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Public Health

**Health determinants**

*SUMMARY*

*STAKEHOLDER CONTRIBUTIONS*

*TO THE CHRONIC DISEASES REFLECTION PROCESS*

*March – May 2012*

**6 June 2012**

In the framework of the chronic disease reflection process, and as a follow-up to the consultation of a variety of stakeholders represented in the Health Policy Forum [http://ec.europa.eu/health/interest\\_groups/docs/euhpf\\_answer\\_consultation\\_jan2012\\_en.pdf](http://ec.europa.eu/health/interest_groups/docs/euhpf_answer_consultation_jan2012_en.pdf) a targeted consultation of stakeholders was launched in March 2012 based on a questionnaire. In addition to specific invitations to a range of organisations, the questionnaire was posted on SANCO's website from 15 March onwards, and responses were received until May 2012.

Stakeholders and interested parties were invited to respond to the questions in order to provide input on areas of interest and the potential need for EU-level action in the field of chronic diseases.

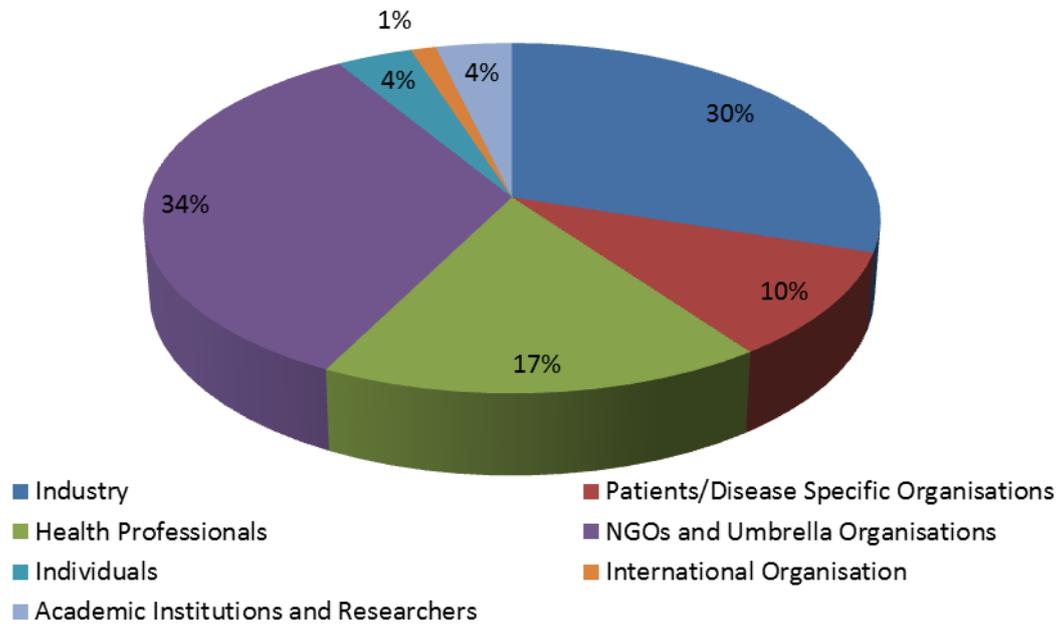
This paper summarises the responses received by 77 different stakeholders, patient organisations, industry and 3 private persons.

A complementary assessment of the responses received is carried out by an external contractor and should be ready for the SLWP on health meeting in September 2012. In the report of the external contractor an analysis of the contributions will be carried out with emphasis on the prioritization of actions, which are evidence based and seen as necessary to be carried out. This does include proposing policy options for decision making as a further input to the reflection process.

### **Contributors**

A full list of the contributions received is attached (ANNEX 1). Of the 80 contributions, 22,5% were received with considerable delay. The contributors can be attributed into the following categories: General public health NGOs and umbrella organisations (27/34%), industry (24/30%), health professionals (14/17%), patients and disease-specific organisations (8/10%) and academic institutions and researchers (3/4%). In addition, there were three individual submissions and one from an international organisation (WHO). Graph 1 presents all the categories by percentage (%) contribution.

**Graph 1: Categorization per representative society**



## **CHRONIC DISEASE - STAKEHOLDER CONSULTATION - QUESTIONS**

### **Question 1:**

What further information and evidence should be taken into account by National Governments and the EU regarding the chronic disease situation?

#### **A) Health promotion and disease prevention: what more should be done?**

A1: What additional actions and developments are needed to address key risk factors to prevent chronic diseases?

A2: How can existing actions on primary prevention be better focussed and more effective?

A3: What potential is there for broad based early detection action?

A4: In what areas is there a particular need for additional action at EU level?

A5: In what areas is there a particular need for action at national level?

#### **B) Healthcare**

B1: What changes could be made to enable health care systems to respond better to the challenges of prevention, treatment and care of chronic diseases?

B2 : What changes could be important to better address the chronic diseases 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 ?

B3: How much emphasis should be given to further developments of innovations, including e-health and telemedicine in prevention and treatment of chronic diseases such as remote monitoring, clinical decision support, e-health platforms and electronic health records?

B4: In what areas is there a particular need for additional action EU level?

B5: In what areas is there a particular need for additional action at national level?

B6: What will your organisation contribute to this challenge?

#### **C) Research**

C1: How should research priorities change to better meet the challenge of chronic diseases?

C2: In what areas is there a particular need for additional action at EU level?

C3: In what areas is there a particular need for additional action at national level?

C4: What will your organisation contribute to address this challenge?

#### **D) Information and information technology**

D1: What more needs to be done on the development of information and data on chronic diseases?

#### **E) Role of Member States, the EU and stakeholders**

E1: What are additional activities on chronic disease beyond the four areas described above should be considered at EU level?

E2: How can the EU engage stakeholders more effectively in addressing chronic diseases?

E3: How can the EU Member States engage stakeholders more effectively in addressing chronic diseases?

#### **F) Other areas**

F1: What additional areas for action should be considered? Which of these should be addressed by activities within the EU Member States? Which should be addressed through activities involving cooperation at EU level? 12

**Question 1: What further information and evidence should be taken into account by National Governments and the EU regarding the chronic disease situation?**

*Chronic diseases are preventable but prevention programs needs to be better informed to be better targeted*

- In order to understand the dimension of the problem and the burden of chronic diseases longitudinal data for Europe would be necessary; this would also allow modelling future scenarios in terms of prevalence and budget so that priorities can be set accordingly (MSD)
- Early detection of relevant risk factors for chronic diseases should be based on scientific evidence (CPME)
- Prevention should be strengthen by applying the principles of health in all policies (CPME)

*The success of prevention and treatment programs depends on a targeted approach*

- Detailed data on chronic diseases is often scarce and fragmented. The prevalence and incidence of chronic diseases may differ, depending on age, social status or education. These differences should be captured by data (MSD)
- The success of prevention and treatment programs depends on a targeted approach. Therefore, the data should be stratified for age groups, social and educational status. Member States and the EU should adopt a comprehensive and integrated approach towards tackling chronic disease, evidence-based and target oriented (AESGP, MSD)
- Information on chronic disease prevalence, incidence, impact on patients (severity, quality of life, disability, dependence, relationships), needs of care, impact on families and caregivers, social and economic impact (burden of disease, social stress, productivity loses, prosperity reduction) varies according to age, social status, and other criteria. This type of information is therefore heterogeneous, fragmented and not standardized. For this reason, data collection on chronic diseases should be improved in these terms (MSD)

- Prevention should be promoted along with a healthy lifestyle (AESGP)

***A more systemic and comprehensive approach is required if a reliable picture on chronic diseases in Europe is to be obtained*** (EGS, PHAE EUROPA, Cancer research UK, CHA, CPME, WHO Europe)

- The environment in which the diseases manifest must be taken into account (evidence and information on a number of factors such as differences in health care systems, urbanization, demographic shifts, sedentary lifestyles and the liberalization of markets should be considered) (EGS)
- A multi-sectoral response, with commitment from world decision makers, support from the global civil society movement and those affected by or living with these conditions; and involvement the business sector, where appropriate are absolutely necessary (Cancer research UK)
- Chronic illness requires complex models of care, involving collaboration among professions and institutions that have traditionally been separate (CHA)
- Both the EU and National Governments need to further extend and structure dialogue across different sectors and with multiple stakeholders need to be further expanded to tackle demographic challenges from multiple approaches, within the immediate environment of the individual: workplace, social and care settings (CPME)
- An holistic approach to the management of chronic conditions should be adopted upholding that all aspects of people needs, preferences and values - psychological, physical and socio-economic - should be taken into account and seen as a whole. The crucial role and contribution of patient organisations and the importance of psychosocial support should be addressed (PHAE Europe)

***Importance of co-morbidity*** (MDS, EGS, EULAR, Uni\_Zaragossa, ELPA, IDF)

- An information gap exists with data on co-morbidity (or MCC, multiple chronic conditions) in Europe (MDS)

- The link between physical and mental diseases would need further analysis (MDS)
- There are no clinical guidelines to address co-morbidity effectively in spite of knowing that it may deeply affect the outcomes of treatment (MDS)
- Collect evidence and more information on the epidemiology of co-morbidities of chronic diseases with chronic infectious diseases on the light of the effects of drug interactions (EGS)
- The importance of obesity as a chief underlying risk factor of multimorbidity, and its effects from early ages (Uni\_Zaragossa)

***Lack of evidence of the economic impact of NCDs*** (MSD, AESGP, CPME, ECDA, EFPIA, EULAR, GSK, ELPA)

- Economic analysis of the impact of chronic diseases should be broad enough so that the full societal impact can be measured. In particular, indirect costs (loss of productivity, impact on relatives etc.) should be taken into account (MSD, AESGP, CPME, ECDA)
- Many chronic conditions affect the ability of an individual to work or return to work. This not only has adverse impacts on a person's health and wellbeing, but also contributes to a greater socio-economic burden (EFPIA)
- consolidation of evidence of predictable medical outcomes, assessment of long-term precise results for those with chronic illnesses while improving quality of public spending (GSK)

***Together tobacco use, poor diet, low physical activity and harmful alcohol consumption are the major risk factors for chronic diseases.***

- In addition, there are many other risk factors including environmental pollution; certain infections; hazards in the home, leisure and work environment, and psychological stress. Socio-economic factors and the quality of living and working

conditions are health determinants that also play an important role (AIM, CPME, EFA)

- Add physical inactivity as one of the risk factors of major chronic diseases (ESC, NCTDFF)
- The population should be more aware of the risk factors and of the impact of the environment on the development of chronic diseases as well of the importance of an early detection (AIM)
- Exposure to indoor air pollutants and other environmental aspects should be included as risk factors (Camfil Farr, EPHA, INCHIS)
- Malnutrition should be considered a risk factor (MNI)
- Bad oral health should be considered a risk factor (Oral\_health)

***More attention should be paid to chronic rare and ultra-rare diseases*** (Alexion, IPOPI, PHAE EUROPA)

-The European Union should ensure that patients with rare and ultra-rare diseases are not discriminated on the basis of the rarity of their condition and have access to the necessary treatment through the policies and legislation that the EU institutions are or will be developing (Alexion)

***The definition of chronic diseases provided in the Commission's consultation paper is too narrow and should be expanded***

- Chronic diseases are non-communicable diseases of long duration and generally low progression. Some can be prevented and treated while others are unpreventable and irreversible in spite of available treatments that only delay the onset of the disease". (Alzheimer Europe)

- Include chronic conditions associated with mental health ‘ordinary’ chronic diseases such as cardiovascular diseases, diabetes etc. can be more difficult to manage when there is multi-chronicity with chronic neurological conditions (EGS)
- Unpreventable chronic diseases such as neurodegenerative diseases, and Alzheimer’s disease and other forms of dementia should be included (Alzheimer Europe, European Brain Council)
- The fact that some chronic diseases like Alzheimer’s disease and other forms of dementia do not yet benefit from clear preventative measures or any treatment should be acknowledged. (Alzheimer Europe)
- European population is ageing and an increase in chronic age-related diseases will follow this trend should be taken into account (Alzheimer Europe)
- Please mention also that for some chronic diseases, there is a certain genetic predisposition and that suffering from a chronic disease is not always preventable (Reumanet)
- Many chronic diseases are indeed preventable, the impression is created that the reflection process pays less attention to chronic conditions which are not caused by environmental or life-style factors (e.g. neurological) (e.g. congenital heart disease, Parkinson’s Disease, Alzheimer’s Disease) (EUGMS)
- Many mental health problems (e.g. depression which is forecast to be the second main cause of disability and premature death after heart disease in developed countries) can also be seen (and certainly experienced) as chronic conditions (EUGMS)

*It would be useful if the chronic conditions reflection were to set some boundaries around the vast area of chronic disease and focus on those conditions that have a prevalence of over 5% (SCA)*

- A list of these conditions could be compiled which would then help to prioritize and group these in clusters, which will support the development of specific actions to address these. The importance of secondary and tertiary prevention should be underlined (PHAE Europe)
- Awareness campaigns and patient empowerment (CPME, EFA, Roche, WHO Europe, Reumanet)
- To facilitate healthy choices in life for all citizens (CPME)
- To establish health promotion communication messages and interventions for all chronic diseases (CPME)
- To integrate health into education programmes (CPME)
- Better informed patients have increased access to healthcare and especially higher quality of the care itself (EFA)
- Launch broad and structured media campaigns (e.g. in Tabloids, TV and Internet) on prevention of chronic diseases and healthy lifestyles to “empower” patients and ensure their health literacy (Roche)
- Individuals need easy access to information which is understandable in terms of the context it is delivered in (e.g., internet, clinics) understandable in terms of content (Roche)
- Empower patients to do as much as possible for themselves, with appropriate access and support from a variety of relevant providers including pharmacists, nurses, home care workers, general practitioners and specialists (Roche)

- Integrate peer education actions in prevention (Reumanet)

*Need of European data and improved cooperation at European level* (ECDA, EGS, EPPOSI, EULAR, GSK, IOA, IOF)

- Expanding the mandate of the European Centre for Disease Prevention and Control (ECDC) to include the monitoring and surveillance of major NCDs (ECDA)
- Comparable data at EU level on incidence, prevalence, risk factors and outcomes, is urgently needed. EU registries are clearly missing (ECDA, EGS)
- Comprehensive reviews of the epidemiology of chronic diseases to provide reliable and context specific evidence for policy (EGS)
- Lacking common European guidelines, references or data on the quality of current management of chronic conditions in Europe is the main obstacle to supporting changes in the present medical and financial care models and to tackling more effectively the growing burden of chronic disease (EPPOSI)
- There is an urgent need to promote the adoption of common health data standards collected across Europe by different stakeholders, whether health institutions, health care organisations, public health entities, health professionals or health care industry (ECDA)
- Cooperation with WHO in view of the Action Plan for a strategy on NCD and OECD and medical/scientific societies should be strengthened ( ECDA)
- Review and standardise the definitions of “good health” and “disability” across the Member States as there may be differences in perception (EGS)
- Relying on death rates alone masks the true extent of chronic diseases as it does not take into account diseases that although do not themselves cause mortality, they are responsible for reduction in the quality of life as the case of chronic diseases of the eye (EGS, EULAR)

- Knowledge sharing, knowledge building and a learning community should be an integral component to the concept of disease management (GSK)

*The prevention of chronic diseases is a long-term commitment and needs to begin before birth* (EFCNI)

*The influence of socio-economic inequalities and health inequalities needs to be addressed* (EFA, WHO Europe, EUGMS)

*Pain should be included as an essential part of the policy making on chronic diseases and to consider pain as a health state to be treated as a chronic disease in its own right.* (EFIC PAE, GRUNENTHAL)

Patients should be at the heart of healthcare systems and all necessary and effective measures should be taken in order to increase patients' quality of life (EFPIA)

*Information and evidence about migrants, Roma and ethnic minorities other mobile, marginalized or hard-to reach populations is a significant gap* (IOM)

## **A) HEALTH PROMOTION & DISEASE PREVENTION**

### **1) What additional actions and developments are needed to address key risk factors to prevent chronic diseases?**

#### *Risk factors*

- Include environmental pollution; specific infections; hazards in the home, leisure and work environment, and psychological stress as risk factors. Socio-economic factors (like migration) and the quality of living and working conditions also play an important role (WECEF, Uni\_Zaragossa, AESGP, European Brain Council, HEAL, IDF, EULAR, IOM). The prevention of chronic diseases also requires paying attention to two other types of genetic/biological risk factors (EULAR)

- Malnutrition in the form of undernutrition should be included in risk factors for developing chronic conditions (ILCUK)
- Overweight and obesity solutions must be part of the preventive strategy (Weight Watchers, EASL, MNI)
- The tobacco story can be taken as a model to underline the necessity of primary prevention in the decrease of certain health conditions linked to a specific/well identified risk factor (WECEP)
- A strong new Tobacco Products Directive will be absolutely fundamental to have a real impact in the tobacco control process, which integrates the prevention of chronic diseases (ENSP)
- More attention must be paid to the long-term health risks associated with alcohol consumption (Cancer Research UK)
- Many chronic diseases and oral conditions share common risk factors and are united by a complex pattern of inter-relationships. Public health measures used to address one are very likely to benefit the control of others (Association of basic science teacher in dentistry)

### *Ways to act*

- Promotion and prevention programmes addressing chronic diseases need to be made gender, age, social-sensitive (EPF, CHA, Lovexair, EGS)
- The community approach should be followed. In this approach, a community at regional level is defined and characterized. By characterizing the community, health problems which play a role in the specific community can be identified. Based on the characteristics of the community, interventions and preventive actions can be developed (EFPC)

