EFA Response to the European Commission Public Consultation on the European Union (EU) Reflection Process on Chronic Diseases

In collaboration with **IPCRG (International Primary Care Respiratory Group)**

www.theipcrg.org

The European Federation of Allergy and Airways Diseases Patients' Associations (EFA) is a non-profit network of allergy, asthma and COPD patients organisations, representing 34 national associations in 21 countries and over 400.000 patients. EFA is dedicated to making Europe a place where people with allergies, asthma and COPD have the right to best quality of care and safe environment, live uncompromised lives and are actively involved in all decisions influencing their health. www.efanet.org

Introduction

EFA very much welcomes and thanks the European Commission for the possibility to provide input for the EU Reflection Process on Chronic Diseases. Such a process is carried out by the EU Member States (MSs) and by the Commission itself and was required by the Council Conclusions on "Innovative approaches for chronic diseases in public health and healthcare systems" (adopted by the Employment, Social Policy, Health and Consumer Affairs Council of the EU in December 2010).[1] In particular, EFA wishes to congratulate the European Commission for its well-researched description of the problem and consequences and wishes to contribute by providing the perspective of people with allergy, asthma and chronic obstructive pulmonary disease (COPD) in Europe, all conditions characterised by remarkable inequalities and suboptimal prevention and management across Europe.

This document was sent out to EFA's network for comments and approval. The following organisations were actively involved in the development of the response: IPCRG (International Primary Care Respiratory Group), ENSP (European Network for Smoking and Tobacco Prevention), NAAF (Norges Astma og Allergiforbund), AIP-BPCO (Associazione Italiana Pazienti BPCO). In addition, EFA warmly thanks the valuable input of all its members that contributed to the EFA Books on Respiratory Allergies and COPD: ÖLU (Österreichische Lungenunion), Astma en Allergiekoepel, COPN (Czech Civic Association against COPD), FFAAIR (Fédération Française des Associations et Amicales de malades, insuffisants ou handicapés respiratoires), PLA (Patientenliga Atemwegserkrankungen e.V.), Irish Thoracic Society, AIP-BPCO, Astma Fonds, Respira – Associação Portuguesa de Pessoas com DPOC e outras Doenças Respiratórias, JUDAH – Association for Asthma and COPD, British Lung Foundation, Association of Bulgarians with Bronchial Asthma, Czech Initiative for Asthma, Astma-Allergi Danmark, Allergy and Asthma Federation Finland, Association Asthme & Allergies, Aniksi, Asthma Society of Ireland, FEDERASMA Onlus, Lithuanian Council of Asthma Clubs, NAAF, Polish Federation of Asthma, Allergy & COPD Patients' Association, Swedish Asthma and Allergy Association, aha!, Allergy UK.

Consultation questions

EFA wishes to submit the following comments for inclusion in any future action and policy on chronic diseases.

The current situation on chronic diseases in the EU

1. What further information and evidence should be taken into account by national governments and the EU regarding the chronic disease situation?

The World Health Organisation (WHO) estimates that chronic diseases are the leading cause of mortality in the European region, accounting for 86% of all deaths and for 77% of the Disability Adjusted Life Years

[1] Available at: http://www.consilium.europa.eu/uedocs/cms_Data/docs/pressdata/en/lsa/118282.pdf.

(DALYs).[2] Among the wide range of chronic diseases, EFA is representing people with allergy, asthma and COPD at the European level.

COPD is a progressive disease that affects almost 10% of all adults (210 million people worldwide and 44 million people in Europe). Currently ranked at number 6 of the WHO's mortality list, it will be the 3rd leading cause of death by 2030 while remaining an unknown disease to most people.[3] WHO forecasts that 235 million people worldwide suffer from **asthma**.[4] Around 30 million people in Europe have asthma, and as many as 6 million of these people suffer symptoms that are characterised as severe.[5] It is estimated that 1 in every 2 Europeans will suffer from an **allergy** by 2015. Among all the different types of allergies (for example: allergies to food, medications, pets, plants, pollen, dust mites, mould), respiratory ones represent the most common allergies and currently affect around 20-30% of the European population.[6]

The impact of chronic diseases, including allergy, asthma and COPD, on people's lives is twofold: they cause serious health problems to the affected people, but they also represent a societal challenge and an economic burden. From a social point of view, they can have a negative impact on employment, education, consumption and quality of life (both of the individual affected and his/her family). Chronic diseases result in less people within the workforce, early retirement and sometimes barriers to enter the labour market and stigmatisation on the part of employers. They affect educational performance, both in the case of a pupil/student and/or family member is affected by at least one chronic disease.[7] From the economic perspective, they account for a considerable part of the healthcare budget. The former aspect is linked to the indirect costs of the diseases, mainly due to the working days/school days lost and the disability whereas the latter correlates to the direct costs (for example: hospitalisation, emergency room or doctors' visits, homecare and medicines).

The Organisation for Economic Co-operation and Development (OECD) estimates that 70% to 80% of total healthcare costs are attributable to chronic diseases and, in the case of the European Union, this

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[2] Data available at: http://www.euro.who.int/__data/assets/pdf_file/0006/140739/NCD_Mtg_Oslo_Apr2011_SumRep.pdf.
WHO defines DALYs as "the sum of years of potential life lost due to premature mortality and the years of productive life lost due to disability" (definition available at: http://www.who.int/mental_health/management/depression/daly/en/).

[3] In 2010, EFA launched its "Book on COPD in Europe – Sharing and Caring" and corresponding Call to Action for Europe at the European Parliament. Based on these documents, EFA organised two separate workshops on COPD at the European Parliament in 2011: the first on "Prevention and Diagnosis of COPD", the second on "Care and research of COPD".
Mariadelaide Franchi, *EFA Book on COPD in Europe – Sharing and Caring*, 2009, available at: http://www.efanet.org/documents/EFACOPDBook.pdf.
David Brennan, Antje Fink-Wagner, Susanna Palkonen, *Policymakers to prevent Europe from suffocating – EU policy recommendations to curb the human and societal burden of COPD*, in Journal of Paramedic Practice, April 2012 (in publication).

[4] Data available at: http://www.who.int/topics/chronic_diseases/en/.

[5] European Respiratory Society (ERS) in conjunction with the European Lung Foundation (ELF), *European Lung White Book*, November 2003.

[6] Last November 2011, EFA launched its "Book on Respiratory Allergies – Raise Awareness, Relieve the Burden" and the corresponding Call to Action at the European Parliament.
Erkka Valovirta, EFA Book on Respiratory Allergies – Raise Awareness, Relieve the Burden, 2011, available at: http://www.efanet.org/documents/EFABookonRespiratoryAllergiesFINAL.pdf.

