back pain prevent thousands of people from working across the EU, costing European economies up to €240 billion a year.¹³
- *Rare diseases*: across the EU, approximately 7,000 rare diseases (defined as affecting not more than 5 per 10,000) are estimated to affect 6-8% of the population, equating to around 29 million people.¹⁴ Rare diseases are a significant public health issue and are recognised as an area where action at EU level has significant added value. This has resulted in a number of initiatives and programmes, such as European Reference Networks and Centres of Expertise, which may potentially be transferable to other types of chronic diseases.¹⁵

Demographic ageing and chronic disease

As the general population ages, so the number of patients with chronic diseases will inevitably grow. Many chronic diseases become more prevalent with age, and patients who developed a chronic disease at a younger age are living longer thanks to modern medical treatments.¹⁶ Moreover, though some chronic diseases are to some extent preventable, many including neurodegenerative and genetic diseases, are not.

Chronic conditions affect 80% of people over 65 and often involve *multiple morbidity*. More than half of all older people have at least three chronic conditions, and a significant proportion has five or

⁶ *Dementia in Europe Yearbook*, Alzheimer Europe, 2008, p.67-70.

⁷ European Commission Communication on a European Initiative on Alzheimer's disease and other dementias (2009)

⁸ Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases (NCD), 19-20 September 2011, para. 18

⁹ European Parliament resolution on Mental Health of 19 February 2009

¹⁰ Consensus document on brain research, J. Olesen, M Baker, T Freund, M Di Luca, J Mendlewicz, I Regan, M Westphal - EBC – *J Neurol Neurosurg Psychiatry*, 2006.

¹¹ ER Dorsey et al "Projected number of people with Parkinson disease in the most populous nations, 2005 through 2030", *Neurology* 68(5) p.384-6 (30 January 2007).

¹² A Gustavsson et al, "Cost of disorders of the brain in Europe 2010", *Eur Neuropsychopharmacol.* 2011 Oct; 21(10): pp.718-79.

¹³ Fit for Work, EUROSTAT (2009). See <http://www.fitforworkeurope.eu/msd-backgrounder.htm>

¹⁴ European Commission Communication "Rare Diseases: Europe's challenges" COM(2008) 679 final

¹⁵ See for example: EUCERD Report "Preliminary analysis of the outcomes and experiences of pilot European Reference Networks for rare diseases", May 2011.

¹⁶ This is now the case even in diseases like Haemophilia and HIV/AIDS: In Haemophilia, 40+ is currently the biggest age group and the proportion of older patients continues to grow. In HIV/AIDS, the proportion of 50+ has grown rapidly, and the 40-50 age bracket is now the largest category. Source: Presentation "Ageing with Chronic Diseases", given by Dr Cees Smit (EGAN/VSOP), Basel, 25.01.2011.

more. These are often unrecognised and untreated.¹⁷ Multi-morbidities can be developed as a result of the evolution of a first chronic disease, or be linked to long-term adverse effects of treatments (e.g. HIV and hepatitis, kidney failure and hypertension, diabetes and kidney failure).

Patients with chronic diseases develop specific needs that are distinct from the general population. Coordinated patient-centred strategies therefore need to be in place to address the needs of patients.¹⁸ An integrated, holistic approach is needed to address multi-morbidity throughout the care process, involving all the different services and care providers. This process must centre on the person rather than the disease, and empower patients and their families to participate effectively in co-management of the condition.

Specific issues related to multi-morbidities include poly-pharmacy and medication safety, over and under-prescribing, and low adherence to therapies. While adverse drug reactions are more common among older patients, most reactions could be avoidable with appropriate medication safety systems in place.¹⁹ Strategies to promote adherence should be based on the concept of concordance and encompass health literacy, user-friendly information, and improved patient-health professional communication.²⁰

Care in the home rather than institutionalization can result in substantial cost savings: a UK study revealed that moving a person with Parkinson's from their home into residential care was associated with an approximate 500% cost increase.²¹ Remaining independent for as long as possible is also key wish of patients for a good quality of life.²² In their contribution to this consultation, EPF member Alzheimer Europe said that dementia patients "cared for in their home fare better than if they are institutionalized or hospitalized."²³

This is only possible if the role and value of informal carers is recognised and adequately supported. Carers are particularly central in certain conditions such as dementia and Parkinson's disease. Adequate training and support services for them can yield a double saving: supporting patients to stay in their own homes and avoid unnecessary institutionalisation; and ensuring that carers – who are often older themselves – remain in good health and are able to provide the care.²⁴ Investment in carers can therefore bring potential savings to the healthcare systems, as well as better health outcomes for citizens. Innovative and inexpensive initiatives have shown good results, e.g. services provided by Alzheimer associations.