- The actions need to pay due consideration to the specific nature of neurodegenerative diseases (Alzheimer Europe)
- The health in all policy approach to address chronic disease and comorbidity risk factors that extend from behavioural risk factors to socio-economic and environmental related factors should be promoted (CPME, EBC, ELPA)

Empowerment and involvement of patients as a key action to address risk factors (MSD):

- Personal Connected Health and Tele-health Opportunity should be promoted to empower patients (CHA)
  - Personalised care plans and educational content for each individual based on their needs, preferences, data, and capabilities (CHA)
  - Active participation of patients in management of their health and wellness should be encouraged and facilitated also through care provider education (CHA, European Brain Council, GSK)
  - The levels of awareness in the population need to be increased with information which is understandable in terms of the context (AIM, EFPIA, EULAR)
  - Launch of structured media/ social media campaigns on prevention of chronic diseases and healthy lifestyles to “empower” patients (EFPIA)
- An holistic approach is to be undertaken to provide the best care for the patient, including having access to patient health records (EFPIA)
  - Integrated regulatory and policy approach are needed to promote behavioural change and assist individuals with proven effective treatments to address effectively and efficiently major risk factors for chronic disease (AESGP, EASL)
  - Key risk factors need to be addressed with the support of evidence-based policies and legislation in key areas (Cancer Research UK, CEFS)

### *What is needed*

- Comparable data on incidence, prevalence, risk factors and outcomes is very much needed at EU level in order to enable a better understanding of the direct and indirect costs of chronic disease and the savings that could be made by ensuring policy measures are in place to encourage healthy lifestyles (EASL, EPPOSI)
- Select new indicators (such as Demographic indicators, Healthcare facilities and human resources, Socio-economic and human costs of chronic disease) in addition to the average EU mortality rates, the number of people suffering from chronic diseases, the number of years spent in good health or with long-term disabilities to provide the more complex picture of chronic disease situation in Europe (Epposi's CCM)
- Quantitative analysis of the cost effectiveness and health gains of health promotion and prevention (EBC, EPPOSI)
- Educational programmes for patients and carers on different aspects. A better training of health professionals on environmental risk factors is necessary (WECF, EDA, EULAR, COCIR)
- Pre-conceptional and maternal care, treatment and care of newborns, as well as aftercare services and follow up, with a view to address risk factors to prevent chronic conditions from the beginning (EFCNI)
- Chronic pain should be included as important factor in policy making (EFIC, EFIP)
- Establishment of a network of chronic disease healthcare professionals who regularly visit schools in order to identify children at risk of chronic diseases (EFPIA)
- Provision of incentives (penalties could also be considered) for citizens to undertake regular health checks (EFPIA)

- EU Coordination efforts on raising awareness about the harmful effects of alcohol consumption (Eurocare)
- Attention to epidemiologic parameters of allergic diseases (GALEN)
- Attention to incontinence (SCA)
- Addressing the social impact of many chronic diseases and how it influences the course of illness and results in an increase in the burden of illness and health disparity (ILAE)
- Attention to neurological disorders and rare diseases (IPOPI, Alzheimer Europe, European Brain Council)

To address key factors diagnosis and therapy protocols should be seen as a priority (IPOPI)

**2) How can existing actions on primary prevention be better focussed and become more effective?**

- Consistent, cost-efficient and high quality health policies in Europe should focus on prevention at all levels, not only addressing common risk factors but encompassing primary, secondary and tertiary prevention interventions (Oral\_health, COCIR, CPME, EFA, EFPIA, EUGMS, EPF, EFCNI)
- Prevention must also encompass actions on better quality of air, take into considerations gender, age, social conditions and co-morbidities aspects of the disease and be part of a holistic approach of disease assessment that shifts away from single-organ and single occurrence event (ECC, WECF). Create different programs for different socio economic groups and ages and develop resource allocation plan according to risk calculations which can be very different country to country (Lovexair, MSD, ROCHE, Uni\_Zaragossa)
- Integrated management and strengthening of the prevention of chronic diseases has become urgent. Prevention of chronic diseases in general implies a comprehensive,

consistent, multi-sectoral approach, including all policy areas, not only in the fields of health and research, but also those of agriculture, taxation, sports and (PRIVATE\_KV, ESC, Alzheimer Europe, CPME, EFPC, EFPIA)

- Support and facilitate the development of early prevention and community-based programmes (Nestle)
- It is important to engage and support all stakeholders, including representatives of people with unpreventable and untreatable chronic diseases (Alzheimer Europe)

Different additional preventive actions can be considered.

- healthier food to all Europeans (EFPC)
  - physical exercise (EFPC, IDF)
  - adapt workplace settings with conditions and ergonomics that are conscious of promoting workplace health and wellbeing (EFPC)
  - Health promotion including health literacy should be coupled with management of existing long-term conditions (FFW, IDF)
  - Reducing exposure to key risk factors and facilitating improved and healthy lifestyle choices and the surrounding physical environment (IDF, EFPC)
  - Strengthening and integration of a health education program at school.
  - Broadcasting on tv and via internet media (social networks; facebook type ...) to address the general population (IOA, IOF, EFA, EULAR, Uni\_Zaragossa), tailored on the specific risk or age groups you want to reach (ELPA, Oral\_health)
- 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 (EPF)
  - Primary prevention actions can be better focused and more effective if they were complemented by easily accessible behavioural modification (WW)
  - An effective exchange of good and best practices between EU Member States on successful measures of primary prevention would be both a gain of time and resources (WECEF)

- A further reduction of inequalities and stigmatization, strengthening actions taken under the current national health and environment action plans based on EU Strategy SCALE and its Action Plan (WECF, EBC)
- Prevention interventions must be evidence-based, with a clear view on cost/effectiveness (AIM, GSK)
- A new prevention model (medical) adapted for each lifetime period has to be established with financial incentives for patients and health care providers (AIM)
- Existing initiatives (such as the EU platform for action on diet, physical activity and health; the EU Alcohol and Health Forum; policies and incentives on tobacco control) must be pursued and rolled out on a large scale (Alzheimer Europe)
- Additional consideration for the discussion on healthcare for irregular migrants (CPME)
- Active and effective surveillance system to monitor the prevalence of alcohol-related liver disease and mortality (EASL)
- A radical shift of priority so that the emphasis is on prevention rather than only on cure of acute situations, to prevent the onset of diseases of tomorrow, rather than treat the conditions of today is recommended (ECC)
- Prevention of chronic pain should be coordinated across the entire spectrum of NCDs, i.e. into a concerted Pain Treatment Plan. This will significantly reduce the societal impact of pain by bringing the knowledge of how to treat chronic pain directly to the sufferers (EFIC)
- The existing measures should be accompanied by measures that would incentivise positive choices by creating the conditions, environments in which people want to make choices for their own benefit and healthy choices are the easy choices (Eurocare, ECC, Roche)

- EU patient groups should be made more aware of the role that nutrition plays in the prevention and/or treatment of diseases (ILCUK)
- Special attention to migrant population (IOM)
- Maternal and newborn care must be recognised as an important priority in healthcare policy and clinical practice at both the EU and national levels, in order to ensure a healthy start in life for Europe's babies; this is an essential precondition for healthy and active living and ageing (EFCNI)
- The ageing population and the expected increase in prevalence of chronic diseases will entail a necessary shift towards a preventive approach, with focus on promoting health and an increased role of citizens in managing their health (GSK)
- Make Public-Private Partnerships an inherent part of public policy on chronic diseases (Nestle)
- EU-wide/national specialists and patient organisations must be included in the planning of prevention and early detection measures. Specialists and patient representatives for diabetes-related comorbidities, like cardiovascular diseases, should be involved as well (Roche)
- Educating the population from childhood on important health determinants (i.e. nutrition and exercise) and coordinating health and education strategies

### **3) What potential is there for broad based early detection action?**

- Early detection requires greater international cooperation, collaboration, implementation of effective, population-based, quality assured screening programmes, evaluation of social inequalities and development of novel tools to detect chronic disease in at-risk populations are all measures that should be encouraged. Age ranges for screening should be regularly updated on the basis of new scientific data. Set of common indicators and definitions would ensure comparable data across the EU and

facilitate better informed health policy for the future (COCIR, ECDA, EFPIA, ERS, Eurocare, GALEN, GSK, PPTA, SFP, J&J, EFPC).

- High risk groups may be identified through a simple questionnaire to assess risk factors such as age, smoking habits, waist circumference, family history, cardiovascular history and gestational history. Simple screening tool adapted to the primary care setting that would detect diseases in early stages would reduce the number of patient referrals. (COCIR, CPME, ERS)
- Good health starts at a young age (beginning of life) and prevention policies and methods must be adapted to life stages. Thus, secondary and tertiary prevention characterised by early diagnosis and early intervention will also greatly contribute to reducing the burden of COPD (ECC, EFCNI, ERS)
- Take into account genetic and hereditary factors that can be detected in the early years of life and can lead to better management of diseases and disorders throughout life (PPTA)
- One should be careful not to interpret “early detection action” as measures focusing on detecting genetic susceptibility to certain diseases. Preventable (such as environmental exposures, behavioural and lifestyle), rather than non preventable risk factors should be addressed under “early detection action” (WECF)
- The sooner obesity is identified the better, since it is a chief determinant of multimorbidity (Uni\_Zaragossa)
- Early detection of any kind of chronic disease, comprehending also dementia and in the area of brain diseases is cost-effective both for health and social care services and for persons with dementia. (Alzheimer Europe European brain council, EULAR)
- Authorities must ensure that existing actions, such as reformulation activities, are correctly tailored to achieve a reduction of the calorie content of products (CEFS)

- In this regard, there is a need to further develop quantitative analysis of the cost effectiveness and health benefits of prevention and early detection (COCIR)
- There are several tools available to detect incipient chronicity of pain already at its beginning, and other tools screen for the presence of a neuropathic pain component that is particularly difficult to treat. These patients can then receive multimodal pain therapy programmes that have proven to be efficacious, including various back to work programmes (EFIC)
- In the area of liver disease huge benefits could be generated, if broad based early detection were in place. This means, if the population knew more about the disease, as well as about the key risk factors including viral hepatitis B and C, and if existing liver patients were to be diagnosed and treated earlier (ELPA)
- Preventing malnutrition in the form of under-nutrition is essential. Routine screening for under-nutrition across all care settings would save lives and ensure better allocation of financial resources away from preventable ill health resulting from malnutrition to where they are most needed (ILCUK)
- Increasing public awareness on osteoporosis and high fracture risk is to be recommended with high priority. Systematic detection of risk factors need some systematic approach for which investment of time and dedicated paramedical physician's practice assistance could be helpful (IOA, IOF)
- Evidence-based early detection is certainly useful. Nevertheless, it should be embedded in a broader information strategy. Early detection action needs to be presented so that citizens can understand and act accordingly; in addition, citizens need to understand the outcomes of early detection (MSD)

**4) In what areas is there a particular need for additional action at EU level?**

- It is important for the EU to promote better and earlier diagnosis at national level, in order to reduce the burden of chronic diseases, and to ensure that policies are appropriately implemented (J&J)

- The role of the EU is critical to facilitate the sharing of best practices on existing screening, early detection programmes, on health inequality using EU frameworks to pool Member State knowledge (J&J, WW, WECF, CHA, CPME, EFPIA, E.S.PKU, Lundbeck, GSK, Uni\_Zaragossa)
- Better regulation of chemicals and pollutants linked to chronic diseases (WECF)
- Awareness campaigns about dementia must be rolled out at European and national level. (Alzheimer Europe)
- EU Joint actions are important EU instruments to collect and share best practice across Europe and support EU and national policy work (Alzheimer Europe)
- Control, certification and compliance natured by EU of health and tele-health. EU structural funds should be used to address chronic diseases through the planning and implementation of community-based disease prevention and management programs enabled by personal health technologies should be further developed. (CHA, EFPIA)
- EC can and should assume the role of correctly educate not only target patients themselves but also key groups including healthcare providers, caregivers (formal and informal), politicians, employers and the industry at large (CHA, CEFS, EASL, E.S.PKU)
- Recognise obesity as a leading cause of chronic liver disease and strengthen policy initiatives in major chronic diseases which are linked to obesity (EASL)
- Brain disorders particularly the most costly, mood disorders including depression, neurodegenerative conditions such as dementia and Parkinsons disease would benefit either from new Europe wide approaches or extension of current approaches (EBC)
- The EU together with Member States, European regions and the support and involvement of civil society and patients' organizations must put in place population-wide prevention campaigns; the EU should finance appropriate public health

campaigns on risk factors; promote and support Member States' measures on early screening and diagnosis for people at risk (ECC, ECDA, ESC, Lovexair)

- The European Commission and EU Member States should allocate more funding to prevention and research on CDs (ECDA, EULAR)
- The EU should build on its expertise and utilise the tools at its disposal to develop an environment that promotes health and encourages citizens to make healthy choices, and pushes for a reform of existing structures (ECDA)
- The EU can use legislative tools such as advertising restrictions on unhealthy products, regulating salt and fat content etc. to promote health and behavioural change in practice (ECDA)
- The EU must put greater emphasis on ensuring the implementation of health in all policies to ensure that policies that have an influence on the health of EU citizens must promote health and healthier lifestyles (ECDA)
- Much more discussion at EU and national level is needed about cost-effective ways to influence behaviour (ECDA)
- To promote health and behavioural change in practice, the EU can use legislative tools such as advertising restrictions on unhealthy products, regulating salt and fat content etc. (ECDA)
- EU has a clear role to play here when it comes to making a commitment to improving maternal and newborn health through targeted and integrated health and social policies (EFCNI)
- EFA asks the EU and its MSs to ensure that allergiology is included in the training of medical students and that dedicated trainings for physicians, nurses and pharmacists are available in all European countries.
- EU should take pain management into consideration (EFIC)

- The EU can play a role in monitoring and reporting on the implementation of National Plans for managing Chronic Diseases. It can build on its experience of monitoring the implementation of National Cancer Plans, and extend this exercise to cover other major chronic diseases such as cardiovascular diseases, diabetes and respiratory diseases to name just a few (EFPIA)
- Recognise that education, mental and social activities need to be integrated in the fight against chronic disease as there is evidence that life long educational and mental activities play a role in promoting increased longevity, improved health outcomes, prevent cognitive decline and delay dementia onset in late- life<sup>3</sup> (EGS)
- Support and facilitate the grouping national patients' organisations within EU by creating coordinating mechanisms that facilitate communication across Member States Create initiatives to support the Member States in their efforts to develop multi-sectoral approach (EGS, Lovexair, Roche)
- ENSP considers that additional actions are needed in order to have Czech Republic ratify the FCTC and to have FCTC fully implemented at the European level.
- Need to establish commonly agreed European indicators and conditions for a regular monitoring and evaluation of adopted changes and initiatives in the area of chronic conditions management. The results of monitoring and evaluation should be publicly available and regularly reflected and updated (EPPOSI)
- Better IAQ should be fully integrated into the EU reflection process on chronic diseases as there is strong evidence that improved IAQ would have valuable benefits in the fight against the development of chronic diseases (Camfill Farr)
- The European Commission has a unique legislative opportunity to improve consumer information about the risks of tobacco use through a robust and strong revision of the Tobacco Products Directive. (ERS, SFP)
- More attention to treatable inherited disorders and to rare diseases (IPOPI, E.S.PKU)

- First of all, more attention needs to be paid to older people (under nutrition, medicine use, right to benefit from the advances of clinical investigation and innovative research, contributing to their quality of life). (EUGMS)
- EU could facilitate and encourage Member States in the fight against alcohol abuse with different initiatives (Eurocare)
- The EFPC advises the EU to invest in horizontal operating networks instead of single disease oriented networks
- The EU could be additionally active in the promotion and reinforcement of community based primary care practices capable of managing chronic diseases in each community in all European countries (EFPC)
- The EU should develop an integrated approach to early detection of chronic diseases; action at the EU level can be possible through a combination of health, social and employment policies (FFW, FoodDrinkEurope)
- EU should address the stigma associated with mental illness that continues to be a barrier to the diagnosis and treatment of chronic physical conditions in people with mental illnesses. (ILAE) and inequalities in health between people in higher and lower educational, occupational and income groups have been found in all Member States (Oral\_health)
- The European Commission and the European Council should implement and extend to different healthcare sectors the innovation partnership concept and indicate the specific commitments they will undertake to make the concept work (GSK)
- In order to effectively tackle malnutrition in Europe it is necessary to support member states in developing nutrition policy and ensure that nutrition remains a key area of policy development within the EU (ILCUK)
- More initiatives targeting migrant communities (IOM)

- EU should pay attention to comorbidity and improving evidence on chronic multimorbidity
- Encouraging research on multimorbidity, coordinating professional and research groups working on multimorbidity (Lundbeck, Uni\_Zaragossa)
- The EU can coordinate the adoption and implementation of Health Impact Assessment at EU level, which is necessary, as mentioned previously, in order to strengthen the prevention of chronic diseases (PRIVATE\_KV)
- The European Commission should be commended for the inclusion of Health Literacy in the European Innovation Partnership on Healthy and Active Ageing (MSD)
- Nestlé calls on the EU decision-makers to continue their support to initiatives that have proven to be effective, in particular in the field of reformulation and consumer communications
- The Commission should call upon the relevant Member States to review their recently introduced food taxation policies (Nestle)
- Individuals should be empowered with the information they need to understand the impact of lifestyle decisions and to make healthier lifestyle choices (RCN, SCA)