[7] Miriam Blumel, Reinhard Busse, David Scheller-Kreinsen, Annette Zentner, *Tackling chrnonic disease in Europe – Strategies, interventions and challenges*, European Observatory on Health Systems and Policies Studies Series No 20, WHO Regional Office for Europe, 2010, available at: http://www.euro.who.int/__data/assets/pdf_file/0008/96632/E93736.pdf.

corresponds to 700 billion EUR.[8] The total annual financial burden of lung disease in Europe amounts to nearly 102 billion EUR and COPD accounts for almost one half of this figure. In addition, COPD accounts for more time off work than any other illness and each year it is estimated that 32.8 billion EUR are lost due to the reduced productivity of COPD patients.[9] The total cost of asthma in Europe is 17.7 billion EUR per year, and productivity lost to patients' poor control of their asthma is estimated at 9.8 billion EUR per annum.[10] Asthma and allergy are the most common chronic diseases in children and the leading cause of school absences, emergency department visits and hospitalisations; consequently the entire family is affected. The Polish Presidency of the Council of the EU underlined this problem in its conclusions on "Prevention, early diagnosis and treatment of chronic respiratory diseases in children" (unanimously adopted by the EU Ministers of Health in December 2011).[11]

The necessity to tackle these diseases in a proper way is also related to the fact that they are **linked to an important aspect of the EU health strategy, subsequently reiterated by several other instruments**: the existence of health inequalities between and within EU MSs and the need to cope with them.[12] The WHO Europe region states the increase of chronic diseases is affecting poorer and disadvantaged people in disproportionate measure, hence widening the afore-mentioned differences and health inequalities.[13] In particular, 90% of COPD as well as most asthma-related deaths occur in low- and lower-middle income countries.[14] This is mainly due to the differences existing in access to healthcare and the quality of the care being provided.

On the one hand, high quality of information for patients may be the response to these problems as better informed patients have increased access to healthcare and especially higher quality of the care itself. This aspect will be expanded later on in the section dedicated to the healthcare systems. On the other hand, health inequalities may be tackled by the EU cohesion policy and its objective of economic and social cohesion between and among MSs of the EU. Health was listed as a priority for the Structural Funds in 2007 for the first time. As a consequence, for the period 2007-2013, MSs have allocated around 5 billion EUR (1.5% of the total available) from the funds in the category "Health Infrastructure."[15]

Finally, it is necessary to underline that the **prevention and management** of chronic diseases will help reach the objectives of active and healthy ageing. To this extent, and with the aims of an employment rate of 75% for 20-64 year-old and of at least 20 million fewer people in or at risk of poverty and social exclusion, the European Union has designated 2012 as the "European Year for Active Ageing and Solidarity between Generations."[16] In addition, prevention and management are linked to the European Commission's pilot project on the "European Innovation Partnership (EIP) on Active and Healthy Ageing"

[8] Data available at: http://ec.europa.eu/health/interest_groups/docs/euhpf_answer_consultation_jan2012_en.pdf.
[9] Mariadelaide Franchi, *op. cit.*, note 3.
[10] ERS in conjunction with ELF, *op. cit.*, note 5.
[11] Available at: http://www.consilium.europa.eu/uedocs/cms_Data/docs/pressdata/en/lsa/126522.pdf.
[12] European Commission, *White Paper "Together for Health: A Strategic Approach for the EU 2008-2013"*, 23 October 2007, available at: http://ec.europa.eu/health/ph_overview/Documents/strategy_wp_en.pdf.
European Commission, *Solidarity in health: reducing health inequalities in the EU*, 20 October 2009, available at: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2009:0567:FIN:EN:PDF.
[13] WHO, note 2.
[14] WHO, note 4.
[15] European Commission, *Solidarity in health*, *op. cit.*, note 12.
[16] See the website: http://europa.eu/ey2012/.

with the objective of increasing by two years the average healthy lifespan in the EU by 2020.[17] In particular, the Operational Plan of the EIP underlines 80% of people aged more than 65 are affected by chronic diseases and often they present several co-morbidities. More than half of older people have at least 3 chronic diseases and a significant proportion of them have 5.[18] COPD is classic example of a disease where co-morbidities are frequent, such as diabetes and heart disease. In fact, COPD affects all organs because of lack of oxygen and therefore causes heart disease, which may often be the final cause of death. In the cases of allergies and asthma, up to 80% of people with asthma have a respiratory allergy and families with allergies may suffer from several conditions at once: food allergy, atopic eczema, respiratory allergy and other types of hypersensitivities.[19] Finally, active ageing is also crucial to achieve EU ambitious goals under the Europe 2020 strategy for smart, sustainable and inclusive growth.[20]

Health promotion and disease prevention

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

In Europe, 97% of health expenses are spent for treatment and care, while only the remaining 3% is dedicated to prevention.[21] Therefore, this percentage needs to be increased as prevention is not just awareness, but action. EFA agrees with the European Patients Forum (EPF) on the need to consider primary, secondary and tertiary prevention as a continuum.[22] The economic aspects of these three phases of the prevention are strictly connected too, as well-functioning primary prevention and timely secondary prevention decisively limit the costs of the tertiary, notably the most expensive and burdensome for the healthcare systems and the economy in general. Therefore, EFA activities and projects aim at empowering the healthy, those at risk and people already affected in order to adopt healthy habits and life-styles. At the same time, EFA emphasises the importance of early stage detection for the disease, and of increased attention paid by policy makers towards people affected by chronic diseases so that they are able to have the right to best quality of care and safe environment while living uncompromised lives.

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[17] See the website: http://ec.europa.eu/research/innovation-union/index_en.cfm?section=active-healthy-ageing.
[18] EIP Steering Group, *Operational Plan for the EIP*, 17 November 2011, available at: http://ec.europa.eu/research/innovation-union/pdf/active-healthy-ageing/steering-group/operational_plan.pdf#view=fit&pagemode=none.
[19] Erkka Valovirta, *op. cit.*, note 6.
[20] See the website: http://ec.europa.eu/europe2020/index_en.htm.
[21] European Commission, *Together for Health, op. cit.*, note 12.
[22] EUHPF, *op. cit.*, note 8.
"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."

In the case of our disease areas, more can be done, both at the EU and MSs levels. The major risk factors for people suffering from allergy, asthma and COPD are related to tobacco consumption, exposure to second-hand smoke, and to environmental pollution (within schools, homes, work and leisure environments, as well as outdoors).