Gender

There are significant differences in how men and women are affected by chronic diseases. Many chronic diseases are disproportionately more common in one sex or the other, while others occur with differing degrees of severity or at different times in the lifespan. In some cases there are established biological explanations for these differences, but often there are not. Gender differences

¹⁷ F Luppi, F Franco, B Beghe, LM Fabbri (2008) "Treatment of chronic obstructive pulmonary disease and its comorbidities", *ProcAm Thorac* Vol. 5. Cited in the Operational Plan of the European Innovation Partnership on Healthy and Active Ageing (2011), p. 26.

¹⁸ European Innovation Partnership on Healthy and Active Ageing, Strategic Implementation Plan adopted by the High-Level Steering Group on 7 November 2011.

¹⁹ W Kaplan and R Laing (2004), WHO report 'Priority Medicines for Europe and the World', pp. 90-91. Available online at <http://archives.who.int/prioritymeds/report/final18october.pdf>

²⁰ Note that concordance is not synonymous with adherence. Concordance is a key concept of patient-centred care, with the aim of creating a "therapeutic alliance" between physician and patient. See: *Br J Clin Pharmacol*, 2007 November; 64(5): 710–711.

²¹ Source: Findley L, Aujla M, Bain PG et al. 'Direct economic impact of Parkinson's disease: a research survey in the United Kingdom.' *Mov Disord* 2003; 18(10): 1139-45

²² <http://www.eu-patient.eu/About-EPF/Responses/EPF-responds-to-the-Commission-consultation-on-European-Innovation-Partnership--Healthy-and-Active-Ageing/>

²³ Alzheimer Europe contribution to the European Commission consultation on chronic diseases, 27 April 2012

²⁴ EIP-AHA Operational Plan, adopted on 7 November 2011, page 26. Available at http://ec.europa.eu/research/innovation-union/index_en.cfm?section=active-healthy-ageing&pg=implementation-plan

not only have a direct impact on the health behaviour, exposures, social factors, but also on needs and access to care of women and men.²⁵

With few highly specific exceptions, men are more likely at all ages to die from all of the most common causes of death recorded by Eurostat.²⁶ Women on the other hand, are more likely to suffer illness and disability in later life. Gender is also recognised to be a specific risk factor for many diseases. For example, more women than men die of heart disease each year in the United States, partly because the symptoms in women can be very different from symptoms in men and are often missed – yet cardiovascular research has long focused on men. Clinical research only recently started to implement gender balance in trials, in recognition of the fact that men and women metabolise and react to medicines differently.

II. Health promotion and disease prevention: what more should be done?

Questions 2.1. and 2.2: What additional actions and developments are needed to address key risk factors to prevent chronic diseases? How can existing actions on primary prevention be better focused and become more effective?

EPF does not directly address issues linked to prevention and health promotion, given our mandate as a chronic disease patients' organisation. We do consider this an important area, and we are very supportive of the work of fellow health NGOs – including several of our member organisations – who focus on these issues at EU level. We refer to the paper developed by the European Health Policy Forum, which gives a comprehensive response concerning prevention and health promotion.

Additionally, EPF would emphasise that men and women have different risk factors and are affected differently by chronic diseases. In order to respond appropriately to their specific needs and to effectively target health promotion and prevention programmes, these need to be made gender-sensitive.

Furthermore, it is important to remember that *not all* chronic diseases are currently preventable; this is the case for example with neurodegenerative, genetic and rare diseases. It may however be possible to delay the onset of the disease, or to slow down its progression.

Question 2.3: What potential is there for broad based early detection action?

EPF sees prevention as including primary, secondary and tertiary prevention.²⁷ Indeed, we believe health promotion, prevention and patient-centred chronic disease management should be seen as aspects of one holistic continuum: effective prevention can free resources to provide healthcare for patients, while investment in high-quality chronic disease management can maximise patients' quality of life, reduce the disease burden and optimise use of healthcare resources.

Even with best efforts, not all chronic diseases can be prevented. Many chronic diseases are degenerative in nature, making early detection essential. This entails adequate and timely access to diagnostic testing and screening. Early diagnosis, *followed by timely treatment*, is crucial to ensure good health outcomes and quality of life for patients, and to avoid deterioration and complications that require complex medical interventions that burden both the patient and the healthcare system.

²⁵ ENGENDER Policy Brief <http://engender.eurohealth.ie>

²⁶ White A. (2011) *The State of Men's Health in Europe*. Brussels: European Commission Directorate-General for Health & consumers.

²⁷ *Primary prevention* is directed at the prevention of illnesses by removing the causes. The target group for primary prevention is those that are healthy with respect to the target disease. *Secondary prevention* aims at identifying the disease at an early stage so that it can be treated. This makes an early cure possible (or at least the prevention of further deterioration). The target group for secondary prevention consists of people who are already ill without being aware of it, or those who have an increased risk or a genetic disposition. *Tertiary prevention* is directed toward people who are already known to suffer from an illness. This is therefore a form of care. Tertiary prevention includes activities intended to cure, to ameliorate or to compensate. For example, the avoidance of complications of the prevention of progress of disease would be classed as tertiary prevention. (Van der Maas and Mackenbach, 1999)

For example, in Parkinson's Disease, where hospitalisation rates and healthcare use is high due to the motor and non-motor aspects of the disease, early intervention has been shown to reduce the economic burden on both the patient and on society.²⁸ Patients, when well treated and supported, are able to function in society and continue working for longer, thus reducing the burden on their families while also benefiting the economy and society as a whole. For example, trial results published in 2010 indicate that a ParkinsonNet network provides improved quality of care at substantially reduced costs compared with usual-care networks.²⁹

Questions 2.4, 2.5 and 2.6: In what areas is there a particular need for additional action at EU level? In what areas is there a particular need for action at national level? What will you/your organisation contribute to address this challenge?