**5) In what areas is there a particular need for action at national level?**

- More attention should be paid to geographic factors, socio-economic factors and other local factors (WECEF, EGS)
- Primary care professionals must be trained to recognise the early signs of dementia. The role of the GP as a major primary care stakeholder must be further recognised (Alzheimer Europe)

- More focus to be drawn to education campaigns at national level to inform, educate and facilitate the adoption of a healthy lifestyle (CEFS, ECDA, ENSP, ESC)
- In the area of prescription and adherence, there is scope for action at regional level, as well as for remote monitoring of chronic diseases, please see the following question (CPME)
- Because of the way health care delivery occurs, national level will be key for all chronic diseases, particularly for care delivery (European brain council)
- Address health inequalities and social inequalities (ECDA, ECDA , EFCNI)
- Government policies should also aim to empower individuals through different initiatives and communities to define the problems and develop community solutions. (ECDA, EULAR, EFPC, Roche)
- Prevention, early detection and diagnosis, greater international, multidisciplinary and multiagency collaboration, implementation of population-based quality assured screening programmes, evaluation of and development of novel tools to detect chronic disease in at-risk populations are all measures that should be encouraged at Member State level (ECDA, EFPIA, EGS, EFPC, FFE, GSK)
- Each Member State should establish a national audit report on maternal and perinatal care as well as on preterm delivery (EFCNI)
- Each Member State should develop parental materials specifically for preterm infants for inclusion in existing national baby health records (EFCNI)
- Health care is primarily in the competency of the member states. Each member state should enact a national plan against pain, following the examples of countries such as Portugal, France and Italy (EFIC)
- Attention to liver disease (ELPA)

- More actions should be taken in the fight against tobacco, alcohol and other risk factors (ENSP, ESC, Eurocare, SPF)
- Routine nutritional screening in hospitals and care homes and for at risk groups in the community is essential in ensuring good nutritional care, thereby preventing undernutrition and the associated disease states related to this condition. Screening should be embedded in a national nutrition policy as a part of a life course approach to nutrition and nutritional care (ILCUK)
- Prevention and control strategies need to be developed on a global, regional, national and community level, which will benefit migrants, host communities, governments as well as communities of origin (IOM)
- Better choice and use of relevant stakeholders to participate in detection programs and education at primary level. Inclusion of capable patient organizations and assessment of the organizations involved. Better communication, planning, implementation and monitoring with appropriate TIC platforms for participants and feedback on success stories (Lovexair)
- Member States should adopt Health Impact Assessment as a key policy tool in the formulation of any law, regarding health, environment, traffic measures, establishment of certain industries etc. In addition, a cost-benefit assessment of existing preventive measures (efficiency, benefiting individuals, etc.) concerning chronic diseases is necessary (PRIVATE\_KV, Oral\_health). Member States can create a similar framework on national level by setting policy priorities that include the empowerment of citizens and health targets (MSD)
- At national level, clear patient pathways should be defined and promoted, indicating the prevention (primary, secondary and tertiary) and cure potential and care needs (SCA)
- Provision of international comparable databases for research, promoting the creation of a Minimum Basic Data Set on Primary Care and encouraging research on multimorbidity (Uni\_Zaragossa)

## **6) What will you/your organisation contribute to address this challenge?**

**AIM**, in association with Epossi, has the intention: to explore the legal environment in the European Members States; to explore the technical methodologies and tools for prediction; to develop specific products and services for concrete implementation of predictive modelling.

Since 1963 **Camfil Farr** designs high quality energy efficient filtration solutions that meet the needs of sustainable ventilation creating the right balance between healthy indoor air and energy savings. Camfil Farr's air filters have contributed for years to people's wellbeing by removing harmful indoor substances that we are exposed to every day such as particles, gases and odours. The technology already exists and has proven to be effective, legislation could allow taking full advantage of its benefits for human health.

An important dimension of **CEFS'** engagement at the EU level is to share its knowledge on sugar and its role in a balanced diet as part of a healthy, active lifestyle. CEFS remains at the disposal of the EU institutions and Member States for any information on the role of sugar in nutrition. More information on this topic can be found on our website at <http://www.comitesucre.org/www/?menu=2&submenu=30>

At EU level, **CPME** is committed to tackle lifestyle related chronic disease risk factors. CPME is engaged within the EU Alcohol and Health Forum as well as the EU Platform on Diet, Physical Activity and Health and is fully committed to the active participation of its membership to combat alcohol-related harm as well as promote diet and physical activity by informing its members, adopting a health at the workplace approach.

The **EBC** is perfectly placed from the perspective of brain disorders to lead and participate in new initiatives, from research to efforts to improved quality of life for patients. Because we encompass all stakeholders from science to society we have a unique insight which we hope to bring to helping address these critical questions.

Since its founding in 2008, **EFCNI** has made a number of contributions to the challenges posed by preterm birth, notably in the leading role we have played in developing a body of EU research to help identify opportunities for improvement and existing best practices in maternal and newborn health. The EFCNI EU Benchmarking Report 2009/2010 *Too Little, Too Late? Why Europe should do more for preterm infants* was one such hallmark effort to assess existing practices in maternal and newborn health. *Caring for Tomorrow - EFCNI White Paper on Maternal and Newborn Health and Aftercare Services* from November 2011 highlights some of the key concerns and recommendations with regard to the growing number of individuals impacted by preterm birth.

**EFIC®**, **PAE** and **Grünenthal** have collected examples of best-practice benchmark programmes for all areas of pain assessment, pain management and education on pain from several member states. The organisations submitting this response are more than happy to share this information with any government wishing to improve their national action plan against pain. These organisations are fully dedicated to the improvement of pain management in Europe. The broad alliance supporting the relevance of the impact of pain in society is demonstrated by their cooperation in the platform “Societal Impact of Pain” 20 – SIP and it’s over 125 endorsing organisations.

**EFPIA** supports the setting up of the Joint Action on registries (PARENT (PAtient REGistries iNiTiative)) cofounded by the European Commission and Member States and due to start in May 2012. The overall objective of PARENT is to support member states in developing comparable and coherent patient registries in fields of identified importance (e.g. chronic diseases, rare diseases, medical technology) with the aim to rationalize and harmonize the development and governance of patient registries, thus enabling analyses of secondary data for public health and research purposes. EFPIA calls for appropriate involvement of stakeholders in this Joint Action.

The **EGS** can assist with: the development of quantitative analysis of the cost effectiveness and health gains of health promotion and prevention in its field (glaucoma) across a number of Member States; the collection of scientific evidence for the exploration of the scope for early detection of relevant risk factors for glaucoma; the creation of public forums that sustainably raise awareness of issues related to its field.

**ENSP** is an independent, international not-for-profit organization, which aims to put an end to tobacco consumption and to develop a common strategy, amongst organizations active in smoking prevention and tobacco control in Europe, by sharing information and experience and through co-ordinated activities and projects. The two top priority objectives are (i) to have the Framework Convention on Tobacco Control (FCTC) implemented in Europe by 2020 and (ii) to reduce the prevalence of tobacco use in Europe to less than 5% by 2040.

**ERS** is dedicated to leading the fight against this epidemic. We launched comprehensive recommendations to policy makers through the publication of the European Respiratory Roadmap. We are currently in the process of producing a European Lung Whitebook which will list the epidemiological and socio-economic burden of respiratory diseases in Europe. Furthermore, we have organised conferences on the topic and worked closely with the European Parliament, Commission and Council to call for action on chronic diseases. We have also pressed at both the WHO and UN General Assembly for efforts to be stepped up to address this major scourge both globally and locally. In this regard, we are currently producing together with other leading respiratory societies a World Atlas on Respiratory Diseases.

The **ESC** strives to reduce health inequalities related to cardiovascular diseases across Europe, by promoting best clinical practice thanks to European guidelines disseminated by national cardiac societies, by collecting data on clinical practice in registries held by the cardiology community and by raising the level of education of the cardiology profession.

In addition, specialties of cardiology represented in Associations as registered branches of the ESC, collect data unfortunately demonstrating inequalities in accessing treatment and care across Europe, with the objective to reduce the geographical discrepancies.

**EULAR**, as an umbrella organisation comprising scientific societies, health professionals and patient organisations, has vast experience in health promotion and disease prevention. EULAR plays a key role in furthering knowledge on RMDs via research activities and the scientific annual conference, as well as in educating and training health professionals, patients and health facilitators, among other actions.

**Eurocare** and its members have been working on addressing the alcohol related harm and promoting healthy lifestyle for a number of years. They will continue these efforts and would

welcome the opportunity to be even more active stakeholder in developing policies that will enable the EU population to enjoy healthier lives.

**ECCF** generates new thinking about better outcomes in critical care. The organisation Proposes to take a small European country as a case study and work with local partners to develop innovative strategies to address the problems that lead to preventable heart attacks. Successful initiatives could then potentially be implemented more broadly across Europe.

Membership of **EFPC** covers more than 60 % of all European countries and therefore EFPC is a suitable vehicle for inter-country exchange of information and dialogue. EFPC offers the commitment and active support of its membership to the EU reflection on chronic disease, in particular in the following domains: • Experience and good practice in the cooperation and coordination between primary care, social services and community services, while addressing life style, aiming at preventing and reducing chronic disease; Because of the long lasting relationship between professionals and individuals, primary care has a potential to contribute to health literacy and self care and thus empower individuals and reduce their dependence on health services. Experience and good practice can be provided, serving as examples and a basis for further policy development.

**FFW** has conducted research in more than 30 countries across Europe and beyond. This research has also developed actionable recommendations for all relevant stakeholders, at the European and national levels in relation to MSDs.

The steps **FoodDrinkEurope** members have taken are progressive and proving very effective as part of the broader efforts and partnerships on NCDs and obesity. These efforts have been acknowledged by WHO, OECD, the European Institutions and others.

The **GALEN** Sentinel Network is an initiative of the EU-wide allergy and asthma network GALEN. The objectives are: to create a central database, collect data (on country and EU-wide level), analyse and publish data regularly; to identify new trends in allergic diseases before they become major public health problems that may cause an additional burden to European health care systems; ultimately saving money for the EU's government and

economy; Report to policymakers and alert them in a timely manner about new allergens where action is needed; Build up a sustainable system for better awareness, starting in schools, to decrease the burden of allergies for society.

**GSK** is already contributing to addressing the challenges of chronic diseases on many different levels for example through the long-standing involvement of GSK's Consumer Health business in supporting EU-wide smoking cessation campaigns and participation in the platforms on obesity/diet & physical activity, GSK's engagement with patient groups and most recently through our participation in the Commission's European Innovation Partnership (EIP) on Active and Healthy Aging (AHA) in a multi-stakeholder project.

The **ENHA** is already fully committed to developing routine nutritional screening at the member state level in Europe via our national implementation plan. In addition our strong partnerships form a basis for future work to raise awareness and work within the EU to ensure undernutrition remains a policy priority at both a member state and EU level. We have already completed research which contributes significantly to the literature on the health and economic consequences of malnutrition.

The IOF and the **Belgian Bone Club (BBC)** is an organisation of scientific workers at the university level, cooperating in the dissemination of knowledge towards mainly to physicians and other researchers. The BBC is making scientific publications in high standing international medical journals, including a yearly consensus paper of a variety of related domains (eg also non-pharmacological intervention for osteoporosis and fracture prevention (see website : [www.bbcbonehealth.org](http://www.bbcbonehealth.org) ). The communication towards the general public for primary prevention is not the main activity, but brochures, website and assistance for osteoporosis patient society have been provided.

The **International Osteoporosis Foundation (IOF)** is a much bigger world wide organisation. For all programs and specifically these on health promotion and public awareness, resulting in primary prevention can be extensively explored at a brand new website : [www.iofbonehealth.org](http://www.iofbonehealth.org)

**IOM** Advocate for and introduce CD health promotion and prevention into programmes targeting migrants, hard to reach, marginalized and mobile population.

**Lovexair:** As a Foundation we aim to create a network of specialized educators, in our case in chronic respiratory disease. Our organization will be a learning organization and we will manage the knowledge through an e-Health platform for users.

**MSD** continues its various activities to empower patients and to advance health literacy.

The mission of the **Platform for Better Oral Health in Europe** is to promote oral health and the cost effective prevention of oral diseases in Europe. It seeks a common European approach towards education, prevention and access to better oral health in Europe.

**Roche:** Supporting the implementation and validation of the personalized diabetes management model as a blueprint for chronic disease management

**SCA** can make a substantial contribution towards increasing the awareness of incontinence, as well as help with the development of educational programmes, for individuals as well as informal care givers and health professionals. SCA also supports the development and exchange of care guidelines and good practice.

**UNI\_ZARAGOSSA:** Provides scientific knowledge on the description and intervention on multimorbidity within different population groups, integrates clinical databases from primary and specialized care, studies multimorbidity patterns and to what extent these are influenced by medications, identifies best practices to improve outcomes in patients with multimorbidity.

**WECF** will contribute to address this challenge by: - Awareness raising activities (publications, workshops, events, etc.) to the general public, in particular vulnerable groups such as women in childbearing age, pregnant women, parents to be, young parents on the existing risks of certain chemical/physical exposures which (may/might) play a role in the development of chronic diseases within a prevention and precautionary approach; - Awareness raising among multipliers (health professionals, etc.) about environmental health; - Advocacy activities at UN, EU and national level for the integration of environmental risk factors in public health policies dedicated to chronic diseases.

**WW** is truly committed to lift the burden of chronic diseases by providing sustainable solutions to the complex problem of obesity in an affordable, evidence based and scalable way. Weight Watchers will continue to support thousands of citizens across the EU every day to manage their weight and will continue to work in partnership with public health and healthcare providers to deliver solutions that reduce the risk of chronic disease. However, despite the documented potential for the significant reduction in risk of chronic diseases, the scale of the response by governments and public health experts is certainly not being matched to the scale of the unhealthy weight problem.

## B) HEALTHCARE

### **B1: What changes could be made to enable health care systems to respond better to the challenges of prevention, treatment and care of chronic diseases?**

- *New models for integrated and personalised care* (AESGP, AIM, Alzheimer, COCIR, CHA, ECDA, ECHAMP, EFA, EFPC, EFPIA, EGS, ELPA, ENOPE, ENSP, J&J, EPHA, EPPOSI, ERS, ESC, ESPKU, EPF, EUGMS, EULAR, FFW, IOF, ROCHE, UNI\_Zaragossa, WCRFI) personalized medicines (EFPIA, ESC)
- *Shift to new model from secondary care to a powerful primary care* (COSIR, ECC, EFA, EGS, ENOPE, J&J, EFPC, UNI\_Zaragossa, WHO Europe) prevention and promotion (ECDA, EFA, EGS, J&J) and to community care, (COCIR, CHA, EBC, EBL, ECC, EFA, ENSP, EGS, ERS, EUGMS, Eurocarers, HLS-EU, IOM, Lovexair, R, UNI\_Zaragossa, WHO Europe) shift towards personalised/tailored care (EPPOSI) a network of specialized outpatient pain services (EFIC-PAE) strengthening the provision of outpatient services (COSIR)
- *Accessibility for optimum treatment* (ALEXION, Cancer Research EU, CHA, ECC, ECDA, EFIC-PAE, EFPIA, EGS, ENSP, ESC, ESPKU, EULAR, ECCF, GAMIAN, IOF, EPF, MSD, UNI\_Zaragossa, WECF, WHO Europe, PRIVATE\_AS) and medicines (GSK, EPF, WHO Europe)
- *Focused on a patients centered system* (AESGP, COCIR, CHA, ECDA, ENOPE, EPPOSI, EFPC, GSK, HLS-EU, EPF, IOM, Lovexair, MSD, ROCHE, UNI\_Zaragossa, WHO Europe) multi-professional/multidisciplinary teams (EPPOSI, ESPKU, GALEN, IDF, IOM, PHA, Oral\_health, Reumanet, UNI\_Zaragossa, PRIVATE\_KV)
- *Self - management with the family involvement* (AIM, COSIR, CPME, EBC, ECC, ECDA, ECHAMP, EFA, EFPIA, ELPA, ENOPE, ENSP, EPHA, EPPOSI, ESC, EULAR, IDF, MF, Nestle, Reumanet, UNI\_Zaragossa)

- ***Holistic management model of chronic conditions - diseases*** (COCIR, EPHA, EPPOSI, ERS, EULAR, FFW,GSK) and elderly (EUGMS) legislation to achieve the objectives of a policy response on Chronic Condition Management (EPPOSI, EULAR GSK, HLS-EU, EPF, IOM, Lundbeck) – national holistic, non-disease specific action plans, inter-sectoral cooperation, collaborative involvement of all stakeholders, monitoring awareness of patient rights, formal involvement of patient representatives/groups in the decision-making process, patient access to information (EPPOSI, EULAR, EPF, GSK, HLS-EU, IOM, ROCHE) including immigrants (IOM)
- ***Collaboration and share knowledge among professionals*** (COSIR, CHA, CPME, ECC, ECDA, EFCNI, EFA, EFIC-PAE, ENOPE, EPHA, ESC, FFW, IOF, EPF, IOM, MSD, RCN)
- ***Provision of home care*** (COSIR, CHA, CPME. ECC, ECDA, EFA, ENOPE, ERS, EUGMS, Eurocarers, IOM, Lovexair, MSD, MF)
- ***Create specialized centers*** (GALEN, PHA, ROCHE) in vitro diagnostic infrastructure, chronic disease consultation centres - clinics (ECDA, EFA, ERS, ROCHE) referral centres (EBC) emergency transport infrastructure (ECCF) supporting centres for excellence for rare diseases (CPME, IPOPI) Standardization of pain management units in the European hospitals(EFIC-PAE)
- ***Service models for prevention and for chronic care supported by rewarding systems, integration of medical and social services*** (AIM, EFA, ELPA, IDF, SCA), workflow system for each single chronic disease (AIM, ENOPE)
- ***Receive the best available treatment*** so as to maximize their autonomy, safety and quality of life (ALEXION, EFA, ENSP, EUGMS, PPTA, SCA, UNI\_Zaragossa)
- ***Innovative cost-saving models, monitoring systems*** with the use of the right technology, ethical issues, involvement of end-users (Alzheimer, ENOPE, ENSP, J&J, EPF)