Concerning **smoking**, the forthcoming revision of the EU Tobacco products directive[23] is an opportunity that needs to be used to strengthen primary as well as the secondary and tertiary prevention: to help in avoiding that people, especially youth, start smoking and to help smokers to quit. EFA, in line with the main EU-wide tobacco and smoking prevention organisations (such as the European Cancer Leagues, ECL; the European Heath Network, EHN; the Forum of European Respiratory Societies, FERS; the Smoke-Free Partnership, SFP; and our partner organisation, ENSP) has 3 key priorities: mandatory pictorial warnings (covering 80% of the front and back of the packet covers), plain packaging and regulation of additives. EFA and its partners want tobacco products to be seen as dangerous to make smoking very unattractive.

According to an Eurobarometer survey on tobacco, conducted in 2008 in all 27 MSs, 3 out of 10 non-smokers responded that health warnings prevented them from starting to smoke, the same percentage of non-smokers said the warnings deterred them from starting again, 1 out 5 smokers estimated the health warnings made them smoke less and helped them to try to quit. In addition, the insertion of pictorial warnings is conceived as effective by more than 50% of Europeans.[24] A campaign on the plain packaging was run in the UK by Smoke-free Action Coalition and the results clearly showed that this decreases the attractiveness of smoking, especially among young people.[25]

Smoking has negative health effects. This is particularly true for people suffering from respiratory diseases. Hence, the results of a 2012 paper that show that amongst those aged 18-45 with clinical/treated asthma a third was current smokers are surprising.[26] This calls for increased education and communication between patients and healthcare professionals on the consequences of smoking, as well as higher investments to support quitting in primary care. Indeed, there is already sufficient evidence for inclusion of clinician support for patients to quit smoking in addition to governmental tobacco control measures. Radical and decisive measures to tackle this major preventable problem are needed. EFA's vision is a smoke-free Europe, a vision that has already been adopted by one MS (Finland) for 2040 and should become the goal of the EU.

Concerning **exposure to second-hand smoke**, in line with the Council Recommendation on smoke-free environments,[27] EFA asks the Member States to adopt and implement laws to fully protect citizens from Environmental Tobacco Smoke (ETS) in enclosed public places, workplaces and all forms of public transportation, as cited by Article 8 of the WHO Framework Convention on Tobacco Control (FCTC).[28]

[23] Available at: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2001:194:0026:0034:EN:PDF.
[24] Eurobarometer, *Survey on tobacco*, March 2009, available at: http://ec.europa.eu/public_opinion/flash/fl_253_en.pdf.
[25] See the website of the Coalition: http://www.smokefreeaction.org.uk/plain-packaging.html.
[26] Teresa To, Sanja Stanojevic, Ginette Moores, Andrea S. Gershon, Eric D. Bateman, Alvaro A. Cruz, Louis-Philippe Boulet, *Global asthma prevalence in adults: findings from the cross-sectional world health survey*, in BMC Public Health, 19 March 2012, available at: http://www.biomedcentral.com/content/pdf/1471-2458-12-204.pdf.
[27] Available at: http://register.consilium.europa.eu/pdf/en/09/st15/st15937.en09.pdf.
[28] Available at: http://whqlibdoc.who.int/publications/2003/9241591013.pdf.

Indeed, it was proven that 7,300 adults including 2,800 non-smokers died as a result of ETS exposure at their workplace in the European Union in 2002. In addition, a further 72,000 adult deaths, including those of 16,400 non-smokers, were linked to ETS exposure at home.[29] A review of the evidence on health of passive smoking showed that it causes lower respiratory illness and contributes to the symptoms of asthma in children.[30] To limit these effects, MSs should adopt a normative law stating children's right to grow up in a smoke free environment. Furthermore, smoking should also be forbidden in cars, as it seriously affects the health of passengers, children in particular, and has a negative impact on concentration.

In conclusion, exposure to second-hand smoke is extremely harmful and it should be limited as much as possible to ensure a high level of protection of human health as stated by the Treaties at the basis of the EU. Besides, a strict ban on smoking is correlated to a lower incidence of smoking, as demonstrated by a special Eurobarometer on tobacco (2009, in 27 MSs)[31] and by the final report of the Impashs project, a 3-year project funded by the EU under the public health programme.[32]

These smoking restrictions are related to another important risk-factor for people with asthma, allergy and COPD: the good quality of a given **indoor environment**. Environmental factors believed to be of importance to the exacerbation of asthma and allergies are emissions from building materials, consumer products such as furniture and electrical equipments, cleaning and household products, poor ventilation, building maintenance and construction exposure to particulate matters, chemicals and combustion products as well as to moulds and dampness. Of particular concern in regards to ventilation and building construction are the new energy saving standards the European Commission advanced in its proposal for an EU directive on energy efficiency, which easily could lead to poor indoor air quality unless a proper risk assessment is undertaken. The aim in the future must be to ensure buildings that provide good indoor air quality and are energy efficient. To this extent, EFA is partner of a two-year project funded under the second health programme, HealthVent, whose objective is to develop health-based ventilation guidelines. They will protect people in places like schools, nurseries, offices and homes against health problems caused by poor indoor air quality, and at the same time will ensure that energy is utilised efficiently.[33] Therefore, EFA asks the European Commission to adopt a strategy to encompass all these elements and the recommendations issued by the EU Expert Group on Indoor Air Quality (IAQ) meetings.[34]

The importance of both IAQ and **outdoor air** needs to be emphasised and mentioned in forthcoming EU documents in the matter, such as the 7th Environmental Action Programme (7 EAP, to be proposed during this year by the Commission) and the Ambient air quality and clearer air directive (to be reviewed in 2013). Indeed, it is estimated that 450,000 people in the EU die prematurely due to exposure to air pollutants each year. These premature deaths account for 1.5-4% of the EU Gross Domestic Product

[29] Council, *op. cit.*, note 27.
[30] National Health and Medical Research Council, *The health effects of passive smoking: a scientific information paper*, Canberra, 1997.
[31] Special Eurobarometer, *Tobacco*, May 2010, available at: http://ec.europa.eu/public_opinion/archives/ebs/ebs_332_en.pdf.
[32] Available at: http://www.impashs.eu/.
[33] See the project website: http://www.healthvent.byg.dtu.dk/.
[34] See the website: http://ec.europa.eu/health/healthy_environments/expert_group/index_en.htm.