EPF believes investment in peer involvement and peer support can contribute to the overall sustainability of healthcare. Patient organisations play an important role in health promotion and prevention, both through participating in research, and through advocacy.

Many of EPF's member organisations are very active in this field. Patients' organisations can support health promotion efforts in the community through facilitating community outreach, community screening, and the development of community support. They regularly liaise with grassroots patient communities that they know well, thus they can help ensure that health promotion and prevention messages are effectively communicated. They can also reach out to populations with specific risk factors, or patients with particular disease, and from diverse ethnic and cultural patient groups.

EPF calls for the recognition of the role played by patient organisations coupled with adequate institutional, structural and financial support mechanisms for patient NGOs.

III. Healthcare

Questions 3.1 and 3.2: What changes could be made to enable healthcare systems to respond better to the challenges of prevention, treatment and care of chronic diseases? What changes could be important to better address the chronic disease challenge in areas such as: financing and planning; training of the health workforce; nature and location of health infrastructure; better management of the care across chronic diseases?

Fragmentation and lack of integration in the health/social care system is constantly identified by patients with chronic diseases as a major obstacle in the way of good quality care and quality of life. Obstacles to integrated care include financial structures, "silo" budgets, productivity targets, and attitudinal barriers. The result of this organisational and financial fragmentation is that patients often need to actively "fight the system" just to get the services they need. Patients may not have the energy, or indeed the health literacy, to do that.

Ideally there should be "one trusted health professional" responsible for the coordination of care. Specialised nurses often play a key role in coordinating care. Diabetes nurses are well known, but other successful initiatives exist for example in Parkinson's disease, Multiple Sclerosis, and breast cancer.³⁰ Such programmes should be comprehensively mapped, evaluated and shared.

²⁸ The European Parkinson's Disease Standards of Care Consensus Statement, Vol. 1 (2011), pp.11-12, available at <http://www.epda.eu.com/parkinsons-consensus-statement/EPDA>

²⁹ Marten Munneke, Maarten J Nijkrake, Samyra HJ Keus, Gert Kwakkel, Henk W Berendse, Raymund AC Roos, George F Borm, Eddy M Adang, Sebastiaan Overeem, Bastiaan R Bloem "Efficacy of community-based physiotherapy networks for patients with Parkinson's disease: a cluster-randomised trial," *Lancet Neurol.* 2010 Jan; 9(1): pp.46-54.

³⁰ The Parkinson's Disease Nurse Specialist programme in the UK – access to a specialist nurse is cited as the top priority by UK patients and their carers. Information about PDNS is available at www.epda.eu.com/projects/learning-in-partnership-lip/past-years/2008/benefit-of-pdns-to-parkinsons-patients-and-carers; on MS nurses see http://www.mssociety.org.uk/for_professionals/developing_services/ms_nurses/index.html and www.emsp.org/ms-need/

The *European Innovation Partnership on Active and Healthy Ageing* identifies integrated care as a priority action area.³¹ Integrated care is both vertical (coordination of primary and secondary care) and horizontal (health, social and community care, institutionalised and informal care). Care should be centred around the individual, not the disease.

Europe's future health/care systems will need to change in order to meet the challenge posed by chronic diseases. Care will increasingly shift from short-term, reactive, acute care centred around the hospital, to long-term, preventive, proactive and patient-specific chronic disease management centred around the home and the community. **Patient-centredness** is increasingly recognised as a core component of high quality care.³² In addition patient-centred care models have been shown to be cost-effective as well as increase patient satisfaction and often clinical outcomes.³³ The benefits of integrated, patient-centred care are seen in terms of reducing avoidable hospitalisations, more effectively allocated healthcare resources, better quality care throughout the "patient journey," and better informed, motivated and empowered patients.

Ultimately, this approach aims to realise the concept of patients and citizens as "co-producers" of health and as an integral part of the entire system. To achieve this, there is a need to **empower patients and citizens** *inter alia* through health literacy, and to equip health professionals with the necessary skills to adapt to the patient's new role and work in partnership with empowered patients.

Patient empowerment³⁴ is in our assessment a vital element in the future sustainability of European healthcare systems, to enable them to cope with the challenges posed by organisational and structural reforms, increasing prevalence of chronic conditions, and the impact of innovative technologies.

Patients will in future be expected to take a more proactive role in managing their health. But patients with chronic diseases are already largely responsible for the management of their own condition. They develop a unique "experiential knowledge" of what it means to live with a condition, and they become experts in managing the condition and its impact on their lives.