- ***Early diagnosis, screening tools*** (Cancer Research EU, ECDA, EGS, ENSP, J&J, ERS, ILCUK, SFP, UNI\_Zaragossa) cancer (Cancer Research EU, UKNCDDTF, WCRFI)
- ***Innovative approaches*** to an affordable and sustainably high standard of care ***for elderly and chronically ill people*** (COSIR, CHA, EFA, EFPIA, ENSP, J&J, EPF, WW, UNI\_Zaragossa, WHO Europe)
- ***Evidence based guidance to treatment plans, disease management*** (CHA, ECDA, EFA, EGS, ENOPE, EPPOSI, ERS, ESC, ILAE/IBE, IOF, Oral\_health, ROCHE) EU guidelines to risk assessment (ROCHE)
- ***Adapting policies on health lifestyle*** (ECC, ERS, FFW, IDF, RCN), psychosocial support from qualified personnel trained in Chronic Condition Management (ECC, EPPOSI, ERS, FFW, MF, PRIVATE\_ER) support via psycho - educational and discussion groups (MF) lifestyle determinants on addressing socio-economic and working determinants, on addressing genetic/biological determinants; and on strengthening the rights of disabled people (EULAR, FFW) labour market policies for disable (FFW) and immigrants (IOM)
- ***European and national registries*** (ECC, ERS, ESC, IPOPI, WECF, ROCHE, UNI\_Zaragossa) with family and medical history data (ECC, ROCHE)
- ***European Platform with central information data source*** (AIM, CHA, EASL, ECC, Alzheimer, EFCNI, EFA, EPPOSI, ESC, ESPKU, EYRADIA, HLS-EU, MSD, ROCHE)
- ***Harmonised approach in the EU on reimbursement policies*** for all available services and treatment, (ESPKU, EFPC, EPF, WCRFI) predictable and balanced use of pricing and reimbursement policies (GSK), for under - nutrition - supplementary nutritional packs (ILCUK)
- ***Guidelines for good practices*** (CPME, EGS) decision making (ESPKU)

- ***Legal framework cross borders*** enabling access to treatment across board (EFCNI, ILAE/IBE, PRIVATE\_AS)
- ***Educating people*** about the importance of a balanced diet for healthy nutrition (EDA, MNI, WCRFI) also for the malnourished (MNI)
- ***Identify and target high risk groups*** (ABSTD, COCIR, EGS, Nestle)
- ***Health literacy*** (EFA)
- ***Integrated pain management programme***, remuneration of outcomes (EFIC-PAE)
- ***Ambulatory care, benchmarking reports, solidarity, equitable price-setting mechanisms*** (EFPIA, GSK)
- ***Banning of all marketing and advertising*** for alcohol beverages, including price-based promotion especially for children and young adults (EASL)
- ***Forecasting and data collections***, establishment of European Dementia Observatory which will collect and maintain the data per specific disease (Alzheimer)
- ***Chronic conditions management centre, enhance reimbursement of prevention programs*** (J&J) cure and care and social programs (SCA)
- ***Maximise physical independence***, autonomy and quality of life, geriatric medicine to become independent medical specialization (EUGMS, MNI, UNI\_Zaragossa)
- ***Community partnerships*** (EPPOSI)
- ***More diagnosis and management*** is needed in general practice and ***among general physicians*** (ERS)

- ***Reduce inequality*** in access to services currently exists between patients dying with malignant and non-malignant respiratory disease (ERS)
- Put in place adequate ***support measures for carers***, better integrate and cooperate with informal care (Eurocarers)
- Holistic ***Health Technology Assessments*** (HTAs) (EFPIA, GSK, IPOPI, Nestle, WHO Europe, PRIVATE\_KV) and ***health economic evaluation*** targets including clinical and societal impacts (FFW, GSK, IPOPI, Nestle, WHO Europe, PRIVATE\_KV) clinical effectiveness for medicines and vaccines (GSK)
- ***Equilibrium between needs of different players***, enhanced competitiveness, reward for innovation, partnership between industry governments and their agencies, R&D-based industry, support innovation across the supply chain - in research and development, manufacturing and the commercial environment, innovation partnerships (GSK)
- ***Citizens empowerment*** (HLS-EU, MSD)
- ***Indicators to compare access*** to quality of care for epilepsies (ILAE/IBE)
- ***Reduce the number of healthcare professionals*** available to give appropriate ongoing healthcare and are create mainly two access points, initial diagnostic and emergency care (Lovexair)
- ***Disease awareness*** (PHA, Oral\_health)
- ***Emphasis to unmet needs*** of the population assess epidemiologically based in Health Needs Assessment (HNA) (EPPOSI, GKS, Nestle, UNI\_Zaragossa, PRIVATE\_KV)
- ***Recruit health professionals***, rheumatologists (Reumanet)
- ***Development of specialised care networks*** (AIM, ELPA, EPPOSI, MF) establish a network of “chronic disease nurses” (ROCHE)

- *Address the stigma around chronic diseases* (Lundbeck)
- *Organ donation and transplants* (PHA)
- *Cross countries studies* (WCRFI)
- *Increase of employability* – work productivity of the chronically ill people (PRIVATE\_ER)
- *EU protection to the chronically ill* who declare abuse and fraud (PRIVATE\_AS)

**B2 : What changes could be important to better address the chronic diseases 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 ?**

- *Financing and planning integrated care models* (Alzheimer, CPME, ECDA, ECHAMP, EFA, EFPIA, EGS, ENOPE, EPHA, ERS, Eurocarers, EFPC, FFW,GAMIAN, EPF, UNI\_Zaragossa) by promoting a healthy lifestyle (CPME, ECDA, EGS, EULAR) and continued care, consideration of conflict of administrative and financial interest (CPME, ECDA, EGS, IOM) regardless migration status (IOM) outsourcing management programmes, funding decentralization (Lovexair)
- *Efficient way of using scarce resources, provision of cost - effective, efficient and quality health care services and increased sustainable medical delivery* (AESGP, COCIR, CHA, ECDA, ECCF, ECHAMP, EFA, EFPIA, EGS, ELPA, ENSP, J&J, EPHA, EPPOSI, EPF, ESC, ERS ,EURADIA, EFPC, FFW, GSK, IDF, ILAE/IBE, IOF, EPF, Lovexair, Lundbeck, MSD,PHA, WW, PPTA, SCA) maximise labour efficiency (MSD) cost benefit analysis (Nestle, ROCHE, PRIVATE\_KV)
- *Common / coordinated training for health care providers/professionals* (COCIR, CHA, EALS, ECC, EFCNI, EFIC-PAE, ELPA, ENOPE, EPPOSI, ERS, ESC, IOF,

Lundbeck, MNI, MSD, PELVIC\_PAIN, UNI\_Zaragossa) training on technologies and professionals, (COCIR, CHA, ECDA, ELPA, ENSP, EPHA, EPPOSI, EPF, ERS, ESC, GSK, Lovexair, MSD, PHA) life long education (EFCNI, ENOPE, ESC, EFPC, FFW, IOM, MF)

- **Specialised training programmes** (GALEN, IOF, MNI, WECF) disease specific programmes (EFA, ENOPE, EFPC, Oral\_health) environmental health (WECF) synergies with the WHO programmes (WHO Europe) for rare diseases (IPOPI) for rehabilitation programmes (ECC, ECDA, EFA, ERS, PRIVATE\_ER) for public health for early interventions measures (J&J) support programmes that recruit patients representatives of primary care populations (EPF), for social or medico-social actors (AIM, ELPA, EPPOSI, MF)
- **Rewarding system** based on data at a unit level in terms of performance, cost reduction, services prevention, delivering treatment (AIM, ELPA, EPPOSI)
- **Sustainable financing system** (AIM, COSIR, EFIC-PAE, EGS, EPHA, IDF, ILAE/IBE, EPF, MF, PPTA) financing harmonisation, long term funding, chronic diseases follow up (AIM, EFIC-PAE, ENOPE, EPHA, EPPOSI, ESC, MF, WCRFI)
- **Reduce inequalities** on the right involvement of the family members and the health care professions (AIM, EBC, EFPIA, ENSP, EPHA, ERS, Lundbeck, MF, Nestle)
- **Support the creation of new jobs and skills that will bridge the gaps in care needs,** dementia-friendly communities, at EU level support young people with dementia to be active with greater participation in the society, development the continuum of care (Alzheimer).
- **Prevent duplications of funding** (Cancer Research EU)
- **Development of Diagnosis Related Groups** (DRGs) and Adjusted Clinical Groups (ACGs) (EFPIA)
- **Top – down management** approaches from national to local (EFPC)

- *Hire immigrants* (IOM)
- *Implement Health Equity Audit* (HEA) so equitable services are agreed and incorporated into local plans, services and practice (Nestle, PRIVATE\_KV)

**B3: How much emphasis should be given to further developments of innovations, including e-health and telemedicine in prevention and treatment of chronic diseases such as remote monitoring, clinical decision support, e-health platforms and electronic health records?**

- *Harness the benefits of technologies by creating a remotely* – collected data for patients and share the info via secured systems by empowering and guiding the patients, training via e-health on education for self-care (Alzheimer, CHA, EFCNI, EFA, ENOPE, ENSP, EPHA, MF, Nestle, RCN)
- *New innovative indicators for self-care practices* (AESGP, ECHAMP, EFA, EFPIA, ELPA, ENOPE, ENSP, EPHA, ESC, IDF, MF) pharmaceuticals and biotechnology (Nestle, PRIVATE\_KV) for caregivers (AIM, EFA, ENSP)
- *Monitoring systems including patients and the care givers* (COCIR, CHA, CPME, ECDA, EFCNI, EFA, J&J, ERS, Lovexair, WCRFI) for the prevalence of alcohol-related liver disease and mortality, evidence-based, in schools and university environments (EASL) cancer (WCRFI)
- *Support healthcare professionals with technology solutions* (COCIR, CPME, EFCNI, EFA, EFPIA, Nestle)
- *Investment in innovation / information technologies and tele-healthcare programmes* (COCIR, CHA, CPME, ENSP, J&J, EPF) investment electronic patients records (COCIR, EFPIA, EFPC, GSK, Nestle) telemedicine (COCIR, CPME, EFCNI, EFIC-PAE, J&J, ESC, Nestle) tele-consulting, tele-monitoring (ECDA, EFIC-PAE,

J&J, EPF, Nestle) efficacy of treatment (ECDA, ERS, EFPC, GSK) via internet and smart mobile phones (ECDA, ERS, EFPC)

- ***Telemedicine and e-health training of patients*** (EFCNI, EFIC-PAE, ENSP, J&J, ERS, HLS-EU, Nestle) and healthcare professionals (EFCNI, EFIC-PAE, ENSP, ESC, J&J, ERS, Nestle) Promote ongoing professional developments of health carers, add e-health related courses within the curricula of the EU medical universities, funding on scientific medical networking across the EU (CPME) Sustained health information and education campaigns (EASL, EFA, EFIC-PAE)
- ***Key issues to improve the delivery of health care are: personal connected health, wireless technology*** (CHA) ***e-health*** (CHA, CPME, ECDA, EFA, ENSP, ESC) ***call centers for e-health back up*** (Lovexair)
- ***Strengthening the relationship of trust of between technology ,health professionals and patients*** (Nestle, PRIVATE\_KV) Support and coordination for patients/carers as end-users for e-health tools (Lovexair, MSD)
- ***Pilot projects via e-health and telemedicine*** for infants stay in the Neonatal Intensive Care Unit (NICU), support parental new technologies (EFCNI),
- ***Public financing for innovative projects*** (CHA, J&J)
- ***E-health at a national regional or supra-national model*** (EFPIA) adequate update to technologies at a national level (ERS, Lovexair)
- ***Reduce inequalities to access the e-health telemedicine*** due to personal, financial and geographical reasons (EPHA, EPPOSI, MF, Nestle) and marginalised population (IOM)
- ***Common clinical treatment pathways among medical disciplines*** (IOF)
- ***User friendly applications*** (IOF, MSD)

#### **B4: In what areas is there a particular need for additional action EU level?**

- *Effective and efficient policies* via expertise and experiences *provision for integrating self-care practices* (AESGP, CHA, CPME, ECDA, ECHAMP, EFA, EGS, ELPA, ENOPE, ENSP, J&J, EPHA, EPPOSI, ERS, FFW, IDF, IOF, EPF, MF, Reumanet)
- *Common / comparable health data and indicators*, standards on incidence, prevalence, risk factors and outcomes for better understanding of direct and indirect costs and have measurable results (EASL, ECC, EFA, EFPIA, EGS, ENOPE, ENSP, EPF, HLS-EU, GSK, IOF, Lundbeck, MSD, ROCHE,UNI\_Zaragossa), stronger cooperation with WHO, OECD and relevant scientific Associations (EASL, ENOPE,WHO Europe)
- *Training for health care providers/professionals*, (COCIR, CHA, EALS, ECC, EGS, ELPA, ENSP, EPHA, EPPOSI, EUGMS, EULAR, ECCF, EFPC, MSD, PELVIC\_PAIN) in geriatric medicine and gerontology (EUGMS, MNI) patients and care givers (CHA, ENSP, EPPOSI, Reumanet) teachers at school (EALS) community workers (EPHA, EPPOSI) informal carers (Eurocarers)
- *Closer cooperation with stakeholders and Member States* (AESGP, AIM, EFPIA, EPPOSI, ILCUK, IOF, EPF, IOM, MF, Nestle, WCRFI), via social network sites (Nestle)
- *Reduce health inequalities in the access to treatment* (AIM, ALEXION, ECC, EFA, EFIC-PAE, EFPIA, EGS, ENSP, ERS, ESPKU, ECCF, EPF, GAMIAN, IDF, IOF, IOM, Lundbeck, MF, Nestle, UNI\_Zaragossa, WECF, WHO Europe, PRIVATE\_KV) to care of patients with rare and ultra-rare diseases, develop supportive rare diseases policies (ALEXION, IPOPI) and to medicines (GSK) between member states health care system needs for the chronic patients (MSD, UNI\_Zaragossa)
- *Implementation and development of coordination system* that facilitates access to essential care in all EU Member States (ECC, ECDA, EFA, EFIC-PAE, ENSP, ECCF, IOF, IOM, WHO Europe), creation of care standards for COPD (ECC, ECDA, EFA)

and migrants, Roma ,ethnic minorities and mobile populations (IOM) inform ethnic and cultural minorities, minimise discrimination (Alzheimer)

- ***Development and implementation of evidence based screening programmes*** (Cancer Research EU, EFPIA, EGS, ENSP, J&J, ERS, IDF, ILCUK, SFP, UKNCDDTF, UNI\_Zaragossa) for cervical, breast and bowel (colorectal) cancer, EU screening guidelines(Cancer Research EU, UKNCDDTF, UNI\_Zaragossa), greater support and information symptoms signs and screening of cancer at EU level (Cancer Research EU, UKNCDDTF) screening at a national level (J&J, UKNCDDTF, UNI\_Zaragossa) standardisation of treatment (EULAR) screening across EU and Member states (ESPKU, IDF, SFP, UKNCDDTF) tobacco (SFP)
  
- ***Financial discussion with all stakeholders and member states on system changes, public private partnership, pilot projects for new models*** (COCIR, ESC, EFPC, FFW, EPF, IOM) with multi-morbidity case management including protocols and individualised care plans (COCIR, ESC, EFPC, ILAE/IBE, EPF, SFP) in “Care & Cure” (COCIR, EFPC, GSK, SCA, WHO Europe)
  
- ***Policies and regulation for the elderly***, development of synergies amongst those institutional stakeholders that are early adopters of policies, sharing of evidence of the benefits and the cross-fertilization of policies, creation of a fertile ecosystem of interoperable products and services for personal connected health (CHA)
  
- ***European guidelines of legal issues concerning data protection, reliability, validity and transparency of sources of information***, (CPME, ESC, ESC, ESPKY, EPPOSI, IOF, SFP, WHO Europe, PRIVATE\_AS) agreement on languages and terminology in health related issues for data analysis facilitate cooperation between Member States and/or regions to address common legal and organizational challenges (ESC) and in primary care (EFPC) and e-health, awareness actions for e-health and telemedicine and other innovative solutions towards citizens, patients, and health carers, nomenclatures international standards (CPME, ESC, ESC) informal carers (Eurocarers)