(GDP).[35] Following the recommendation of the 2010 Parma Ministerial Commitment to Act (adopted by the responsible European Ministers and WHO representatives),[36] there is a clear need for a Second EU Environment and Health Action Plan (EHAP) to bring all policies together to work for health as well, and not least to make it understandable for the EU citizens what the EU is doing regarding health and environment across policies, and how great progress in EU supported research is implemented across policies to support MSs in their efforts.[37]

In addition, action on primary prevention may be improved through the dissemination of information materials, and the organisation of workshops and educational programmes. Short videos presenting these diseases and the perspective of affected patients may be uploaded on the EU/MSs/other stakeholders' responsible websites as they represent a suggestive and effective way to raise awareness within the population and the decision-makers.

Figure 1 – The integration of prevention and management of allergy and airways diseases in all EU policies

4. What potential is there for broad based early detection action?

Early detection and correct diagnosis are fundamental to guarantee a timely, right treatment and preventive plan enabling patients to properly manage the disease in their life and cope with unexpected situations, such as environment, indoors or outdoors, which can exacerbate their condition(s). This is particularly true for **COPD** which, although irreversible, is both a preventable and treatable disease.

[35] Data available at: http://www.env-health.org/IMG/pdf/110913_HEAL_fact_sheet_-_Chronic_disease_and_environment-final.pdf.
[36] Available at: http://www.euro.who.int/__data/assets/pdf_file/0011/78608/E93618.pdf.
[37] See the document EFA and HEAL adopted during the EU Open Health Forum meeting in 2010, available at: http://ec.europa.eu/health/interest_groups/docs/ohf2010-wg1-recommendations.pdf.

EFA's first workshop at the European Parliament included top experts from medicine, patient perspective and policy makers and focused on the prevention and diagnosis of COPD and identified three main actions to guarantee early detection of COPD, based on best practices in MSs:

a. **Education of healthcare professionals**: co-operation between those working in primary care and specialists need to be established with a view to a correct interpretation of lung function test results, and rigorous training needs to be given to those who do not have access to specialist knowledge as COPD still remains an unknown disease to most people;

b. **Access to spirometry testing** to all those at risk: at the age of 35, smokers, former smokers and those with an occupational exposure need to undergo lung function tests, provided they present at least one respiratory symptom (dyspnoea, cough, wheeze, phlegm and/or recurrent respiratory infections);

c. **Registration**: establish a register for COPD patients to support evidence based policy-making.

People who suffer from COPD do not usually go to see a specialist or primary care physician as they believe to have just a smoker's cough or the flu. Instead, a timely detection of the disease could improve the quality of life for patients and their families while reducing the economic burden of COPD. An example of best-practice is the case of Denmark. The Danish Health Board recommended screening for COPD on the basis of a study that had demonstrated that, with 10% of General Practitioners (GPs) participating and 3,095 people screened, 35% were diagnosed as suffering from COPD and, among these, 80% with a mild to moderate condition of the disease. It was estimated that 180 million EUR of annual healthcare costs were saved with this early detection system.[38]

Respiratory allergy is, despite the scenario that 113 million European citizens suffer from allergic rhinitis and 68 million from allergic asthma, often underdiagnosed, with approximately 45% of patients having never received a diagnosis.[39] Early detection is important to avoid the so-called "allergic march" (a sequence of increasing sensitisation to allergens and manifestation of allergic symptoms: food allergy, atopic eczema, other types of allergies) to help people manage and control their respiratory allergy, and to limit its high burden on economies. Indeed, during the launch event of the EFA Book on Respiratory Allergies at the European Parliament last November 2011, it was shown the estimated costs of untreated patients amounted to a reduction in performance at work by 10-30%, which is a monetary loss of 24-72 EUR per day. This is quite a contrast compared to the cost of treatment, which amounts to 1 EUR per day.[40]

The Call to Action launched by EFA identified as priorities:

- to improve **accurate and early diagnosis**;
- to **promote training in allergic diseases for all healthcare professionals**.

[38] Data available at: http://www.efanet.org/documents/EFANewsletterCOPDWorkshop1.pdf.
[39] Erkka Valovirta, *op. cit.*, note 6.
[40] Report on the EFA Respiratory Allergy Book, Launch Event, available at: http://www.buildup.eu/system/files/content/EFA%20Respiratory%20Allergy%20Book%20Launch%20SummaryReport%20PDF.pdf.

Indeed, in most European countries allergology is not recognised as a specialisation and therefore allergies are often dealt with in primary care. However, due to low education of primary care physicians on allergy issues, patients often receive a late diagnosis and not always the appropriate treatment in line with the most recent international evidence-based guidelines. Due to the lack of appropriate diagnosis, many patients turn to alternative medicine for a cure. This is particularly true for food allergy, as it is poorly understood amongst general practitioners. In worst cases, this could lead to inappropriate diagnosis and malnutrition of children in their growth period.

Allergology involves a number of specialties (such as lung, skin, gastro, ear-nose-throat, clinical nutrition, physiotherapy, podiatry, occupational allergy, etc.), which must work collaboratively together. Such collaboration needs to be enforced through interdisciplinary medical centres across the EU and its MSs. Only then would we:

- ensure early diagnosis, appropriate treatment and an holistic health service for the increasing number of patients with complex disease manifestations (allergies with multiple organ manifestations), both in regards to children and adults;
- provide patients with new hypersensitive conditions (e.g. multiple chemical sensitivity) with an appropriate diagnosis and treatment;
- avoid patients seeking to unserious practitioners within alternative medicine;
- give patients with drug allergy a qualified service;
- ensure early diagnosis and an appropriate treatment plan for people with occupational allergies and asthma, who in many instances today are detected too late for a recovery.

Nurses and pharmacists could potentially play an important role in promoting early diagnosis since both these groups of health care professional encounter people who believe to have allergies, without having received a proper diagnosis.

Therefore, EFA asks the EU and its MSs to ensure that allergology is included in the training of medical students and that dedicated trainings for physicians, nurses and pharmacists are available in all European countries. In addition, interdisciplinary medical centres need to be established to meet the complex challenges of today and tomorrow. Since allergy will soon be a disease that every second citizen may have, primary care physicians need to be trained extensively in treating all kinds of allergies.[41]

5. In which areas is there a particular need for additional action at the EU level?
6. In which areas is there a particular need for additional action at the national level?
7. What will you/your organisation do to contribute to address this challenge?