The Council Conclusions adopted under the Belgian EU Presidency invited Member States to "identify and share good practices regarding ways to enable patients with chronic diseases to maximise their autonomy and quality of life" and on implementation of innovative chronic care models including ways to reduce health inequalities and improve access.³⁵ The Chronic Care Model³⁶ is an example of a widely used model for the management of chronic diseases, which recognises the central role of the patient. Given the opportunity, patients can also provide invaluable insights for developing the healthcare system, so that it better meets the needs of users, and that resources are targeted cost-effectively.

; On breast cancer nurses (BCN) see the European Guidelines for Quality Assurance in Breast Screening and Diagnosis (4th edition, European Commission, published 2007) [here](#), Some European countries (the UK, Netherlands) have specialised BCN training at their universities and a few (Germany, Switzerland) have "non-academic" training; the European Oncology Nursing Society (EONS) published its post-basic curriculum for breast care nursing see http://www.cancernurse.eu/education/post_basic_curriculum_in_cancer_nursing.html

³¹ EIP-AHA Strategic Implementation Plan

³² S Jayadevappa and S Chhatre (2011) "Patient-centred care – a conceptual model and review of the state of the art", *Open Health Services and Policy Journal*, 4, 15-25

³³ K Parsi, CJ Chambers, AW Armstrong (2011), "Cost-effectiveness analysis of a patient-centered care model for management of psoriasis, *J Am Acad Dermatol*, Aug 9 (epub ahead of print); LE Olsson, E Hansson, I Ekman, J Karlsson (2009) "A cost-effectiveness study of a patient-centred integrated care pathway", *J Adv Nurs*, Aug; 65(8):1626-35;

³⁴ Empowerment is defined as a process that helps people gain control over their lives, increasing their capacity to act on issues that they themselves define as important. (ref)

³⁵ Council conclusions 'Innovative approaches for chronic diseases in public health and healthcare systems' (2011/C 74/03).

³⁶ More information available on the "homepage" of the CCM at

http://www.improvingchroniccare.org/index.php?p=The_Chronic_Care_Model&s=2

Patient involvement is in fact one of the “shared operating principles” of European health systems, as recognised in the Council Conclusions of 2006; nevertheless in practice there is wide divergence across the EU in the level of involvement.

EPF believes that with appropriate support, patients can be part of the solution to the future sustainability of healthcare. The necessary support includes implementation of the principles of patient-centred healthcare³⁷ in healthcare systems; meaningful involvement of patients and their representative organisations in healthcare reforms; and concrete measures to promote patients’ empowerment, in each Member State.

The results of the European Health Literacy Survey indicate that the way the health system is organised can be empowering (or dis-empowering) for citizens;³⁸ further research is needed to identify the specific factors that contribute or hamper empowerment. Given the differences in the health systems in EU Member States, patient organisations can play a highly effective role in identifying interventions that work for different patient groups in the different cultural and social contexts.

Question 3.3: How much emphasis should be given to further development of innovations, including eHealth and telemedicine, in prevention and treatment of chronic disease – such as remote monitoring, clinical decision support systems, eHealth platforms, and electronic health records?

Innovation, in all its forms – technology, process and social – can be a crucial contributing factor to improving the health and well-being of citizens, as well as the sustainability of care systems, and to enhancing Europe’s global competitiveness and growth. Innovation should be based on a user-centred approach.³⁹ eHealth solutions, if implemented appropriately, can carry huge potential for improving the quality of health services for patients, while serving the needs of the health professionals. For patients with chronic conditions, eHealth can significantly improve health outcomes and quality of life.⁴⁰ For instance, tele-monitoring can empower patients with diabetes to monitor and report their glucose levels to healthcare professionals on a continuous basis, without having to disrupt their professional or personal lives. Appointments with healthcare professionals can be conducted on the basis of accurate data, saving time and allowing for a more structured dialogue.

A great number of research studies have been undertaken over the last decade on eHealth. As an example, the Swedish EU Presidency report “eHealth for a Healthier Europe! A Presidency Report on opportunities for a better use of healthcare resources” (2009)⁴¹ pointed out concrete measurable economic benefits of adopting eHealth solutions in Europe: 5 million outpatient prescription errors each year could be avoided through the use of electronic transfer of prescriptions; 100,000 inpatient adverse drug events annually could be avoided through computerised physician order entry and clinical decision support, which would in turn free up 700,000 bed-days each year, an opportunity for increasing throughput and decreasing waiting times, corresponding to a value of almost €300 million. Nine million bed-days each year could be freed up through the use of computer-based patient records, corresponding to a value of nearly €3,7 billion.