- ***EU forum, platform to share - promote best practices in disease specific areas*** (EFA, EPPOSI, EULAR, EFPC, FFW, GAMIAN, EPF, Lovexair, MSD, Oral\_health, WECF) share best practices among professionals (EFCNI, EFA, EFIC-PAE, EFPIA, ENOPE, EPHA, EULAR, EFPC, FFW, EPF, IOM, MNI, RCN) stakeholders public and private (EFCNI, EFIC-PAE, EFPIA, EGS, EPPOSI) inter-sectoral collaboration and support for primary care (EFPC, GAMIAN) of individualized records (SFP, WECF)
- ***Encourage the role of mass media*** (EGS, IOF) and popular community opinion leaders and the cultural realities of the patients, the impact of transition such as retirement, harmonisation in diagnosis and treatment at an EU level (EGS)
- ***EU should address task shifting from the health care professional to address shortages in health workforce***, have adequate number of workforce in the health care systems (ECC)
- ***Political awareness*** (CHA, EPPOSI, SFP)
- ***Funding for healthcare professionals*** for the use of the existing e-research to disseminate key information about chronic diseases (J&J)
- ***European audits*** (ERS)
- ***Identify priorities and implement EU labour laws, pensions and long-term care policies*** around Alzheimer's disease and other forms of dementia (Alzheimer)
- ***Generation of preventative strategies, long term benefits, both human and socio-economic*** (ABSTD)
- ***Strategy development of Indoor Air Quality (IAQ)***, integration of the IAQ in the reflection process on chronic diseases (CAMFIL)
- ***At EU level***, linking the national initiatives together (GSK)

- *New EU Health strategy* (HLS-EU) EU chronic disease management plan (ROCHE)  
EU plan for epilepsy care (ILAE/IBE)
- *Set nutritional care as a priority area* (ILCUK, MNI)
- *Health literacy at EU level* (EPF, MSD)
- *Policies that reduce poverty, empower solidarity and equity, on transferability / portability of social benefits* (IOM)
- *Avoid random investment in a multitude of e-health projects for healthcare services,*  
Avoid over-dependency on remote tele - monitoring for older patients (Lovexair)

**B5: In what areas is there a particular need for additional action at national level?**

- *Closer cooperation with stakeholders* (AESGP, Alzheimer, IOM, Nestle, WCRFI, PRIVATE\_KV) and stakeholders partnership (Cancer Research EU, ILAE/IBE, ILCUK, WCRFI) Public private partnership (COCIR)
- *Change management* (AIM, MSD, Nestle) systematic and multilevel (MSD) institutional and ideological change (Nestle)
- *Reduce health inequalities in the access to treatment* (J&J, ESC, EULAR, ECCF, GAMIAN, IOF, IOM, Lundbeck, MSD, Nestle, UNI\_Zaragossa, WECF, WHO Europe) and care of patients with rare and ultra-rare diseases, develop supportive rare diseases policies (ALEXION, IPOPI)
- *Share best practices among professionals,* (ECDA, EFCNI, EFA, EFPIA, ENOPE, EPHA, EULAR, FFW, EPF, IOM, MNI, MSD, Nestle, Reumanet) Continues communication between care givers and professionals (ENOPE, Lovexair, ROCHE)
- *Framework strategy and policy actions* on IAQ, on ventilation and air filtration systems (CAMFIL)

- ***Greater support and information of symptoms signs and screening at national level***, early diagnosis of all chronic diseases (Cancer Research EU, J&J, IDF, UKNCDDTF, UNI\_Zaragossa, WCRFI)
- ***Shifting of the health care to communities level***, (COCIR, CHA, EBL, ECC, EFA, EGS, ERS, Eurocarers, IOM, UNI\_Zaragossa, WHO Europe) with the introduction of referral centres (EBC)
- ***Training for health care providers***, (COCIR, CHA, ELPA, EPHA, EPPOSI, EFPC, FFW, IOF, EPF, MSD, PELVIC\_PAIN, MF, Nestle) patients and care givers (CHA, MF, Nestle, Reumanet) training of professionals regarding the use of new technology, evidence based e-health and telemedicine systems (ESC, Lovexair, MF)
- ***Interoperability between EU, national and local and regional level and raise public awareness about e-health solutions*** (CPME, ECDA) obesity nutrition (EASL, ILCUK, WW) and liver disease(EASL)
- ***Minimum pricing per unit of alcohol sales***, increase of minimum excise duty rates on alcohol, health warnings on all alcoholic beverages (EASL)
- ***Closer coordination between the ministries at a national level for long-term economic planning and increasing labour productivity*** (EFPIA, IOM)
- ***Share information on patients behaviour*** (EGS, ENOPE, EPHA, EPF, Reumanet)
- ***Identify and support of risk groups*** (EGS, EFPC, Nestle, UKNCDDTF)
- ***Territorial repartition of diagnostics centre and the effectiveness of the referral process***, national and regional strategies better coordinating the capacity building of health care professionals in managing chronic diseases (J&J)
- ***Establishment of quality indicators*** (EULAR, ILAE/IBE) for epilepsies (ILAE/IBE)

- ***Close cooperation with national health social and employment ministries, national plans*** (FFW, IDF, ILAE/IBE, ILCUK, IOF) and professionals (GAMIAN, ILCUK, IOF) EU chronic disease national management plan (ROCHE)
- Support and engage in initiatives on chronic diseases ***national advisory boards on health literacy*** (HLS-EU, EPF, MSD)
- ***Political awareness*** (CHA)
- ***Implement a national dementia strategy*** (Alzheimer)
- ***Remote monitoring systems*** for maternal and newborn health (EFCNI)
- ***National audits*** (EFCNI)
- ***Increase investment in research*** (EFIC-PAE)
- ***Adapt innovative technological solutions*** (GSK)
- ***National workshops*** including partners and stakeholders (IOF)
- ***Recognize and utilize of the clinical,*** linguistic and socio-cultural skills of migrant healthcare and social workers (IOM)
- ***Upgrade existing healthcare technology platforms,*** for coordination between secondary and tertiary healthcare (Lovexair)
- ***National guidelines for tobacco*** (SFP)
- ***Financial support to patients organisations at a national level*** (Reumanet)

**B6: What will your organisation contribute to this challenge?**

**AESGP:** Identify and promote new and innovative indications for self-care practices

**AIM:** Generic workflow systems, change management, products and services

**Alexion :** Focused on providing treatments for patients with rare and ultra-rare diseases, particularly those that profoundly affect a person's survival and quality of life, and for which there are few, if any, effective treatment options

**Alzheimer:** Contribution to EU and national discussions and support the implementation of the recommendations

**ABSTD:** Promote understanding of the scientific basis of oral disease

**CAMFIL:** Design high quality energy efficient filtration solutions

**Cancer Research UK:** Funds research into all aspects for cancer from exploratory biology to clinical trials of novel and existing drugs as well as population based studies and prevention research

**CEFS:** At EU and national level they can share knowledge on sugar and its role in a balanced diet as part of a healthy, active lifestyle

**COCIR:** Trade association representing the Medical Imaging, Healthcare IT and Electromedical Industry

**CHA:** Facilitate incorporation between remote monitoring medical technology devices, with the health care industry and service providers and the patients

**CPME:** Inform and raise awareness and advices about e-health and telemedicine

**EASL:** Focus on measures and suggestions on alcohol consumption, liver disease, obesity

**EBC:** Participate in new initiatives and disseminate information

**ECC:** No-for-profit association created to work with all parties interested in fighting chronic obstructive pulmonary disease (COPD) and public health officials to boost awareness of COPD and decrease the morbidity and mortality caused by this respiratory illness, through advocacy and policy development

**ECDA:** Proposes concrete evidence-based policy recommendations that can be adopted to address risk factors, both by European Institutions for EU level and by national governments for Member States

**EFCNI:** Gather the expertise needed for the development of new ICT competences for maternal and newborn health

**ECHAMP:** Offering contacts with stakeholders concerning homeopathic and anthroposophic products

**EFA:** Share best practices collected by its members and tries to implement them in other MSs through EU funded projects and/or EFA projects

**EFIC-PAE:** Create a greater awareness of the condition of Chronic Pain and the negative societal impact of the disease

**EFPIA:** Health promotion programmes support any mechanism of sharing of best practice in the field of medicines

**EGS:** Assist with research in mapping the inequalities of diagnosis and treatment of glaucoma in the EU and to propose protocols to improve overall care in glaucoma

**ELPA:** Sharing experience of successful case examples as regards the management of the disease for Liver patient groups

**ENOPE:** Contributes to the development of chronic disease self management in Europe

**ENSP:** Develop a strategy for co-ordinated action among organisations active in tobacco control in Europe by sharing information and experience and through co-ordinated activities and joint projects and to promote comprehensive tobacco control policies at both national and European levels

**EPHA:** Bring together organisations across the public health community to protect and promote public health in Europe, to share learning and information and to bring a public health perspective to European decision-making

**EPPOSI:** To overcome both the existing gaps and obstacles in the management of chronic conditions in Europe and promote initiatives to tackle the alarming situation and impacts of chronic diseases

**ERS:** To alleviate suffering from respiratory disease through advocacy, research, knowledge sharing and education

**ESC:** Is actively engaged in the education of the cardiology community

**EUGMS:** To identify issues, gaps and suggestions for action to improve current policies and activities on geriatric and chronic diseases, both at national and EU levels'

**EULAR:** Established different recommendations for management, covering various issues such as management of specific musculoskeletal diseases

**EURADIA:** Improve the lives of people affected by diabetes through advocacy of diabetes research in Europe

**Eurocarers:** Contribute to the development of a future initiative on chronic conditions

**EUPHA:** Can add to this policy process on chronic disease by being a platform for the exchange of expertise, knowledge and good practice examples in the field of PHMR

**ECCF:** Promotes rigorous examination of the multiple barriers impacting the implementation of optimal care practices in critical care

**EFPC:** Offers the commitment and active support of its membership to the EU reflection on chronic disease

**EPF:** Represents patients organisations, which are national patients' platforms and chronic disease - specific patient organisations at EU level

**FFW:** To shift the perception of musculoskeletal disorders from being disabling conditions to manageable conditions, ensuring that more European citizens stay in work or return to work, while helping to improve the sustainability of Europe's health and social care systems

**FoodDrinkEurope:** Committed to tackling obesity and diet-related noncommunicable chronic diseases (NCDs)

**GAMIAN:** Could contribute to ensure that the mental health aspects of chronic conditions will be an explicit part of any future action in this field and help formulate required action steps

**GSK:** Offer health communications across multiple new areas from health technology to intelligent medicine, to new services and patient support

**HLS-EU:** Provide business initiative to support the advancement of health literacy at work, hence also for people with chronic diseases in the work force

**IDF:** To promote diabetes care, prevention and cure worldwide

**ILCUK:** Develops routine nutritional screening at the member state level in Europe via our national implementation plan

**IOF:** Launch a new campaign “capture the fracture” reflection secondary fracture prevention care, which is a domain which is reported to be “cost-saving”

**IOM:** Continue to advocate for and support all above as well as the development of migrant friendly health services enabling culturally sensitive health care services

**IPOPI:** Improve awareness, access to early diagnosis and optimal treatments for primary immunodeficiency (PID) patients worldwide

**J&J:** Contribute actively to the development and delivery of chronic care management

**Lovexair:** Developing an e-health platform with an initial clinical history for each patients

**Lundbeck:** Improve the quality of life of people suffering from disorders of the Central Nervous System

**MNI:** Committed to summarising the evidence base for prevalence of nutritional risk and benefits of nutritional intervention, collating information on guidelines related to nutritional intervention and gathering and disseminating good practice examples in order to help drive evidence based practice, legal restrictions for differences in taxation for the beverages and rich in sugar - fat food

**MSD:** Deliver innovative health solutions, increase access to healthcare through far-reaching policies, programs and partnerships

**Oral health:** Providing expert advice and communicating on the need for more integrated oral health and general health to the European oral healthcare workforce (1 million professionals), as well as decision makers

**PELVIC\_PAIN:** Contribute towards a more consistent approach across establishments/disciplines to undergraduate and post graduate initiatives relating to pain education and/or the development of patient pathways for pelvic pain from the patient perspective

**PHA:** Enhance awareness of pulmonary hypertension (PH) across Europe, promote optimal standards of care for people living with the disease, ensure the availability of approved treatments, and encourage research for new medicines and therapies

**SFP:** Promotes tobacco control advocacy and policy research at EU and national levels

**MF:** Enhance user participation in the proposed actions conducive to health and strengthen health democracy

**Nestle:** Apply the best available nutrition knowledge to the development of products that contribute to the health and wellness of our consumers

**PPTA:** Producers of plasma-derived and recombinant analogue medicinal products

**RCN:** Promotes patient and nursing interests on a wide range of issues by working closely with stakeholders

**Reumanet:** Active in rheumatology

**ROCHE:** Expertise in and contributing to joint projects e.g. with different stakeholders at EU and at national level

**SCA:** Expertise in incontinence care and management

**UKNCDTF:** Continue to undertake a wider range of information provision, research and advocacy work

**UNI\_Zaragosa:** Research in the topics of chronic diseases

**WW:** Recommendations to tackle obesity

**WECF:** Advocates at national, EU and international level and implements projects in the fields of water/sanitation, chemicals and health, sustainable agriculture and energy/climate policies, in a global gender perspective

**WCRFI:** Scientific expertise to produce evidence-based policy recommendations for the prevention of cancer that target, among other actors, multinational bodies, governments and the private sector

**No responses on healthcare section B**

**CEFS:** no response in terms of healthcare system but answer on organisation contribution

**EDA:** no comment on organisation contribution

**ESPKU:** no comment on organisation contribution

**EuroCare:** only about prevention nothing on healthcare system

**EUPHA:** no response in terms of healthcare system but answer on organisation contribution

**FAHRE:** only about research

**FoodDrinkEurope:** no response in terms of healthcare system but answer on organisation contribution

**GALEN:** no comment on organisation contribution

**HEAL:** no response in terms of healthcare system

**ILAE/IBE:** no comment on organisation contribution

**INCHES:** no response in terms of healthcare system

**WHO Europe:** no comment on organisation contribution

\*no replies from the **PRIVATE** responses in the QB6

## C) RESEARCH

### C1: How should research priorities change to better meet the challenge of chronic diseases?

*Common message: improved research and harmonised collection of data and indicators.  
Biomedical and Public Health Research are both important*

#### 1. TOPICS OF RESEARCH

##### *Public Health*

- More research is needed on e.g. the 'health in all policies' approach to health and health promotion. More emphasis should be given to research related to the everyday lives of people living with one or multiple chronic diseases - from their perspective and by involving them more. More case studies are needed about the factors that influence individual behaviour and social norms. More studies on social, life style, behavioural determinants (AIM, Alzheimer Europe, COCIR, CPME, ECC, ECDA, EGS, ERS, EFPIA, ENOPE, EPPOSI, EFPC, FoodDrinkEurope, GSK, IDF, Lovexair, MF, WCRF)
- Studies on innovation and integrated health care systems, programmes to develop patient empowerment and patient-centered personalised health care (AIM, Alzheimer Europe, COCIR, CPME, ECC, EFPIA, ENOPE, EPPOSI, EFPC, IDF, GSK, Roche, SCA, UK NCDTF)
- Developing a plurality of health choices and promote access to and availability of the services that consumers and patients require and prefer (ECHAMP)
- Move away from research of risk factors at individual level towards population health approaches and addressing health inequalities and global public health issues (IOM)
- Focus on delivery methods to increase communication and education for prevention of chronic diseases (AESGP, CPME, EASL)

- Research to understand how disease awareness campaigns can be improved to focus on elderly care and the related health and societal impacts.