EFA believes an increase of synergies at the EU and the national level is needed; in particular, an EU strategy on the prevention and management of chronic diseases is deemed necessary. This approach may be built upon the more general EU health strategy and be focused on the same principles, namely the sharing of best practices (based on universality, access to good quality of care, equity and solidarity, citizens' empowerment, reduction of health inequalities and scientific evidence), and the Health In All Policies (HIAP). This overall action should then present focused disease specific channels including

[41] Erkka Valovirta, *op. cit.*, note 6.

allergy, asthma and COPD and address their specific problems, challenges and most of all, offer patient centred, cost effective solutions.

The Commission proposal of the third multi-annual programme of EU action in the field of health presents positive novelties and increased budget, from 321 to 446 million EUR. Article 4 of the proposal lists among the eligible actions that can be financed "promoting good health and preventing diseases," and especially "supporting the prevention of chronic diseases including cancer."[42] Therefore, cancer is the only chronic disease mentioned and EFA believes it is necessary to emphasise allergy, asthma and COPD as well because of their prevalence, impact and cost. Besides, the same approach had been followed by the European Parliament in its Resolution on the EU position and commitment in advance of the United Nations (UN) high-level meeting on the prevention and control of Non-Communicable Diseases (NCDs)[43] and by the adoption of a Political Declaration of such a high-level meeting by the General Assembly of the UN itself.[44] Both these documents mention chronic respiratory diseases together with cancer, diabetes and cardiovascular diseases as the major NCDs.

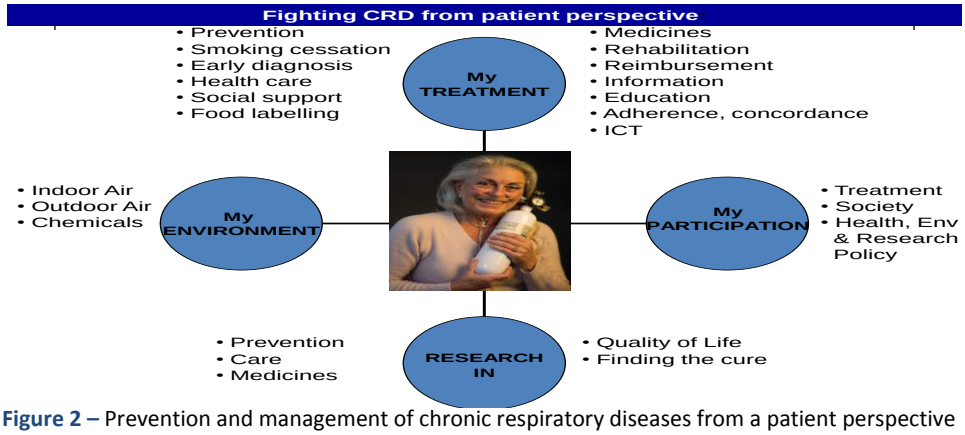

Figure 2 – Prevention and management of chronic respiratory diseases from a patient perspective

The EU needs to support the sharing of best practices. At the national level, governments need to learn from each other and implement these best practices, adapting them to their particular circumstances. As shown in Finland, a comprehensive approach manifested in national programmes for specific diseases, like allergy, asthma and COPD, which includes all stakeholders including patient associations, can significantly increase the quality of life of people suffering from these diseases and reduce related costs. EFA, as the European federation representing people with allergy, asthma and COPD, has always been involved in the sharing of best practices among its members and policy makers in broad partnership with other NGOs, and the advocacy for raising the quality of life and the standards of care for patients. From the patients' perspective, EFA is ready to contribute to any strategy/programme on

[42] European Commission, *Proposal for a Regulation of the European Parliament and the Council on establishing a Health for Growth Programme, the third multi-annual programme of EU action in the field of health for the period 2014-2020*, 9 November 2011, available at: http://ec.europa.eu/health/programme/docs/prop_prog2014_en.pdf.

[43] European Parliament, *Resolution on European Union position and commitment in advance to the UN high-level meeting on the prevention and control of non-communicable diseases*, 15 September 2011, available at: http://www.europarl.europa.eu/sides/getDoc.do?type=TA&reference=P7-TA-2011-0390&language=EN.

[44] UN General Assembly, *Political declaration of the high-level meeting of the General Assembly on the prevention and control of non-communicable diseases*, 16 September 2011, available at: http://www.un.org/ga/search/view_doc.asp?symbol=A/66/L.1.

our disease areas. In addition, being part of the Global Alliance against Chronic Respiratory Diseases (GARD), EFA is already active at the global level.[45]

Healthcare

8. What changes could be made to enable health care systems to respond better to the challenges of prevention, treatment and care of chronic diseases?
9. 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?

The sustainability of healthcare systems will be challenged by the ageing population and the parallel augmentation of people suffering from chronic diseases. Hence, their response to the defies posed by the increased incidence/prevalence should be based upon the prevention, screening and early diagnosis to keep people healthy and postpone the onset of the illness, as discussed in the previous section, as well as integrated care. Indeed, preventive actions reduce the costs of treatments and a more holistic and personalised approach to health needs improves their effectiveness and the quality of life of individual patients.

To this extent, EFA agrees with EPF on the main issues that need to be addressed to enable healthcare systems to improve responses to the challenges of chronic diseases: in particular, patient-centered approaches and health literacy. Both entail cost-effectiveness and quality of life: patients who know more about their chronic conditions are more willing to participate in the decision-making process so that the results will be tailored on the basis of patient needs. In addition, being able to make more informed choices and to take better decisions, patients seek early diagnosis and recover faster, in most cases avoiding emergency visits and hospitalisations as well as their related costs for the healthcare systems. A recent study estimates that low health literacy for patients may account for 3-5% of the total healthcare costs per year.[46]

To reach these objectives, a fruitful cooperation and exchange of information among the different healthcare professionals, properly trained to face the challenges posed by multiple chronic diseases and an ageing population, is necessary. EFA shares the concerns of its partner organisation IPCRG that believes that guidance for primary care should be pragmatic and evidence-based, thus underlining the growing need for investment in and support for programmes that recruit patients representative of primary care populations, evaluate interventions realistically delivered within primary care, and draw conclusions that will be meaningful to professionals working within primary care. Practical answers about how to implement guidance in diverse primary care settings are needed. In addition, integration between hospitals, rehabilitation centres, community homes and guided self-care would allow for the

[45] See the website at: http://www.who.int/respiratory/gard/en/.

[46] Klaus Eichler, Simon Wieser, Urs Bruegger, *The costs of limited health literacy: a systematic review*, in International Journal of Public Health, 2009, available at: http://www.springerlink.com/content/n7327r1tl81665t3/fulltext.pdf.
The importance of patients' involvement was firstly recognised by the Council conclusions on common values and principles (adopted in June 2006 and available at: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2006:146:0001:0003:EN:PDF).

management of the disease to be constantly guaranteed either through professionals or by informed patients themselves.