³⁷ International Association of Patients’ Organizations, *Declaration on patient-centred healthcare*, 2006
<http://www.patientsorganizations.org/attach.pl/547/269/IAPO%20Declaration%20on%20Patient-Centred%20Healthcare%20-%20Colour.pdf>

³⁸ HLS-EU presentation, 9 May 2012. Other information available at: <http://inthealth.eu/research/health-literacy-hls-eu/measuring-health-literacy-in-europe/>

³⁹ European Innovation Partnership on Active and Healthy Ageing, *Strategic Implementation Plan* adopted by the High-Level Steering Group on 7 November 2011.

⁴⁰ Chou C, Brauer D. Temperament and satisfaction with health status among persons with rheumatoid arthritis. *Clinical Nursing Specialties* 2005;19:94-100; Grosset K, Grosset D. Patient-perceived involvement and satisfaction in Parkinson’s disease: effect on therapy decisions and quality of life. *Movement Disorders* 2005;20:616-9

⁴¹ retrieved from www.calliope-network.eu/LinkClick.aspx?fileticket=Tmkyr/QNsaU=&tabid=277&mid=633 on April 20, 2011.

Electronic health records are a cornerstone for most eHealth services, but also for the development of other innovative approaches such as personalised medicine. In the context of chronic disease management, they can also be used to track patients likely to develop chronic diseases or to monitor patients' medication and treatment regimes. Furthermore, giving patients access to their records empowers them to be more active in the management of their disease. They can add information on their status that can support better diagnosis and treatment from healthcare professionals and they can better adhere to treatment by having the possibility to refer to information on their medications and related instructions.

Whether eHealth services will ultimately be adopted on a large scale is really going to depend on users, including the patients' perceptions of real benefits and safety of these services and interest in using them. Enhancing "e-health literacy" of patients and carers is a key requirement for the acceptance and confident use of ICT-based tools. Other barriers include low awareness of existing solutions by patients and health providers, lack of acceptance and trust on the part of end-users, organisational barriers such as 'silo' budgeting, lack of clarity concerning reimbursement, need for training on new skills and competences.

Innovation in medical and assistive technologies can also make a major contribution to patient-centred chronic disease management to increasing life expectancy and improving quality of life of patients. To achieve this potential, patient involvement from the onset is crucial. The upcoming revision of the EU legislative framework for medical devices is in this respect a key opportunity to encourage a process that ensure innovation in this sector are better centred on users' needs, while ensuring patient safety, as was recommended by the Council.⁴²

EPF recommends that the EU strategy on chronic diseases should explore synergies with the priority areas identified by the Innovation Partnership on Active and Healthy Ageing that seeks to break down barriers to the uptake of innovative solutions. End users (including patients and health professionals) should be included in the design of such solutions from the "idea" stage, through to implementation and evaluation, on the basis of the Value+ model for meaningful patient involvement.⁴³

Questions 3.4, 3.5 and 3.6: In what areas is there a particular need for additional action at EU level? In what areas is there a particular need for additional action at national level? What will you/your organisation contribute to address this challenge?

At national level, health systems reform should result in integrated service provision that embraces prevention (primary, secondary and tertiary), health promotion and patient-centred chronic disease management AND seamlessly links health services to social and community services across the continuum of the "patient journey". This would involve organisational and systems changes to address the persistent barriers and boundaries ("silos") of healthcare delivery, management and budgeting.

Chronic disease programmes should be established in all healthcare systems, according to European standards, clear objectives and quality assurance mechanisms.

Patients and their representative organisations should be meaningfully involved in healthcare design and delivery in all Member States, to ensure that services are properly targeted and will deliver high-quality, meeting patients' needs and expectations while avoiding unnecessary spending on measures that do not add value for patients. EU level action is needed to coordinate the collection of and dissemination of good practices between and within Member States and disease-areas. Furthermore there should be more research funded through EU instruments on the impact of patient involvement and empowerment on various aspects of healthcare and health status, including health inequalities.

⁴² Council Conclusions on innovation in the Medical Device sector, 6 June 2011

http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lsa/122397.pdf

⁴³ <http://www.eu-patient.eu/Initatives-Policy/Projects/EPF-led-EU-Projects/ValuePlus/Resources/>

Health literacy should be a priority at EU level (see below, Section VI.)

Education and training of health professionals is needed to implement patient-centred healthcare in their clinical practice, such as communication skills, concordance/shared-decision making, and attitudes towards patients. Core competences should be established at EU level to ensure that the health workforce across the EU has adequate training, and to facilitate the mobility of health professionals without compromising safety and quality of patient care.

IV. Research

Question 4.1: How should research priorities change to better meet the challenges of chronic disease?

More research should be undertaken on the prevalence and incidence of chronic diseases – but also on their impact on the daily lives of patients, families and caregivers. Clinical research approaches should be reconsidered to reflect the real conditions patients live in. Currently inclusion criteria exclude co-morbidity factors, thus failing to provide treatments that respond effectively to the needs of many patients who have more than one chronic disease.

Patients should be closely involved in biomedical research, starting from the identification of unmet needs. The results of research should be rapidly brought to the patients who need them.