### ***Biomedical Research***

- Studies on genetic determinants and host factors (Alzheimer Europe, EPHA); on the molecular and cellular basis of specific diseases (rheumatic diseases, osteoarthritis and osteoporosis EULAR, IOA and IOF); on nutrigenomics, functional genomics and epigenetics, metabolomics and proteomics, stem cells and mitochondrial function (Nestle) and on known and emerging risk factors (e.g. environmental factors) (AIM, Camfil Farr, EFCNI, FoodDrinkEurope, HEAL, INCHEM, MF); on cell therapies of rheumatic diseases, especially immune ablation of pathogenic cells, reinstallation of tolerance and regeneration of degenerated or inflamed tissues (EULAR)

### ***Therapeutic approaches***

- Patient focused, patient tailored and innovative therapeutic approaches (ELPA, EULAR, GALEN, Reumanet)
- Finding appropriate and effective treatment for many chronic diseases for which cures currently do not exist (PHA)
- Developing markers that are useful for personalized care approaches, for disease progression and prediction of treatment responses (EULAR, GALEN)

### ***Additional more specific topics***

- Studies on co-morbidities (EFA, EFPIA, EULAR, EFPC)
- Studies on the correlation between different chronic diseases, in order to prevent extrapolation (SCA)
- Studies on the interactions of behaviour, environment and genetics in framing risks and determining outcomes taking into account gender, culture, national health system (EGS)

- More attention to rare and ultra-rare diseases (Alexion, IPOPI, PPTA)
- Implementing research in maternal and newborn health in upcoming research programmes (EFCNI); priority to research aiming to decrease preterm birth rates and prevent chronic diseases related to preterm birth (EFCNI, ECCF)
- Studies on effects of ageing on people in general and/or with specific pathologies, e.g. with PKU (ESPKU, EULAR)
- Priorities should be given to research in those disease areas that are expected to have a higher impact in tackling the physical barriers that prevent people to remain healthy and active for longer years. (EULAR)
- Pain as a focus area (EFIC, PAE, Grunenthal)
- Studies focused on different specific chronic diseases (Chronic Obstructive Pulmonary Disease (ECC), EFA, ESC, Alzheimer Europe, EULAR) e.g. “EU and national authorities should invest in programmes that evaluate opportunities for long-term strategies improving prevention of cardiovascular disease” (ESC)
- Research addressing effective organisation of services to prevent health problems among carers and to improve the prevention of health problems for those who are cared for would therefore be highly relevant. How being a carer influences one’s social participation and inclusion (with a potential effect on mental health and wellbeing) should also be more thoroughly investigated (Eurocarers)
- To establish a research strategy for food and health research (FAHRE)
- With the increasing burden of MSDs on not only health and social care systems, but also the number of days lost to sick-leave and long-term absence from the labour market, funding needs to be targeted on MSDs in order to provide more effective solutions – as well as effective ways for prevention and early intervention. Therefore, MSDs including rheumatic and inflammatory diseases must be prioritised in the next EU Research Framework Programme for 2014-2020 (Horizon 2020). Key areas for

research funding should include more research on developing tools for prevention, early detection and screening (FFW)

- The Commission's new health strategy, Health for Growth, should focus on gathering more evidence on the impact of disease-related malnutrition and formulate tools and instruments for better health and social care planning and implementation (MNI)
- Research in children (PHA)
  
- Research priorities should reflect the impact of oral hygiene on general health by including oral health. There is a need to develop research priorities to bridge the oral health data gap in Europe and specifically to develop epidemiological studies on the healthcare burden of oral disease, as well as to develop the evidence-base related to the socio-economic effectiveness of prevention policies and awareness raising campaigns. More research is also needed to explore and identify the effect of certain treatment protocols for chronic diseases on oral health (e.g. bisphosphonates), with the ultimate purpose to develop agreed guidelines for the dental management of chronic disease patients (Oral\_health)
  
- Observational trials funds should be allocated to studies to demonstrate/prove the concept of post prandial testing as "early diagnosis parameter" in diabetes (Roche)
  
- Acknowledge the value of "observational trials" (Roche)
  
- A strong science base for tobacco-control policy and interventions is essential to improve societal understanding of the effects of tobacco on health and to best direct resources towards its control (SPF)

## **2. METHODOLOGY**

- More involvement of governments, civil society (EPHA, EPPOSI, stakeholders in industry, drug regulatory agencies, academic groups and patient organisations, (GSK) in identifying research priorities

- Multidisciplinary and large-scale / better coordinated/ multinational research/ Joint programming (ECDA, EFCNI, EFA, EGS, ESC, EUGMS, EULAR, EURADIA, GSK, IDF, UKNCDTFF)
- Cost-effectiveness studies or mathematical modelling to predict the impact of research, different programmes of promotion, prevention and management of chronic diseases (AIM, Alzheimer Europe, ECC, ECDA, EFCNI, EFA, EULAR, EURADIA, FFW, IDF, ILAE IBE epilepsy, WHO Europe) on the patient, the public health burden and the losses to society (Lundbeck)
- Studies based on early screening and patient stratification according to risk and response to therapy (EGS)
- Research priorities should change away from research on possible treatments of individual chronic diseases to research on successful lifestyle intervention programmes and behavioural change programmes who might have a much broader effect (EFPC)

### **3. EPIDEMIOLOGY**

- There is a need for developing more harmonised, unified, robust, cost-effective methods to collect data at EU-level e.g. on incidence, prevalence, risk factors and outcomes (EASL, ECDA, EFCNI, ECC, EFA, EFIC, PAE, EFPIA, ENSP, EPHA, ERS, ESC, ESPKU, EULAR, ECCF, FoodDrinkEurope, IDF, WCRF)
- EU should increase efforts to gather data on the prevalence of chronic diseases and to link it with geographic monitoring of pollutants and Human Biomonitoring (HEAL, INCHEM)

### **4. FUNDING**

- Involvement of biomedical community in the definition of the EU funding strategy and research priorities (ESC)
- The next EU Research Framework Programme needs to include specific funding for research which focuses on the linkages between health and employment. The theme

addressing 'Societal Challenges' should include a special focus on health in the workplace and include funding for research on the impact of work on wellbeing. (FFW)

- Greater focus should also be given to funding evaluation, monitoring and surveillance activities relating to ongoing and/or innovative public health policies – not only local and micro-scale interventions, but also population-based interventions (UKNCDTFF)
- Provide infrastructure and funding for important and necessary studies, which are often not accepted by high impact peer reviewed journals and or health technology assessments (examples can be provided on request) when they are financed by industry (Roche)

## **C2: In what areas is there a particular need for additional action at EU level?**

*Common message: coordination in data collection*

### *Harmonization of data*

- Creation of European Institutes for management and research on chronic conditions (AIM, Cancer Research UK, ECC, EUGMS, Uni\_Zaragossa) possibly under the umbrella of an 'European Council for Health Research (EUCHR) that could provide the best strategic scientific leadership to EU programmes in health research (ERS, ESC, EURADIA)
- European coordinated research agenda to create a strategic framework. There is a major gap in translational research in Europe and better care delivery will only be possible if sustainable networks across Europe join together and share their resources to tackle the scientific challenges. (Cancer Research UK, COCIR, EBC, ECC, ECDA, EFCNI, ENSP, EPPOSI, ERS, ESC, EULAR, EURADIA, EFPC, FAHRE, GALEN, GSK, IDF, ILAE IBE, UKNCDTFF)
- Sharing of information on project outcomes (FAHRE, GSK, Oral\_health, Roche, FAHRE recommends that each programme (Horizon 2020, JPI, KICs and also key national programmes) exchange annual (or bi-annual) reports on activities relevant to

food and health research. A summary of progress towards shared objectives, with recommendations for future programming, should also be provided

- Integration of research and its applications, and inter-changeability and boosting of existing structures and resources to optimise efficiency without stifling individuality of approach at the subject level is an outstanding priority and recommended approach towards achieving harmonisation and avoiding duplication of European research policy (AIM, Cancer Research UK, COCIR, ECC, EFPIA, EPPOSI, ECCF, EFPC, PPTA, Roche, UKNCDTFF)
- Common health indicators and common EU data standards to allow the collection of comparable, consistent healthcare indicators. If, as WHO Director General Margaret Chan said, “what gets measured gets done”, the EU needs to better measure its citizen’s health in order to better target its policy efforts (SPF)
- More communication and transparency about different policies and different successes in all Member States can lead to uniformisation and to the adaption of successful policies (EFPC)
- Development of a common framework of data to be collected on Disease Management Programmes within European countries (EFPC)
- Development of European guidelines for specific diseases/ common health data standards/ benchmark for the quality in management (Alzheimer Europe, ECC, ECDA, EFIC, PAE, Grunenthal, EFPIA, ERS, ESC, EFPC, WCFR)
- Use of Health Impact Assessment as a means of promoting effective intersectoral decision making (AIM, WHO Europe)
- Supporting more research frameworks such as the Innovative Medicine Initiative (IMI) (GSK, IDF, MSD, Roche, Uni\_Zaragossa)
- Comparative effectiveness research to obtain evidence based information on best therapies independent of pharmaceutical industry activities (EULAR)

- Processes to narrow any potential gap between researchers and policy-makers are needed, including open and transparent consultation mechanisms and expert advisory committees (WCRF)
- The European Union must close the gap with existing innovation leaders such as the United States, Japan and South Korea.(ILAE IBE)

### ***Funding and Specific research topics***

- Facilitate better access to finance (Cancer Research UK, COCIR, EBC, ECC, EURADIA, UKNCDTFF)
- Increasing the funding available for tackling chronic diseases in all the possible financial instruments at EC disposal (EFA, ESC, EURADIA , Lundbeck)
- Increasing the budget reserved for both basic & clinical research programs in fracture prevention (IOA and IOF)
- R&D incentives for research in specific patient populations, such as the development of specific indication patent extensions, or other such targeted incentives, could also stimulate research efforts towards areas of unmet medical need (EFPIA)
- EU can support "smart regulations" in areas such as the Clinical Trials Directive or the Data Protection Regulation. These regulations give the opportunity to lower the administrative burden for R&D while attracting or at least maintaining the current level of R&D in Europe (MSD)
- EURADIA strongly endorses the Commission's plans to set up this first health-related KIC, which should have a strong focus on chronic disease research
- At EU level, research on the coordination and cooperation in primary care settings should be promoted. Moreover, research on the complexity of the management of combination of several chronic diseases in one patient and his family is necessary to improve the care for chronically ill (EFPC)

- A focus on research on multi-morbidity and co-morbidity can be seen as an area where an additional action at the EU level is needed. Such research covers many domains, and seeks comprehensive tools to elucidate the co-morbidity disease course, while such endeavours expects to seek a different taxonomy and impact on disease management costs (EFPC, Roche, Uni\_Zaragossa); promoting scientific production that addresses crucial conceptual and methodological aspects related to multimorbidity (terms definitions, types of analyses, etc.) and promoting a research network on this issue (Uni\_Zaragossa)
- Creation of an “EC inter service group” on food and health issues (FAHRE)
- Foster the development of national surveillance systems of CDs that include migrant and mobility specific indicators to ensure standardized and comparable data on CD and risk factor burdens among migrants to improve public health planning.
- Funding of EU-wide smoking prevalence surveys that can overcome current methodological limitations should receive a high priority (SPF)
- Update the EC funded ASPECT report which was a summary of tobacco control policies already in place and needing to be introduced across the EU (UKNCDTFF)
- Implement EU wide monitoring of smoking prevalence (currently the different surveys do not match up and we do not have an EU-wide picture so it's hard to measure progress (UKNCDTFF)
- Set up a collaborative network of academic centres based on the model of the UK Centre for Tobacco Control Studies (UKCTCS) but at EU level, engaged in tobacco control and public health research and translating the findings into policy recommendations (UKNCDTFF)
- Greater focus should also be given to funding evaluation, monitoring and surveillance activities relating to ongoing and/or innovative public health policies – not only local and micro-scale interventions, but also population-based interventions (WCRF)

- Toxicology: Research priorities should focus on assessing effects of exposures to multiple chemicals/substances through multiple routes of exposures, taking into account new elements identified by a growing body of scientific evidence, namely: the timing of exposure, combined exposures, non-linear dose-response curves, etc. which challenge classic toxicology (WECF)
- Epidemiology: More epidemiological data should be generated (WECF)
- Biomonitoring: More biomonitoring studies should be generated (WECF)

### *Methodologies*

- Support to a multidisciplinary approach of chronic diseases in the research area should be strengthened (WECF)
- Research methodologies and protocols should evolve to reflect concerns among the scientific community about the incapacity of long-adopted research methods to deal with the chronic disease challenge (WECF)

### **C3: In what areas is there a particular need for additional action at national level?**

- Greater coordination between ministries of research and ministries of health (Cancer Research UK, UKNCDTFF)
- Address the lack of comprehensive epidemiological and economic data on prematurity, prevalence, mortality, acute morbidity and long-term impairment, outcomes and costs (EFCNI)
- Implementation of clear clinical pathways for the treatment and management of Chronic Pain (EFIC, PAE, Grunenthal)
- Member States have a very strong role to play in the adoption of agreed common health standards which will make possible the comparison of data collected across Europe and will consequently contribute to reducing inequalities across Europe (ESC)

- The diversity of European health care systems has the potential to be a laboratory for Chronic Disease care experiments and comparisons. Different conditions and effects can be studied in a scientifically sound way and results of local and national evaluations will be shared among the research community (EFPC)
- Member states are requested to invest more in studying their own health care provision and support the comparative research, in particular how health systems with a strong Primary Care add to better health outcomes for their citizens suffering from Chronic Diseases (EFPC)
- Stepwise models can be implemented in countries with limited capacity and resources that do not have the ability to conduct research in family practice. Stepwise models can include; to be able to identify common ill conditions and health problems, to start with an assessment of population health needs, to identify the burden of common diseases and measure diagnostic probabilities (EFPC)
- National funding programmes should encourage further research into MSDs and work ability. This should include allocation of resources in support of early intervention and treatment and care of MSDs, as well as funding research on the epidemiology and impact of MSDs on the economy (FFW Europa)
- Stronger cooperation and better harmonized standards, e.g. in the area Clinical Trials, to facilitate multinational research projects (MSD)
- Although aligned oral health indicators and collection methodologies agreed by a broad range of experts and public authorities exist at European or international level, national health data collection systems do not always reflect these, resulting in a lack of comparable, well updated and trustworthy healthcare data, which limit the evidence based available for high quality healthcare policymaking, identification and sharing of best practices (Oral\_health)
- Develop new business models at national level involving payers and chronic disease specialists representing diseases with common risk factors and/or dependencies (Roche)

- Develop specific education and care programmes for people with different ethnic and cultural backgrounds, which fully account for the fact that some immigrants may not speak the national language, have different lifestyles and food habits that have to be accounted for (such as fasting periods), especially for diseases where food habits play a decisive role (Roche)
- Research Centres of Excellence involving universities and NGOs across Europe working in the field of tobacco control, conducting research on various tobacco control topics and providing policy work at national and international level to reduce burden caused by tobacco use should be created (SPF)
- Adopting international standards when gathering health information (i.e. adopting international classifications of diseases like ICD or ICPC) (Uni\_Zaragossa)

**C4: What will your organisation contribute to address this challenge?**

**AESGP:** Development and expansion of self-care for new indications and as part of integrated care and self-management programmes

**AIM:** Creation of an European centre of excellence for chronic diseases and conditions

**EFCNI :** as a multi-stakeholder platform for discussions on maternal and newborn health, is regularly engaging with Europe's top experts in these fields and thus is able to identify partners for future EU-funded research projects in this area

**EFIC PAE:** and Grünenthal organise and support platforms and congresses where various stakeholders from the European member states interact. EFIC®, PAE and Grünenthal are committed to moderate the consensus on the benchmark standards in pain management and to provide expertise in setting up pain registries

The European Respiratory Society (**ERS**), the European Society of Cardiology are member of the Alliance for Biomedical Research in Europe (BioMed Alliance), a unique initiative representing 21 leading research-oriented medical societies that include over

200.000 researchers across Europe. The mission of the BioMed Alliance is to advance and strengthen biomedical research, in particular translational research, which is crucial for innovation

**EULAR** is willing to provide its expertise and network to further develop EU strategies for research and innovation in the chronic diseases field

**Eurocarers** would be happy to stay involved with the next steps in the chronic conditions reflection process, to ensure the appropriate inclusion of carers' issues. Given our experience, knowledge and expertise, we would be able to help develop and strengthen the carers dimension of a future initiative. We would like to offer our help with the dissemination of information on a future initiative

**ECCF** will raise awareness of the need for better data at a European level particularly in countries where the greatest inequalities in critical care outcomes can be seen, making the link between critical care and the consequences of sub-optimal outcomes on chronic conditions

The **EFPC** aims to create opportunities for primary care researchers from different disciplines and countries to share knowledge for the benefit of primary care research in the field of chronic diseases. Insufficient coordination continues to be a major cause for lack of responsiveness and poor efficiency of health systems, in particular when it comes to chronic diseases

**FAHRE** Strategic Proposals report” published for consultation in October 2011 recommended the creation on the EU-level of a Coordinating Research Agency, with budget and representation from the three EU directorates Agriculture, Health and Research, the member states, and non-governmental stakeholders including and civil society and industry.

**FFW** has developed FFW country reports and a pan-European report which assesses the impact of MSDs on countries and provides recommendations for policymakers and stakeholders. These reports have provided information, data and statistics on the impact of

MSDs, as well as highlighting solutions to the issues by providing recommendations for policymakers, healthcare professionals, employees and employers.

**GSK** is actively participating in the IMI, collaborating with academia and SMEs and engaging in innovative public private partnerships that foster research

**IOF** has a lot of research supporting activities; see website: [www.iofbonehealth.org](http://www.iofbonehealth.org)

In Belgium the **BBC** is a well organized university-level research group, representing all involved clinical discipline in fracture prevention. The BBC is rewarding researchers by a variety of awards : carrier award, travel award for young scientist, yearly awards for the best congress presentation, best publication and best clinical or preclinical research project

**MNI** is committed to gathering and summarising the evidence on the prevalence of nutritional risk and financial consequences of malnutrition

**MSD** is involved in several work streams through industry associations such as EFPIA, EBE, EuropaBio and AmCham EU

The **MF** develops little research, but subsidizes research organizations on priority issues such as reducing health inequalities

The Platform for Better **Oral\_health** in Europe seeks to develop the knowledge base and strengthen the evidence-based case for EU action on oral health

**Roche** is actively involved in the public-private partnership IMI, the Innovative Medicines Initiative, in order to improve collaboration between all stakeholders involved in healthcare research and contribute to pre-competitive findings that help us better understand the underlying mechanisms of the disease.