In the case of **COPD**, pulmonary rehabilitation should be improved and individualised therapies, which involve patients in setting objectives for the management of the disease and may limit the exacerbations and their related costs (currently estimated at 2.9 billion EUR per year), guaranteed. In addition, the harmonisation of strollers for patients under oxygen therapy should be achieved to allow these people to travel safely throughout the EU. The recently revised Global Initiative for Chronic Obstructive Lung Disease (GOLD) strategy document[47] can help doctors in developing personalised treatment, in managing COPD, exacerbations and its co-morbidities. An example of best practice in this area is the **Finnish COPD programme**, which reduced the societal costs of COPD by 88% during the period 1998-2007, mainly diminishing those related to disability from more than 550 million EUR to less than 100 million EUR.[48]

The success of this programme was due to several reasons: first of all, a COPD awareness-raising campaign was run among the public. Furthermore, multidisciplinary educational programmes were developed involving specialists, as well as private doctors and nurses. As a result, the attitude of healthcare professionals towards smokers and COPD patients improved, patients were empowered to self-manage their disease and the general population was provided with a better understanding of COPD. Primary care was improved both in terms of resources and tools as 700 asthma nurses were trained in smoking cessation support and testing devices were made available in all healthcare stations. Finally, 700 pharmacists throughout Finland were not only trained to able to take care of asthma patients, but also to advise on COPD and smoking cessation.[49]

The example of the **Finnish asthma and allergy programmes** are also best practice in these two disease areas and can serve as a model for other disease areas as well. Everyone benefits as both of them are 10-year programmes with the double objective of reducing the costs for the healthcare systems and increasing the quality of life of people with allergy and asthma. Thanks to the Finnish **asthma** programme (1994-2004), the number of patients' hospital days fell by 54% and the costs per patient per year decreased by 36%, from 1,611 EUR in 1993 to 1,031 EUR in 2003. It showed a cost-effective reduction of deaths (80%), hospitalisations (85%) and pension disabilities (60%). On the basis of these encouraging results, the Finnish **allergy** programme was launched for the period 2008-2018 with the goal of, among others, decreasing costs related to allergies by 20%.[50] The national allergy programme is the first of its kind in Europe and could ultimately lead to significant outcomes in demonstrating means for both improving the lives of people with allergy and decreasing the economic burden allergy imposes upon a society.

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[47] Available at: http://www.goldcopd.org/uploads/users/files/GOLD_Report_2011_Feb21.pdf.
Launched in 1997 by the United States of America (USA) National Institute of Health and the WHO, GOLD works with health care professionals and public health officials to raise awareness of COPD and to improve prevention and treatment of this lung disease.

[48] Data available at: http://www.efanet.org/enews/documents/EFANewsletterCOPDWorkshop2.pdf.

[49] Vuokko Kinnulaa, Tuula Vasankarib, Eva Kontulac, Anssi Sovijarvid, Olli Saynajakangase, Anne Pietinalhof, *The 10-year COPD Programme in Finland: effects on quality of diagnosis, smoking, prevalence, hospital admissions and mortality*, in Primary Care Respiratory Journal, March 2011, available at: http://www.thepcrj.org/journ/vol20/20_2_178_183.pdf.

[50] Erkka Valovirta, *op. cit.*, note 6.

10. How much emphasis should be given to further developments of innovations, including e-Health and Telemedicine in prevention and treatment of chronic disease such as remote monitoring, clinical decision support systems, e-health platforms and electronic health records?

The development of innovations, such as e-Health and Telemedicine, will entail a better and more efficient management of the disease areas discussed, including follow-up, an increased integrated care through solutions that help, rather than hinder, integration. However, people should bear in mind that these innovative solutions should not divert resources for meeting the basic needs on managing a disease. Innovation may enhance the capacity of healthcare systems to address the challenges posed by both chronic diseases and the related complications for autonomy in daily life among patients and their caretakers. Indeed, these innovative instruments may facilitate the access to and the provision of care, contribute to the empowerment of patients, reduce hospital stays, emergency and doctors visits, improve communication and cooperation between the patients and the healthcare professionals, ensure constant monitoring of the disease and continuity of care, and stimulate better compliance and adherence to treatments.

These innovations will be facilitated by an increase of EU spending in the field of research and technological developments, a topic that will be treated in the following section. However, to guarantee an optimal use of innovative solutions by the public (patients, informal/family carers and all healthcare professionals, from nurses to specialists), it is necessary to develop training/coaching programmes for patients in their use, as well as to raise awareness of their availability and benefits. In addition, users should always be involved in the design of these e-health solutions so to ensure that the final outcomes correspond with their needs and expectations and, as a consequence, are constantly used and implemented.[51]

The newly proposed third EU public health programme as well as several other EU-funded projects, such as the Renewing Health (Regions of Europe working together for Health) and the before mentioned EIP, underline the importance of these new technologies in the management of chronic diseases, including COPD.[52] In particular, the Renewing Health project is interesting for EFA as it focuses on the treatment of chronic patients suffering from diabetes, cardiovascular and COPD. The use of innovative solutions in the treatment of COPD may provide timely and qualified input for decision-making to patients, increasing their quality of life, reduce their need to go to hospitals and specialists, and enhance communication with their healthcare professionals to improve their health literacy and subsequently empowerment.

The 7th Framework Programme for research and technological development (FP 7) programme and Innovative Medicines Initiative (IMI, Europe's largest public-private partnership between the European

[51] EPF led a two-year project (2008-2010) financed under the Second Public Health Programme, *Value+ Promoting Patients' Involvement in EU supported health-related Projects*, available at: http://www.eu-patient.eu/Initatives-Policy/Projects/EPF-led-EU-Projects/ValuePlus/.
With this project, EPF and its associated partners (EFA was one of these) aimed at increasing patients' involvement, therefore contributing more effectively to policy towards patient-centeredness and equitable healthcare throughout the EU.
[52] European Commission, *op. cit.*, note 42.
See the website at: http://www.renewinghealth.eu/.
EIP Steering Group, *op. cit.*, note 18.

Commission and the European Federation of Pharmaceutical Industries and Associations – EFPIA) are indirectly supporting innovation in treatment and potential for prevention in allergy, asthma and COPD, through for instance U-BIOPRED, MeDALL and AirPROM projects, where EFA is an active partner.[53] No cure exists for allergy, asthma and COPD; in the cases of allergy and asthma, there are no truly effective primary preventive methods, and in especially severe cases, current treatments do not work. Therefore, striking a balance between supporting innovation and creating the necessary conditions for it based upon real needs is fundamental – but not with the expense of cutting back in care and prevention while, most importantly, incorporating patient perspective.