Advances in personalised medicine should also be taken into account in research, with its profound implications including the need for more open sharing of data; use of clinical and patients' data for research; issues of privacy, confidentiality and informed consent; to mention only a few. Again we would stress the need to involve patients and the public in legislative, ethical and political developments at EU and national levels.

Questions 4.2, 4.3 and 4.4: In what areas is there a particular need for additional action at EU level? In what areas is there a particular need for additional action at national level? What will you/your organisation contribute to address this challenge?

A coordinated research agenda at EU level is crucial to eliminate unnecessary duplication and target research funds effectively. More research is needed to identify and scale up innovative approaches to integrated chronic disease care⁴⁴ in order to identify examples of models that 'work' from the users' viewpoint in delivering good quality services, and to identify 'critical success factors' or common elements of such models that are transferable across EU Member States or across disease areas.

User-driven research is an untapped resource with the potential to greatly contribute to innovation. Moreover, being driven by users' needs it has great possibilities to lead to innovative solutions that meet the real needs of end-users. There is therefore a need for increased policy attention and investment in this type of research. Research should be centred on patients' medical and social needs. This can only be achieved if patients are meaningfully involved throughout the research process, from the "idea" stage to the proven intervention.

⁴⁴ Innovation should be understood in a broad sense as including social and organisational innovation, low-tech, and people-focused – for example in the design of health and social care systems, and how care is delivered. Innovation should be valued for its potential to improve the quality of health services, quality of care and quality of life, while increasing equity of access.

To ensure that research results in successful innovative solutions in healthcare, patients' involvement in the process is crucial.⁴⁵ The involvement of patient organisations, and other civil society organisations, in research projects should be made easier with simpler rules, less bureaucracy, and adequate funding.

The European Patients' Forum can play a role in translating relevant research findings into the policy environment and ensure their dissemination to interested patient organisations.

V. Information and Information technology

Question 5.1: What more needs to be done on the development of information and data on chronic diseases?

The lack of a common definition of chronic diseases (see above, section I) results in diverging lists of diseases being used by different institutions,⁴⁶ so that there is currently no precise data on the number of patients affected by chronic diseases in the EU. There is also insufficient evidence on the impact of chronic disease, particularly the concrete impacts on patients, their families and their quality of life (as explained under question 1.1).

Questions 5.2, 5.3 and 5.4: In what areas is there a particular need for additional action at EU level? In what areas is there a particular need for additional action at national level? What will you/your organisation contribute to address this challenge?

Comparative data needs to be collected and made available at EU level. EPF calls for more research in this area, including more data on patients' access to good quality chronic disease care across EU Member States. Information is also needed on existing solutions and good practices in integrated care services, patient involvement and empowerment.

In order to integrate the patient perspective in evaluation of health services, it is necessary to include a direct user experience through qualitative research. The European Patients' Forum has a network of 54 member organisations, many of which are umbrella organisations in specific disease areas and can contribute to efforts to collate data particularly on the patients' direct experiences.

EPF would also like to highlight the importance of high quality health-related information to patients and citizens. (See also below, Section VI.) Improving citizens' health literacy in order to support citizens in making healthier choices and patients in engaging with the health system, there is a need for high-quality information presented in an accessible, user-friendly formats. A strategy for information to patients (and citizens) needs to be developed at EU level, including making better use of already existing resources, and taking account of the cultural and linguistic differences between Member States. To ensure information is high quality, a set of core quality criteria should be used.⁴⁷

VI. Roles of Member States, the EU and stakeholders

⁴⁵ Studies on patient organisations' participation in research have shown the benefits of their engagement: they provide information, effective advocacy, policy support and services. Many are already actively engaged in research and innovation, working with researchers, contributing their knowledge for better outcomes, and disseminating new knowledge to communities across Europe. The Value+ project has developed one model of meaningful patient involvement, along with political recommendations and practical tools to support this, although others exist in specific disease areas. See for example the outcomes of the FP7 project PatientPartner (www.patientpartner-europe.eu) and the PHP project Value+ (www.eu-patient.eu/Initatives-Policy/Projects/EPF-led-EU-Projects/ValuePlus)

⁴⁶ For example the situation as regards data on chronic disease in France is described in les [im]Patients,Chroniques & Associés' white paper "Vivre comme les autres" 2nd edition 2011, p3, available at http://www.afh.asso.fr/IMG/pdf/2ndeedit_livre-blanc_vivre_comme_les_autres_2011.pdf

⁴⁷ We refer to the core quality principles developed by the High-Level Pharmaceutical Forum (2008), available at http://ec.europa.eu/enterprise/sectors/healthcare/competitiveness/pharmaceutical-forum/wg_infopatients_en.htm

Question 6.1: What additional activities on chronic disease beyond the four areas described above should be considered at EU level?

EPF would like to emphasise three areas that are not sufficiently addressed in the paper and are should be integral elements of an EU Strategy on chronic diseases: health inequalities, health literacy/information, and accommodating patients with chronic diseases in the workplace.

i. Health inequalities

Reducing health inequalities is crucial for the overall health and wealth of society, and a key success factor in achieving the EU2020 triple goal of “smart, sustainable *and inclusive* growth”.