## D) INFORMATION AND INFORMATION TECHNOLOGY

### **D1: What more needs to be done on the development of information and data on chronic diseases?**

*Common message: it is imperative that the interpretation, dissemination and transferability of the information be effective and accessible. In addition, data and information pertaining to the monitoring and knowledge of chronic disease in Europe could benefit from a central coordination point, making available this information to the public in a user friendly manner.*

- Development of an appropriate policies to promote, facilitate and regulate the use of innovative technology, identifying obstacles in the collection of data and developing standards for interoperability - always in compliance with applicable legislative, regulatory, ethical and privacy protection requirements and policies (AESGP, AIM, EFIC, PAE, ENSP, EFPC, EFPC, GALEN, IOF, MNI, MF, Roche, WHO Europe)
- Mechanisms for providing and strengthening data linkage in the face of privacy and data protection concerns. Even as the need for intersectoral action increases, the ability to link and disaggregate data is being threatened (WHO Europe)
- EU should promote data to be centrally collected and support standardisation to obtain comparable and meaningful figures on different aspects of chronic diseases , e.g. through the development of Registries at European level (AIM, Alzheimer Europe, CHA, ECDA , EFA, EFIC, PAE, Grunenthal, EGS, ERS, ESC, ESPKU, ECCF, EFPC, FfW Europe, GSK, IDF, IPOPI, Lovexair, MNI, MF, Nestle, Oral\_health, PPTA, Reumanet, Roche, UKNCDTFF, Uni\_Zaragossa, WECF)
- The pre-eminent need here is for the development of integrated monitoring systems. Work is needed to reconcile monitoring systems, to standardize data collection among agencies, and to create new capacity for defining the social determinants of health. This needs discussion between the Member States, the EC, and WHO/Europe (WHO Europe)

- Interoperability of health data on chronic diseases is an important factor to conduct clinical trials more efficiently, to address significant unmet medical needs more expediently, to improve patient safety, and to enhance quality of patient care (Roche)
- Implementation of ICT, e-Health, e-Prescribing, tele-health systems, Imaging technologies, use of electronic patient files/electronic patient records (EHR) in general practices (AIM, Alzheimer Europe, COCIR, CHA, ECC, ECDA, EFA, EFPIA, EGS, EUGMS, Eurocarers, EFPC, GALEN, IOF, Lovexair (but without losing the human contact), Nestle, RCN UK, Reumanet)
- Clinical-administrative databases resulting from registries and electronic health records available to researchers, so that long term follow-up studies could be designed and developed (Uni\_Zaragossa)
- Creation and dissemination of peer-reviewed, non-commercial and sound information on chronic diseases, medicines and treatments as part of a coherent strategy for EU health information (ECC, EFA, Lundbeck)
- An European database on health-care organisation for chronic conditions is needed (EFPC, FFW Europe)
- Development of European Observatories (Alzheimer Europe)
- Key indicators of progress of chronic diseases and associate determinants must be agreed amongst the Member States that take into account the resources available in each one and other national specifics (EGS)
- Expanding the mandate of the ECDC to include the monitoring and surveillance of major NCDs (ECDA)
- Cooperation with WHO in view of the Action Plan for a strategy on NCDs and OECD and medical/scientific societies should be strengthened (ECDA, Lundbeck)

- The Management of Chronic Diseases could be used as a pilot from the EU Commission in order to generate relevant information and data in order to measure the value of diseases management programmes (GSK)
- Data collection can become more complicated in the case of chronic diseases that are stigmatised by public opinion (often the case for mental health and dependence-related diseases). Policy makers should therefore collaborate with the scientific community in order to ensure the best procedures for the collection of information (Lundbeck)
- Awareness campaigns for patients at risk of chronic disease targeted awareness campaigns and training programmes are needed for those chronic conditions that are currently less visible, such as Pulmonary Hypertension (PHA)
- On-line courses covering the basics on intervention of diseases based on best practice guidelines (EGS)
- Inclusion of pain management quality outcomes in Heidi - Health in Europe:
- Information and Data Interface (EFIC, PAE, Grunenthal)
- Inclusion of liver disease tests and questions in both the European Health Examination Survey and the Health Interview Survey (ELPA)
- Mapping of Vitamin D deficiencies as well as overall of populations that are exposed to a higher risk of developing a chronic disease needs to be further considered (CPME)
- Addressing the oral health data gap in Europe should be a key priority. Across Europe, there is a need for consistent, regularly updated and comparable data on all healthcare issues to support better evidence based policy making and planning of healthcare systems and strategies (Oral\_health)

## **E) ROLE OF MEMBER STATES, THE EU AND STAKEHOLDERS**

### **E1: What are additional activities on chronic disease beyond the four areas described above should be considered at EU level?**

- To ensure an effective EU strategy on chronic diseases (COCIR, EFA, EPPOSI, ERS, Eurocarers, EPF, ROCHE), it is essential that all relevant stakeholders, including patient organisations, older persons' organisations, youth organisations, health professionals' organisations, and health and civil society organisations, are engaged and involved in the policy-making process as well as implementation of the strategy (COCIR, EPF, FDE, GSK, IDF, SFP, WCRFI, PRIVATE\_KV) EU strategy focus on inequalities (EPF, IOM, EUPHA), and accommodating patients with chronic diseases in the workplace (EPF) health literacy / information (EPF, EUPHA, HLS-EU, PRIVATE\_KV) on healthy eating and food safety (FAHRE) employment and social affairs policies (FFW) to allergies and asthma (GALEN) chronic pain (EFIC-PAE) prevention, early detection, personalised diabetes management model (ROCHE) cross country studies, investment in evaluation, monitoring and surveillance activities (WCRFI), children and people with impairment or handicap (PRIVATE\_AS)
- Sharing with and collaborating with OECD and WHO on chronic disease topics, going beyond health issues by taking overall social organisation into consideration and evaluating its impact on health, systematically considering the impact on health of decisions taken in other fields (AIM,UKNCCDDTF) reinstate the WHO original ten targets at the World Health Assembly in May and extend the range of indicators including alcohol, obesity, diet (Cancer research UK, UKNCDDTF)
- Monitoring: any initiative on chronic diseases will have to be assessed and reviewed on a regular basis to ensure that the gaps and needs are fully addressed. It will be important to monitor how the Member States will implement the various recommendations produced by the different EU initiatives (Alzheimer Europe, ALCOVE, EIP AHA, EU 2020, EUPHA) creation of EU 'body' whose main responsibility will be the monitoring and reporting of the situation of chronic diseases, EU coordinating role via the formation of a European governance mechanism to coordinate across stakeholders (EGS, EUPHA)

- Improve medical education curricula (EFCNI), ensure equal level of education that exists between Member States, awareness and education to all stakeholders (CHA, ILCUK, Lovexair, PELVIC\_PAIN, PRIVATE\_KV) specialized training, education for citizens concerning health economics (Lovexair) improve education and post-academic formation of health care professionals in the field of chronic diseases, accreditation of professionals and the quality labelling (EFPC) education campaigns across society (MNI, Nestle, PELVIC\_PAIN)
- Patient centred EU guidance, (EFA, Lundbeck) higher coordination with Member states, promotion of best practices and best interventions on chronic disease (ERS) best practices at the Member States level, national measures (EFA, FFW, Lundbeck, MNI, Nestle)
- Strengthening financing programmes, public private partnership (PPP) (GSK, IOM, Nestle) cross - sectoral partnership (IOM, Nestle) multi-stakeholder partnership (Nestle)
- Close cooperation among different EC DGs, create flexible working environments and conditions (EULAR, Eurocare) among inter-sectoral approach (IOM)
- Setting targets: in the case of dementia, we should envisage to increase the diagnosis rate by at least 50 % by 2020 (Alzheimer Europe)
- Indoor Air Quality (Camfil Farr)
- UN High Level Meeting on prevention and control of NCDs in September 2011. We are concerned that there have been some significant changes to the goals on NCDs proposed in the WHO discussion paper<sup>19</sup> including:
  - The number of proposed targets has gone down from 10 to 5
  - Two of the original targets are still in: mortality and blood pressure, but both have 25% relative reductions
  - Two of the original targets have been changed:

- tobacco down from 40% to 30% relative reduction
- salt from 5gms per day to 30% relative reduction with aim to achieve 5gms per day
- Gone are the targets on diabetes, alcohol, transfats, obesity, multi-drug therapy, cancer screening (Cancer research UK)
  
- The global targets need to be realistic, with a process and timeline for additional targets. Also call on the EU and Member States to invest time and resources to this and invite civil society into this process (Cancer research UK)
  
- Recognise obesity as a leading cause of chronic liver disease, promote data gathering through the monitoring, reporting and surveillance of obesity trends as well as its correlation to liver disease incidence, strengthen policy initiatives in major chronic diseases which are linked to obesity, develop soft-law measures and tools into monitored and measurable results at the EU and national level, raise public awareness on the correlation between ill-nutrition, obesity and liver disease amongst European citizens (EASL, MNI)
  
- Collection of comparable data (EPPOSI)
  
- Extending the mandate of the European centre of Disease control (ECDC) to cover the chronic non-communicable epidemic (ERS)
  
- Consideration of Health Technology Appraisals (HTA) and health economics evaluation with a societal and health care system perspective (FFW)
  
- Facilitate voluntary commitments made by stakeholders (FDE)
  
- For airway disease, the role of microbiome, but also specific germs and their survival techniques to chronically colonize the airway mucosa need to be determined, support from the EU (GALEN)
  
- Implementation of routine nutrition-risk screening across the EU (ILCUK, Nestle)

- Patient perspective and preferences should be taken care of in order to optimise compliance (IOF)
- Exploring opportunities in the priority areas set by the European Innovation Partnership on Active Healthy Ageing (AHAIP) (MNI)
- Need to ensure effective implementation of FCTC Article 5.3 and its guidelines (SFP)
- Secondary and tertiary prevention (PRIVATE\_AS)

**E2: How can the EU engage stakeholders more effectively in addressing chronic diseases?**

- Stakeholders and EU-institutions should have a sincere dialogue on how to best tackle chronic disease, use the experience and expertise of stakeholder groups by the EU and Member States, as they share common objectives and interests (AESGP, EPPOSI, WECF) increase participation of all stakeholders involving subgroups stakeholders at EU level (EGS, EPPOSI, ERS, EULAR, EPF) updating the invitation list including newcomers (EGS) encourage the EU to support stakeholders' initiatives that truly deliver the expected health benefits to consumers, based on the European scientific opinions (CEFS)
- Raise public awareness (EFCNI, EULAR, J&J, ILCUK, MNI, MSD, Nestle), establishment of 'Chronic Condition Day' (EFCNI)
- The EU should set up a Chronic Diseases Task Force with EU policy makers, national policy makers, healthcare professionals and patient representatives covering both chronic diseases and unpreventable chronic diseases (Alzheimer Europe, ERS, ILAE/IBE) like Alzheimer's disease and other forms of dementia (Alzheimer Europe) on epilepsy (ILAE/IBE). Adequate logistic and financial support must be granted to the patient representatives who will be on the Task Force (Alzheimer Europe) Ensure coherence with on-going WHO and UN initiatives in this field, to avoid unnecessary duplication and to benefit from the work already done so that we can make a real step

forward (COCIR, EULAR, Eurocare, EUPHA). Ensure coherence and synergies among EU initiatives/policies. Cooperation among different EC DGs (COCIR, EULAR, Eurocare). Consultation with all relevant health stakeholders, patients, insurers, health professionals, industry, etc, should be increased (COCIR)

- Joint actions for projects, support stakeholders on specific chronic disease areas / issues (CPME, EBC, EPHA, ESPKU, GALEN, WW) specific funding for collaborative projects (MSD) increase funding for nutrition (Nestle) maximise the use of resources in (PELVIC\_PAIN) focus on specific topics in simultaneous programmes rather than all chronic disease on one program, support funding participation by pain patients organisations and experts (EFIC-PAE) funding European patient organisations and patient – related projects (EULAR, EFPC, EUPHA)
- Partnership between scientific societies and healthcare professionals, patients and industry (EBC, EPPOSI, EULAR) development of shared agendas and act as single point of contact to their area (EBC) consultation procedures among stakeholders to gather most appropriate inputs (EPPOSI)
- Invitation for prevention projects that go beyond the determinants that are directly linked to health, evaluation of the projects and creation of a database of actions and programmes of which the effectiveness and efficiency would be known (AIM)
- Stakeholders and patient associations may help chronic diseases reach the top of the political agenda, constructive participation of stakeholders in relevant policy formulation should be guaranteed (EFA)
- EU should exclude the tobacco industry from any engagement in addressing chronic and other diseases, and public health in general (ENSP) protection of public health policies from the commercial and other vested interests of the tobacco industry (SFP)
- Developing an expert patient partners' platform (EULAR, Oral\_health, WW) communication and stakeholders partners' platform (IOF, Oral\_health) innovative platforms for knowledge exchange among best practices (EFCNI, FFW, J&J, IOF)

- Through definition of key objectives and support stakeholders and patients participation (Lovexair)
- Evidence based medicine (GSK) information (PELVIC\_PAIN) actions (WCRFI)
- Supporting creation of an European Research Network on this issue, integrating efforts coming from the fields of health, education, technology and social services, avoiding a commercialization of this issue, which is likely to deliver in a disorganised development of technologies (UNI\_Zaragossa)
- EU must oblige the member states to contact the patients organisations the patients and the carers (PRIVATE\_AS)
- New technologies, address target groups, social networking sites (PRIVATE\_KV)

**E3: How can the EU Member States engage stakeholders more effectively in addressing chronic diseases?**

- Harmonised approach to specific disease (ESPKU, PELVIC\_PAIN)
- Invitation for prevention projects that go beyond the determinants that are directly linked to health, evaluation of the projects and creation of a database of actions and programmes of which the effectiveness and efficiency would be known (AIM)
- Encourage the Member States to support stakeholders' initiatives that truly deliver the expected health benefits to consumers, based on the European scientific opinions (CEFS)
- Involvement of the society (CPME)
- Participation in EU platforms that encourage an exchange of best practices, implementation approved guidelines, set up targeted action plans, participation in expert groups at EU level and engagement with patient groups nationally (EFCNI,

FFW, J&J, Oral\_health, WW) establishment of a national, regional and community platform for the exchange of knowledge and best practices (EPPOSI, WW)

- Focus on specific topics in simultaneous programmes rather than all chronic disease on one program, support funding participation by pain patients organisations and experts (EFIC-PAE) including pelvic pain (PELVIC\_PAIN)
- Increase participation of all stakeholders involving subgroups stakeholders at national level (EGS, J&J, WECF) and updating the invitation list including newcomers (EGS)
- EU to exclude the tobacco industry from any engagement in addressing chronic and other diseases, and public health in general (ENSP)
- EU Member States should consult with relevant stakeholders (ERS, EPF, (PRIVATE\_KV) Member States together with stakeholders should jointly focus on how new strategies on continuity and integrated care systems have a strong component for the sustainability of health systems, implementation of integrated care models can be addressed within the existing national and regional EU funding schemes (EPHA, IDF)
- Develop supportive CCM programmes and policies, guidelines, measures and resources at the practice level, mutual exchange of data and information, common planning and managerial responsibilities and agreed mechanisms of cooperation (cross-departmental committee, inter-disciplinary committee, joint task force) (EPPOSI)
- National strategic plans for users involvement, national governments and insurers should fund national and regional patients' organisations, promote access to self-management at local level (EULAR)
- Re-orientating their interventions towards more equity, solidarity, cost-effectiveness, quality, personalised care, sustainability innovation and replacing commercialisation of care (EFPC)

- Build small and efficient chronic disease management committees representing different chronic diseases, composed of representatives from the stakeholder community, perhaps following the EUCERD (European Union Committee of Experts on Rare Diseases) model (ROCHE)

## **F) OTHER AREAS**

### **F1: What additional areas for action should be considered? Which of these should be addressed by activities within the EU Member States? Which should be addressed through activities involving cooperation at EU level?**

- Opportunities to the adoption of personal connected health and tele-health (CHA) different national and regional regulations, general reimbursement policies and levels of awareness (CHA, ILCUK, Nestle)
- Joint actions across EU (EBC, ESPKU, Oral\_health)
- Health care policies including targeting chronic conditions should integrate perspectives of health inequalities (EPHA, ESC, EULAR, IDF, IOM, Lundbeck, MF, Oral\_health) and gender inequality (EPHA)
- Chronic pain should be considered as an essential part of European and national policy-making on chronic diseases and as a health state to be treated as a disease in its own right, (EPPOSI) EU Member States should follow the examples of countries enacting national plans (EPPOSI, FFW, Lundbeck) against pain and implementing integrated approaches in pain management, extending the targeted population of policy response to chronic conditions and diseases to newborn infants (EPPOSI) phenylketonuria (ESPKU) on Musculoskeletal disorders (MSDs) (FFW)
- EU to ensure that the EU rare-disease policies are fully implemented and that patients suffering from rare and ultra-rare diseases are not discriminated. Member States should prepare national plans. European Union to coordinate national efforts and

avoid the development of incoherent approaches to rare and ultra-rare diseases (Alexion)

- Informal carers of people are a population prone to chronic diseases themselves. They need to be an integral part of the chronic disease strategy (Alzheimer Europe, Eurocarers)
- Indoor Air Quality (Camfil Farr)
- Keep 10 goals from UN NCD Summit, the Statement (on Conflicts of Interest) focuses on the lack of clarity regarding the role of the private sector in public policy-making and calls for the development of a Code of Conduct and Ethical Framework to help protect the integrity of, and to ensure transparency in, WHO's Europe public policy decision-making, by safeguarding against, identifying and managing conflicts of interest (Cancer research UK)
- ICT solutions, development of synergies amongst those institutional stakeholders that are early adopters of policies favoring the uptake of ICT-enabled products and services for chronic disease and the whole of the EU. The sharing of evidence of the benefits and the cross-fertilization of policies will contribute to a gradual harmonization of the market conditions in Europe, creation of a fertile ecosystem of interoperable products and services, the development of public financing of innovative demonstrator projects and pre-commercial procurement of innovative solutions, sustained support for the use of EU structural funds through community-based disease prevention and management programs (CHA)
- Professional autonomy of health care professionals and task shifting, safe and high quality delivery of health services (CPME)
- Promote the adoption of common health data standards collected across Europe by different stakeholders (ECDA, ESC) implementation of cross-border health care directive, strengthening cooperation with WHO, OECD and medical / scientific societies in view of action plans, introduction at EU level a unique patient

identification number, avoid duplication of data collection, monitoring and reporting on action taken by Member States (ECDA)