11. In which areas is there a particular need for additional action at the EU level?
12. In which areas is there a particular need for additional action at the national level?
13. What will you/your organisation do to contribute to address this challenge?

EFA shares best practices collected by its members and tries to implement them in other MSs through EU funded projects and/or EFA projects, as we are currently doing through our respiratory allergy and COPD projects. As the management of chronic disease is inevitably linked to its prevention and early diagnosis on one hand and rehabilitation on the other, bearing in mind the issues dealt with in the previous section, EFA recalls the need for an EU-wide strategy on chronic diseases focused on prevention, rehabilitation and management. In addition, EFA believes there is a need for the establishment of an EU forum/platform to share best practices in our disease areas. These programmes/action plans have already been adopted in the case of other diseases (Alzheimer, diabetes, cancer and rare diseases). Such a forum could be composed of MSs representatives, EU officials and all interested stakeholders concerned at the EU and/or national levels. *Inter alia*, it could provide with updated information on the management, challenges, successes and prevalence of allergies and respiratory diseases in the EU, therefore allowing the EU policies in the field or affecting these diseases to be evidence-based.

Research

14. How should research priorities change to better meet the challenges of chronic disease?
15. In which areas is there a particular need for additional action at the EU level?
16. In which areas is there a particular need for additional action at the national level?
17. What will you/your organisation do to contribute to address this challenge?

As previously highlighted, an increase in EU research funding should be dedicated to find innovative ways of integrated chronic diseases care, such as the afore-mentioned e-health and telemedicine.

Concerning EFA's areas of expertise, more research needs to be undertaken to prevent the risk of future exacerbations in the case of **COPD** patients. Studies on how to increase the cooperation within multidisciplinary, multilingual and multicultural teams are necessary to guarantee an optimal sharing of best practices among the different EU MSs. Enhanced biomedical research is also essential as only few pharmacological treatments are currently available for COPD patients. EFA supports research projects

[53] See the websites of the projects: http://www.ubiopred.european-lung-foundation.org/, http://www.airprom.european-lung-foundation.org/, http://medall-fp7.eu/.

on lung stem cells, phenotypes, emphysema markers, alpha 1 anti-tripsine markers. At the same time, it needs to be emphasised that the proper effectiveness of these new drugs should be tested in the real-life environment. Hence, real-life studies should complement the randomised controlled trials so to assess the efficacy of COPD care in realistic situations, for example when patients present co-morbidities. Finally, research of these co-morbidities, and especially on depression, is key as a surprisingly high percentage (40% according to a US study) of COPD patients suffers from depression and this further worsens their quality of life and that of their family. To this extent, the positive impact of patient self-help groups is under-researched and under-estimated.[54] With regards to co-morbidities, EFA agrees with IPCRG that emphasises the positive holistic role played by primary care professionals and calls for a shift in the industry approach. Indeed, industry seems to be excessively single disease-focused, yet patients that suffer from a chronic condition generally have other co-morbidities that need to be treated as well.

COPD is often seen as self inflicted disease and therefore any activity to improve the situation for people with COPD may be seen as less desirable; however, it is COPD in particular which creates high costs. Therefore, EFA suggests researching the influence of COPD based upon the belief of the disease as self-inflicted and whether or not this perception influences the performance of patients with respect to dedicated costs. Such research may check if COPD would reduce costs and people with COPD would have better a quality of life in the absence of such a self image.

In the case of **allergies** and **asthma**, EFA underlines the need to better understand the epidemiology of these common diseases in Europe through national studies based on the severity of the disease and its control management. Only when we know the causes of asthma and allergies, will we be able to put in place effective measures to prevent these diseases from increasing and to reduce their societal costs. In addition, EFA would welcome EU-wide research on how the increased prevalence of respiratory diseases and their tendency to progress from mild to severe conditions will affect EU and national health systems.[55]

The need for increased investments and research is reinforced by the analysis the WHO made in preparation for the afore-mentioned UN high-level meeting on NCDs. In particular, a set of evidence-based best buy interventions to prevent and control these diseases was identified. This best buy concept does not relate exclusively to economic efficiency and cost-effectiveness, but it refers to actions that have to be at the same feasible, low-cost and appropriate to implement within the constraints of the local health system. Unfortunately, very few best buy interventions are directly or indirectly linked to respiratory diseases and this is due to the lack of evidence.[56]

In conclusion, and more generally, EFA calls on the European Commission to increase the funding available for tackling chronic diseases in all the possible financial instruments at its disposal. An indicative budget of 1.4 million EUR was allocated to prevent chronic diseases under the Work Plan (WP) 2012 to implement the second health programme. In a similar way, tackling chronic diseases with a high impact on the quality of life was one of the key priorities of the WP 2012 to implement the 7th

[54] EFA, *op. cit.*, note 48.
[55] Erkka Valovirta, *op. cit.*, note 6.
[56] List of best buy interventions available at: http://www.who.int/nmh/events/2012/discussion_paper1.pdf.

Framework Programme and 12 million EUR were dedicated to it. These figures are interesting but not totally satisfying as the European Respiratory Roadmap estimates that only 261 million EUR among the overall 6 billion EUR FP 7 budget devoted to health matters (4.3% of the total) are allocated for respiratory research. In addition, only 0.5% of the total FP 7 health budget was devoted to COPD and asthma.[57] These figures disproportionate to the impact these specific diseases have on the economic burden created by them.