There is already a very good body of research on health inequalities across the EU, using life expectancy and healthy life years as indicators. The key socio-economic drivers are well known. A recent study attempted to measure the economic impact of health inequalities by calculating the economic losses currently due to inequalities. These were found to amount to over 700,000 deaths and 33 million cases of ill health annually in the EU as a whole, accounting for 20% of the total costs of healthcare *and* 15% of the total costs of social security benefits.⁴⁸ Although more targeted research is needed, the existing evidence base should now be translated into coherent, targeted actions.

In many chronic diseases, inequalities persist both in terms of access to healthcare and the quality of care. While there is no accurate overview covering all disease-areas, EU-wide data has been collected in some, including musculo-skeletal disorders⁴⁹, Multiple Sclerosis,⁵⁰ Alzheimer’s disease⁵¹ and Parkinson’s disease.⁵² The recent European Commission report “The State of Men’s Health in Europe,”⁵³ likewise points to huge inequalities across the Union.

Within the spectrum of “health equity” of citizens, patients with chronic diseases form a distinct constituency with particular needs. Patients and their families are in a vulnerable position due to the effects of the illness itself, which are often very serious and disabling and have a physical, psychological and emotional impact on the person, their family and immediate environment. They are also dependent on timely access to safe, high quality healthcare and other related support services, as well as vulnerable to other factors often linked to chronic illness – inability to work and the resulting loss of income and risk of poverty, the direct and indirect costs of illness, social discrimination and stigma.

EPF calls for effective measures from the European Commission and Member States to ensure *equitable access to healthcare* for all citizens, as well as addressing the social determinants of health. The strategy should also aim to identify and highlight good practices on how the needs of specific patient populations can be addressed – whether in physical or mental illness, urban or rural environment, or diverse cultural contexts. A mechanism should be developed to ensure that identified “critical success factors” can be transferred into more ambitious, large-scale policy and projects.

⁴⁸ Mackenbach J, Meerding W J, Kunst A E, “Economic costs of health inequalities in the European Union”, *J Epidemiol Community Health*, 2011;65; 412-419.

⁴⁹ Data presented by Prof. Ingemar Petersson, Research Director MORSE Programme, at a meeting of the Interest Group on Rheumatic and Musculoskeletal Diseases, European Parliament, 30 November 2010

⁵⁰ Results of the European MS Barometer 2009, published in November 2010, available at http://www.emsp.org/index.php?option=com_content&view=article&id=121:ms-barometer-2009-results&catid=55:multiple-sclerosis-information-dividend&Itemid=152

⁵¹ Alzheimer Europe country comparisons: <http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons>

⁵² European Parkinson’s Action Day Survey 2011 published in the October 2011 issue of the European Journal of Neurology. <http://onlinelibrary.wiley.com/doi/10.1111/j.1468-1331.2011.03532.x/abstract>

⁵³ European Commission, 2011. Available at http://ec.europa.eu/health/population_groups/docs/men_health_report_en.pdf

ii. Health literacy

Patient expertise needs to be recognised, and individual patients should be seen not only as passive recipients of services and benefits, but as active citizens and participants in self-management. In order to take on this role, patients need to be empowered and informed. Health literacy is a critical strategy towards empowerment.

The EU Health Strategy 'Together for Health' recognises health literacy as a necessary competency for citizens' well-being.⁵⁴ Health literacy is defined as "the capacity to obtain, interpret and understand basic health information and services and the competence to use such information and services to enhance health"⁵⁵. Another definition is "the ability to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, the healthcare system, the market place and the political arena."⁵⁶ However, no universally accepted definition exists currently.

Health literacy is a concept that encompasses literacy skills, but also the capacity to use information and effectively navigate the health system. The importance of health literacy will increase with the ageing population and rise in chronic diseases, as well as increasing use of electronic information sources, decision aids, eHealth and electronic health records.

Well-informed, health literate people have been shown to be more discerning about their health, in a position to make more informed choices and decisions, and more likely to seek earlier diagnosis and recover faster. Conversely, people with low health literacy have been shown to have poorer self-management skills, higher hospitalisation rates and more emergency visits, poorer health overall, more inappropriate use of healthcare resources and less effectiveness of health interventions.⁵⁷ While more research is needed, indications are that the costs of limited health literacy may be substantial, amounting to 3–5% of total healthcare cost at system level.⁵⁸

Health literacy should be a priority in the EU strategy on chronic diseases, as well as a horizontal priority area in the "Health for Growth" Programme. Actions should include developing a common definition of health literacy for use as basis for policy at EU level; mapping existing resources and innovative good practices, including evaluation where possible of their impact, critical success factors and barriers. Good practices should be shared and made available to all stakeholders. Health literacy interventions can be particularly useful to reach out to specific vulnerable groups, such as the young and the old, persons with mental illness and their families, and certain minority/migrant groups.

iii. Chronic disease and the workplace

Europe needs more workers to counter the shrinking work force. This means that older people, and people with chronic diseases, should be supported to stay in employment longer.

One important area that we think need to be further explored through this reflection process is impact of chronic disease on patients in the workplace. While some patients cannot continue their professional activity due to their health condition, many patients with chronic diseases continue working, or wish to do so. With adequate support they can – this results in a hugely improved quality of life and helps avoid the negative financial impact of chronic illness and the risk of social exclusion.

⁵⁴ White Paper COM(2007) 630 final, page 4.

⁵⁵ Ratzan and Parker 2000; IOM 2004.

⁵⁶ Report of EPF Spring Conference on Health Literacy, 2008. Available at at <http://www.eu-patient.eu/Publications/Conference-and-Seminar-Reports/>

⁵⁷ "Health Literacy – part 2: evidence and case studies", World Health Communication Associates, 2010, pp. 20-22. Available online at <http://www.whcaonline.org/uploads/publications/WHCAhealthLiteracy-28.3.2010.pdf>

⁵⁸ "The costs of limited health literacy: a systematic review", Eichler K, Wieser S, Bruegger U, Int J Public Health, 2009;54(5):313-24.

For this reason the needs of patients with chronic conditions must be considered in the context of employment policy, on a par with the needs of people with disabilities.⁵⁹

For patients that do remain at work, combining health issues with professional preoccupations and timetables is in itself a challenge. This can be worsened by symptoms such as pain, tiredness, or anxiety. Experiential knowledge shows that patients will first sacrifice their leisure, social and resting time to deal with health issues, which can lead to isolation and worsening of the health condition.⁶⁰ They may need to adapt their working situation to the constraints of treatment, e.g. through working time adjustments, change of job, workplace adaptation, or even relocation. Discrimination and social stigma are a crucial issue: Because of negative perceptions, patients may not mention they have a disease, or may not ask for the necessary adaptations.

Strategies for chronic disease should aim to enable and support patients to remain in employment. An important part of such a strategy would be guidelines and education for employers, more awareness regarding non-discrimination legislation e.g. the EU Directive on Equal Treatment in the Work Place, and the use of Structural Funds for workplace adjustments, flexible arrangements and reasonable accommodation. Adapted systems and protective legislation are not always in place to allow patients with chronic diseases to remain in the workplace with acceptable conditions. Where they exist they are usually under-used; employers and the population at large tend not to be aware of their existence.⁶¹ Actions to raise awareness within companies or trade unions and for the public could contribute significantly to tackling this problem.⁶² Innovation in this area is also important – remote working/telework can be an ideal solution for some patients with certain diseases.⁶³

Questions 6.2 and 6.3: How can the EU engage stakeholders more effectively in addressing chronic diseases? How can EU Member States engage stakeholders more effectively in addressing chronic diseases?

To ensure an effective strategy on chronic diseases, it is essential that all relevant stakeholders, including patient organisations, older persons' organisations, youth organisations, health professionals' organisations, and other public health and civil society organisations, are engaged and involved in the policy-making process as well as implementation of the strategy.

Patients are experts in their own right as a result of living with and managing their chronic diseases, and an essential part of the solution towards high quality care and improved well-being and quality of life. Patient organisations need to be involved from the onset in the setting of objectives and targets, in concrete actions and initiatives, and in monitoring and evaluation. This will ensure that measures developed “work” from an end user's perspective, corresponds to the needs of patients with chronic diseases, their preferences and capabilities.

In relation to patient involvement within the reflection process and its follow up, we would like to highlight the relevance of the EPF recommendations and practical tools produced as part of the project Value+.⁶⁴ These tools are being used as points of reference in some European Commission calls for proposals, and they can be applied more widely to facilitate effective engagement of patient organisations in programmes and policy work, both at EU and national level.

⁵⁹ Although not all people with disabilities are patients, and not all patients are disabled, nevertheless these groups can overlap to some extent and encounter similar barriers, such as discrimination and stigma.

⁶⁰ [im]Patients,Chroniques & Associés' white paper “vivre comme les autres” 2nd edition 2011, p17-18, available at http://www.afh.asso.fr/IMG/pdf/2ndeedit_livre-blanc_vivre_comme_les_autres_2011.pdf

⁶¹ For example that is the situation in France. Source: *ibid*.

⁶² The white paper “ vivre comme les autres” indicates that through local actions, these negative perceptions can be significantly modified. Source: [im]Patients,Chroniques & Associés' white paper “vivre comme les autres” 2nd edition 2011, p18, available at http://www.afh.asso.fr/IMG/pdf/2ndeedit_livre-blanc_vivre_comme_les_autres_2011.pdf

⁶³ This is one of the recommendation of the white paper, *ibid*, p17

⁶⁴ <http://www.eu-patient.eu/Documents/Projects/Value+%20Policy%20Recommendations.pdf>

EPF and our 54 member organisations across the EU are strongly committed to participating and being a constructive partner in the reflection process, the definition of a strategy at European level to address chronic diseases, and its implementation.