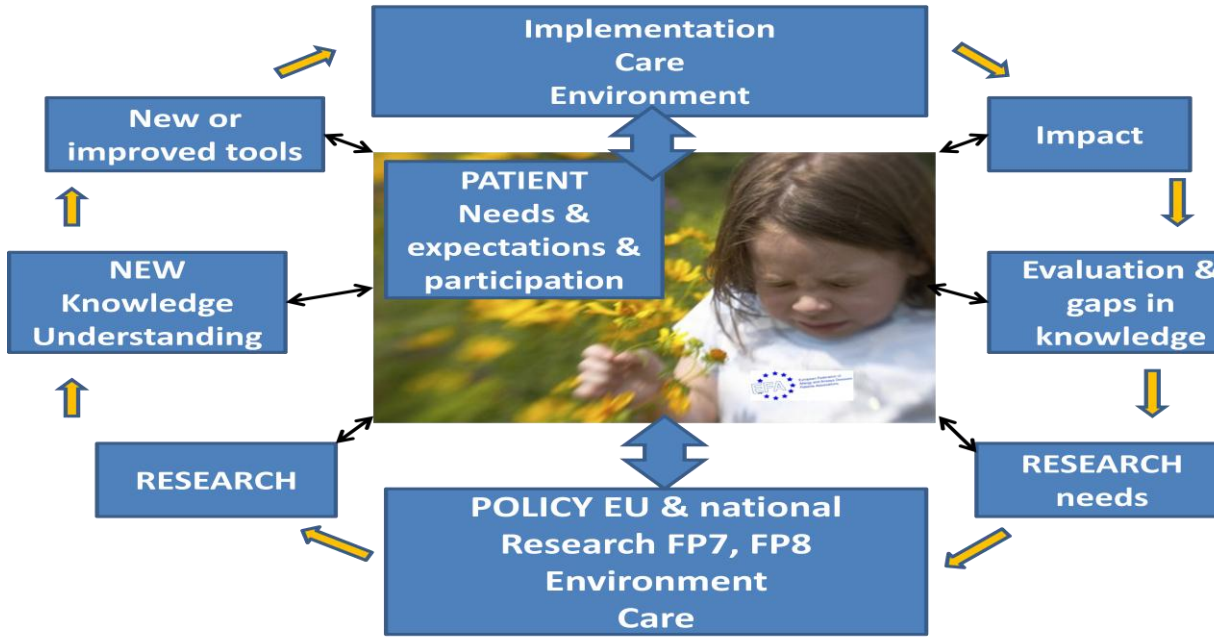

Figure 3 – Allergy and airways diseases and the EU research policy

Information and information technology

18. What more needs to be done on the development of information and data on chronic disease?
19. In which areas is there a particular need for additional action at the EU level?

With regards to information, EFA deems it necessary that up-to-date and comparable statistics at the EU and national level are made available to all interested stakeholders to study and monitor the incidence of chronic diseases, their risk factors and their consequences on the quality of life of affected people.

All information data on chronic disease must be collected through health channel, registries and other sources, and reviewed identifying the needs of population. It needs to be clear that only information posted by health authorities, scientific medical associations or patients organisations and their scientific committees are reliable. In addition, and especially for patients' organisations, the most important way to provide information is the website. Therefore, redesigning the web in a comprehensive and accessible way and appropriate language will help people to find information that properly match their

[57] ERS, *The European Respiratory Roadmap*, September 2011, available at: http://www.ersroadmap.org/healthcare-professionals/introduction-policy-makers/item/healthcare-professionals.html.

needs. Discussions should draw the attention of people, pushing them not only to read, but also to share them.

Regarding the information technology facet, a complimentary role is played by innovative technologies. As previously emphasised, their development may lead to better quality of life for patients due to better/easier monitoring, enhanced cooperation and communication with healthcare professionals as well as to economic benefits for the healthcare systems. Concerning the management of chronic diseases, a report of the EU Swedish Presidency particularly focused upon the opportunities for a better use of healthcare resources showed that "over 11,000 diabetic deaths could be avoided every year…by educating the patients and enabling them to better manage their condition through the use of…Chronic Disease Management."[58]

If nearly one in every two citizens has predisposition for an allergy soon in Europe, public lay information is needed to inform the population about symptoms to have a better chance for early diagnosis. Regarding COPD, due to the costs and burden for society, as well as the fact that soon every third death will be related to COPD, EFA sees a clear need for lay information to be made available for the public about symptoms. This is necessary to inform the symptoms are often not a sign of ageing but rather the need for a proper diagnosis and encourage visits to physicians.

Roles of MSs, the EU and stakeholders and others

20. What additional activities on chronic diseases beyond the four areas described should be considered at the EU level?
21. How can the EU engage stakeholders more effectively in addressing chronic diseases?
22. How can EU MSs engage stakeholders more effectively in addressing chronic diseases?
23. What additional areas for action should be considered? Which of these should be addressed by activities within EU MSs? Which should be addressed through activities involving cooperation at EU level?

As previously mentioned, EFA would welcome an EU strategy on chronic diseases stemming from the common EU concern for their wide breadth which tries to find practical solutions to improve the quality of life of affected patients and their families while limiting the economic burden on societies of the diseases. Such an action should be based on the HIAP approach and take into consideration the links between health and other EU relevant policies, such as single market and harmonisation, environment, research, regional, cohesion and agricultural policies, energy as well a justice and home affairs. Patient-centred EU guidance on the prevention and management of chronic diseases should be drafted taking into account the best practices at the MSs level, including the practices previously described in allergy, asthma and COPD, and EU funded projects, should be dedicated to make this possible.

When deciding their national measures, MSs should allow the participation of all health-related stakeholders, including patients, to ensure a high level of protection of human health and measures that are coordinated and workable. At the EU level, constructive participation in relevant policy formulation

[58] Swedish Presidency of the EU, *e-Health for a Healthier Europe! – Opportunities for a better use of healthcare resources*, 2009, available at: http://www.calliope-network.eu/LinkClick.aspx?fileticket=Tmkyr%2FQNsaU%3D&tabid=277&mid=633.

should be guaranteed to, *inter alia*, patients' organisations, older persons' groups, health professionals' representatives, and environmental groups. This broad participation, however, should be limited through similar provisions to article 5.3 of the already mentioned FCTC. The Convention states "in setting and implementing their public health policies with respect to tobacco control, Parties shall act to protect these policies from commercial and other vested interests of the tobacco industry in accordance with national law."[59] Therefore, in the case of tobacco control policy formulation, the European Commission and the MSs should follow the provision of this highly political document and avoid listening to the tobacco industry.

In conclusion, stakeholders such as patients associations may help chronic diseases reach the top of the political agenda of the EU institutions and policy makers. The real value of patients associations is to provide help to people, and to be a reference point for everyone concerned.

Conclusions

EFA would like to thank the European Commission for having given the possibility to all interested stakeholders of expressing their point of view on this crucial concern for the health of Europeans. EFA´s comments are given with the aim that this reflection process will open the door to an EU strategy on chronic diseases which will tackle their incidence, the determining risk factors, the negative consequences for the health of affected people, their families and the economies of the EU and MSs.

This strategy should contain the strengths presented and include disease specific best practices and national programmes, such as the Finnish allergy, asthma and COPD programmes and the Danish COPD prevention programme. In elaborating this approach, the European Commission and the MSs should take into account the perspective of all relevant stakeholders, and especially of patients' groups and primary care organisations.

[59] WHO, *op. cit.*, note 28.

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