- Chronic pain needs higher prioritization by both healthcare policy makers and relevant government department, EU base to development bench marketing tool together with stakeholders, right to receive pain management into European policy paper (EFIC-PAE)
- Carry out a comprehensive assessment of the chronic disease landscape and identify those conditions that can be classified as chronic (EFPIA)
- Direct link between chronic disease and funding programmes with long term commitment of national funding agencies around an agreed set of priorities, political support from governments (EGS) ensure short and medium term resources allocation, reduce the burden of chronic conditions (ECCF)
- Common health care standards (ESC)
- Measures that support carers, facilitate combining work and family life, protection of pension eligibility and entitlements (Eurocarers)
- The contribution of health systems to equity in health from a 'human rights' perspective, the need for innovation on health professional education (EFPC)
- Information and best practices on HTA and health economic evaluation strategies, increase cross-governmental discussions (FFW)
- Environmental prevention opportunities (HEAL, INCHEM, WECF)
- Newborn screening (IPOP)
- Definition of chronic conditions, conditions that are caused by a genetic defect such as plasma-related disorders (PPTA)

- NCDs must be integrated into national goals as well as the Millennium Development Goals (MDGs) and into any successor framework after 2015 when the MDGs expire (UKNCDDTF)

**No contribution in both E and F sections.**

ABSTD, ECC, ECHAMP, EDA, ELPA, ENOPE, EUGMS, EURADIA, GAMIAN, PHA, RCN, Reumanet, SCA, WHO Europe, PRIVATE\_ER

## ANNEX 1.

### List of responses

a/a	Acronym	Society	Received	email	Contact Person	Description
1	Alexion	Alexion Pharma	13 APR	<a href="mailto:LeDezL@alxn.com">LeDezL@alxn.com</a>	Le Dez, Lugdivine	Industry
2	Alzheimer	Alzheimer Europe	30 APR	<a href="mailto:annette.dumas@alzheimer-europe.org">annette.dumas@alzheimer-europe.org</a>	Annette Dumas	Health Professionals
3	AESGP	Association of the European Self-Medication Industry	17 APR	<a href="mailto:G.Yiangou@AESGP.eu">G.Yiangou@AESGP.eu</a>	George Yiangou	Industry
4	ABSTD	Association of Basic Science Teachers in Dentistry	15 APR	<a href="mailto:jon.bennett@pds.ac.uk">jon.bennett@pds.ac.uk</a>	Dr Jon Bennett	Health Professionals
5	AIM	Association Internationale de la Mutualité	15 APR	<a href="mailto:philippe.swennen@aim-mutual.org">philippe.swennen@aim-mutual.org</a>	Philippe Swennen	Industry
6	CAMFIL	Camfil Farr	30 APR	<a href="mailto:Cecile.Nourigat@bm.com">Cecile.Nourigat@bm.com</a>	Nourigat, Cecile	Industry
7	COCIR	European trade association representing the Medical Imaging, Healthcare IT and Electromedical industry	13 APR	<a href="mailto:libert@cocir.org">libert@cocir.org</a>	Marie-Astrid Libert	Industry
8	CHA	Continua Health Alliance	15 APR	<a href="mailto:mario.romao@intel.com">mario.romao@intel.com</a>	Romao, Mario	Industry
9	Cancer Research UK	Cancer Research UK	17 APR	<a href="mailto:Layla.Theiner@cancer.org.uk">Layla.Theiner@cancer.org.uk</a>	Layla Theiner	NGOs and umbrella organisations
10	CEFS	Comité Européen des Fabricants de Sucre	12 APR	<a href="mailto:emilie.leibovitch@cefs.org">emilie.leibovitch@cefs.org</a>	Emilie Leibovich	Industry
11	CPME	Comité Permanent des Médecins Européens	18 APR	<a href="mailto:anamaria.corca@cpme.eu">anamaria.corca@cpme.eu</a>	Anamaria Corca	Health Professionals
12	EASL	European Association for the Study of the Liver	15 APR	<a href="mailto:margaret.walker@easloffice.eu">margaret.walker@easloffice.eu</a>	Margaret Walker	Health Professionals
13	EBC	European Brain Council	15 APR	<a href="mailto:Alastair.g.benbow@btinternet.com">Alastair.g.benbow@btinternet.com</a>	Alastair Benbow	NGOs and umbrella organisations
14	ECC	European COPD Coalition (ECC)	15 APR	<a href="mailto:catherine.hartmann@copdcoalition.eu">catherine.hartmann@copdcoalition.eu</a>	Catherine Hartmann	Industry
15	ECHAMP	European Coalition on Homeopathic and Anthroposophic Medicinal Products	11 APR	<a href="mailto:amandine.oset@echamp.eu">amandine.oset@echamp.eu</a>	Amandine Oset	Industry
16	EFA	European Federation of Allergy and Airways Diseases Patients' Associations	25 APR	<a href="mailto:roberta.savli@efanet.org">roberta.savli@efanet.org</a>	Roberta Savli	NGOs and umbrella organisations
17	EGS	European Glaucoma Society	13 APR	<a href="mailto:dime@btinternet.com">dime@btinternet.com</a>	Ioanna S M Psalti	NGOs and umbrella organisations
18	ELPA	European Liver Patients Association	14 APR	<a href="mailto:kautz@elpa-info.org">kautz@elpa-info.org</a>	Achim Kautz	Patients Disease specific org.
19	ENOPE	European Network on Patient Empowerment	14 APR	<a href="mailto:kickbusch@bluewin.ch">kickbusch@bluewin.ch</a>	Ilona Kickbusch	NGOs and umbrella

						organisations
20	EPHA	European Public Health Alliance	13 APR	<a href="mailto:m.kosinska@epha.org">m.kosinska@epha.org</a>	Monika Kosinska	NGOs and umbrella organisations
21	EFPIA	European Federation of Pharmaceutical Industries and Associations	16 APR	<a href="mailto:francoisbouvy@efpia.org">francoisbouvy@efpia.org</a>	Francois Bouvy	Industry
22	EPPOSI	European Platform for Patients Science and Industry	14 APR	<a href="mailto:andrea.pavlickova@epposi.org">andrea.pavlickova@epposi.org</a>	Dr Andrea Pavlickova	NGOs and umbrella organisations
23	ERS	European Respiratory Society	13 APR	<a href="mailto:brian.ward@ersnet.org">brian.ward@ersnet.org</a>	Brian Ward	Health Professionals
24	EUGMS	European Union Geriatric Medicine Society	4 APR	<a href="mailto:cmarking@skynet.be">cmarking@skynet.be</a>	Christine Marking	Health Professionals
25	EuroCare	European Alcohol Policy Alliance	13 APR	<a href="mailto:aleksandra.kaczmarek@eurocare.org">aleksandra.kaczmarek@eurocare.org</a>	Aleksandra Maria Kaczmarek	NGOs and umbrella organisations
26	Eurocarers	European Association Working for Carers	7 APR	<a href="mailto:info@eurocarers.org">info@eurocarers.org</a>	Frank Goodwin	Patients Disease specific org.
27	EULAR	European League Against Rheumatism	23 APR	<a href="mailto:brussels@eular.eu">brussels@eular.eu</a>	Frederico Torres	NGOs and umbrella organisations
28	ECCF	European Critical Care Foundation	13 APR	<a href="mailto:h.brewer@euroccf.org">h.brewer@euroccf.org</a>	Helen Brewer	Health Professionals
29	ECDA	European Chronic Disease Alliance	16 APR	<a href="mailto:Emilia.Miloiu@interel.eu">Emilia.Miloiu@interel.eu</a>	Miloiu, Emilia	NGOs and umbrella organisations
30	EFCNI	European Foundation for the Care of Newborn Infants	14 APR	<a href="mailto:silke.mader@efcni.org">silke.mader@efcni.org</a>	Silke Mader	NGOs and umbrella organisations
31	EDA	European Dairy Association (EDA)	11 APR	<a href="mailto:MPRELLER@euomilk.org">MPRELLER@euomilk.org</a>	Mareike Preller	NGOs and umbrella organisations
32	EFPC	European Forum for Primary Care	14 APR	<a href="mailto:d.aarendonk@euprimarycare.org">d.aarendonk@euprimarycare.org</a>	Diederik Aarendonk	Health Professionals
33	ENSP	European Network for Smoking and Tobacco Prevention	13 APR	<a href="mailto:francis.grogna@ensp.org">francis.grogna@ensp.org</a>	Francis Grogna	NGOs and umbrella organisations
34	EPF	European Patients' Forum	11 MAY	<a href="mailto:laurene.souchet@eu-patient.eu">laurene.souchet@eu-patient.eu</a>	Laurène Souchet	Patients Disease specific org.
35	ESC	European Society of Cardiology (ESC)	13 APR	<a href="mailto:sokelly@escardio.org">sokelly@escardio.org</a>	Sophie O'Kelly	Health Professionals
36	ESPKU	European Society of Phenylketonuria	23 APR	<a href="mailto:langelizzard@hotmail.com">langelizzard@hotmail.com</a>	eric lange	Patients Disease specific org.
37	EURADIA	Alliance for European Diabetes Research	13 APR	<a href="mailto:Sarah.Hills@euradia.org">Sarah.Hills@euradia.org</a>	Sarah Hills	NGOs and umbrella organisations
38	FAHRE	Food and Health Research	19 APR	<a href="mailto:olivier.chartier@euroquality.fr">olivier.chartier@euroquality.fr</a>	Olivier Chartier	Health Professionals
39	FDE	FoodDrinkEurope	13 APR	<a href="mailto:d.jacobs@fooddrinkeurope.eu">d.jacobs@fooddrinkeurope.eu</a>	Dirk Jacobs	Industry
40	FFW	Fit For Work Europe/ Abbott	15 APR	<a href="mailto:fitforwork@webershandwick.com">fitforwork@webershandwick.com</a>	Stephanie	NGOs and umbrella

					Chauvet	organisations
41	GA2LEN	Global Allergy and Asthma European Network	16 APR	<a href="mailto:Ingrid.Van-Hofman@charite.de">Ingrid.Van-Hofman@charite.de</a>	van Hofman, Ingrid	NGOs and umbrella organisations
42	GAMIAN	Gamian Europe	4 APR	<a href="mailto:executive.director@gamian.eu">executive.director@gamian.eu</a>	Paul Arteel	Patients Disease specific org.
43	GRU - EFIC - PAE	Grunenthal EFIC	8 APR	<a href="mailto:Norbert.vanRooij@grunenthal.com">Norbert.vanRooij@grunenthal.com</a>	Rooij van, Norbert	Health Professionals
44	GSK	GlaxoSmithKline	13 APR	<a href="mailto:sandra.x.gaisch@gsk.com">sandra.x.gaisch@gsk.com</a>	Sandra Gaisch	Industry
45	HEAL	Health and Environment Alliance	18 APR	<a href="mailto:anne@env-health.org">anne@env-health.org</a>	Anne Stauffer	NGOs and umbrella organisations
46	HLS-EU	Maastricht University	13 APR	<a href="mailto:k.sorensen@maastrichtuniversity.nl">k.sorensen@maastrichtuniversity.nl</a>	Sorensen Kristine (INTEGRITY)	Academic institutions and researchers
47	ILAE/IBE	International League Against Epilepsy/International Bureau for Epilepsy	13 APR	<a href="mailto:eoin@epilepsycongress.org">eoin@epilepsycongress.org</a>	Eoin Sheanon	Health Professionals
48	IOF	International Osteoporosis Foundation and Belgian Bone Club (BBC)	15 APR	<a href="mailto:Stefan.Goemaere@UGent.be">Stefan.Goemaere@UGent.be</a>	Stefan Goemaere	NGOs and umbrella organisations
49	IDF	International Diabetes Federation European Region	13 APR	<a href="mailto:Katie.Gallagher@idf-europe.org">Katie.Gallagher@idf-europe.org</a>	Katie Gallagher	NGOs and umbrella organisations
50	ILCUK	International Longevity Centre - UK , European nutrition for health alliance	13 APR	<a href="mailto:LisaWilson@ilcuk.org.uk">LisaWilson@ilcuk.org.uk</a>	Lisa Wilson	NGOs and umbrella organisations
51	INCHES	International Network on Children's Health, Environment and Safety	13 APR	<a href="mailto:pvdhazel@upcmail.nl">pvdhazel@upcmail.nl</a>	Peter van den Hazel	NGOs and umbrella organisations
52	IOM	International Organisation for Migration	14 APR	<a href="mailto:RPETROVABENEDICT@IOM.INT">RPETROVABENEDICT@IOM.INT</a>	Petrova-Benedict Roumyana	NGOs and umbrella organisations
53	IPOPI Firside	Interantional Patient Organisation for Primary Immunodeficiencies	13 APR	<a href="mailto:magda@ipopi.org">magda@ipopi.org</a>	Magda Lourenço	Patients Disease specific org.
54	JnJ	Johnson & Johnson	10 MAY	<a href="mailto:shogan10@its.jnj.com">shogan10@its.jnj.com</a>	Stephen Hogan	Industry
55	Lovexair	Lovexair Foundation	15 APR	<a href="mailto:contacto@lovexair.com">contacto@lovexair.com</a>	Shane Fitch	Health Professionals
56	Lundbeck	Lundbeck	14 APR	<a href="mailto:MDAO@lundbeck.com">MDAO@lundbeck.com</a>	Maria Brandao	Industry
57	MNI	Medical Nutrition International Industry	13 APR	<a href="mailto:Ceri.Green@nutricia.com">Ceri.Green@nutricia.com</a>	Dr Ceri Green	Industry
58	MF	Mutualite Francaise	13 APR	<a href="mailto:Cornelia.FEDERKEIL-GIROUX@mutualite.fr">Cornelia.FEDERKEIL-GIROUX@mutualite.fr</a>	Cornelia Federkeil	Health Professionals
59	MSD	Merck Sharpe Dome	15 APR	<a href="mailto:alexander_roediger@merck.com">alexander_roediger@merck.com</a>	Roediger, Alexander	Industry
60	Nestlé	Nestlé	25 APR	<a href="mailto:Cecile.DuprezNaudy@nestle.com">Cecile.DuprezNaudy@nestle.com</a>	Cécile Duprez-Naudy	Industry

61	Oral_health	OralHealth Platform	13 APR	<a href="mailto:david.carroll@hkstrategies.com">david.carroll@hkstrategies.com</a>	David Carroll	Industry
62	Pelvic_Pain	Pelvic Pain Support Network	13 APR	<a href="mailto:info@pelvicpain.org.uk">info@pelvicpain.org.uk</a>	Judy Birch	NGOs and umbrella organisations
63	PHMR	EUPHA section on Public Health Monitoring and Reporting	13 APR	<a href="mailto:Marieke.Verschuuren@rivm.nl">Marieke.Verschuuren@rivm.nl</a>	Marieke Verschuuren	Industry
64	PHA	European Pulmonary Hypertension Association	13 APR	<a href="mailto:p.ferrari@phaeurope.org">p.ferrari@phaeurope.org</a>	Pisana Ferrari	Patients Disease specific org.
65	PPTA	PPTA Europe	13 APR	<a href="mailto:laura@pptaglobal.org">laura@pptaglobal.org</a>	Laura Savini	Industry
66	Reumanet	Reumanet	16 APR	<a href="mailto:renee@reumanet.be">renee@reumanet.be</a>	Renée Idzerda	Patients Disease specific org.
67	RCN	Royal College of Nursing UK	13 APR	<a href="mailto:Matthew.Hamilton@rcn.org.uk">Matthew.Hamilton@rcn.org.uk</a>	Hamilton Matthew	Academic institutions and researchers
68	Roche	Roche - Diabetes	15 APR	<a href="mailto:dagmar.kownatka@roche.com">dagmar.kownatka@roche.com</a>	Dagmar Kownatka	Industry
69	Roche	Roche (general)	15 APR	<a href="mailto:dagmar.kownatka@roche.com">dagmar.kownatka@roche.com</a>	Dagmar Kownatka	Industry
70	SFP	Smoke Free Partnership	18 APR	<a href="mailto:Anca.Toma@ersnet.org">Anca.Toma@ersnet.org</a>	Ana Toma	NGOs and umbrella organisations
71	SCA	SCA Hygiene Products	15 APR	<a href="mailto:Eszter.Kacskovics@sca.com">Eszter.Kacskovics@sca.com</a>	Kacskovics Eszter	Industry
72	Uni Z	University Hospital Zaragossa	15 APR	<a href="mailto:sprados.iacs@aragon.es">sprados.iacs@aragon.es</a>	Alexandra Prados Torres	Academic institutions and researchers
73	UKNCDTF	UK NCDs and Development Task Force	20 APR	<a href="mailto:Layla.Theiner@cancer.org.uk">Layla.Theiner@cancer.org.uk</a>	Layla Theiner	NGOs and umbrella organisations
74	WCRF	World Cancer Research Fund International	17 APR	<a href="mailto:j.jewell@wcrf.org">j.jewell@wcrf.org</a>	Jo Jewell	NGOs and umbrella organisations
75	WECF	Women in Europe for a Common Future	14 APR	<a href="mailto:elisabeth.ruffinengo@wecf.eu">elisabeth.ruffinengo@wecf.eu</a>	Elisabeth Ruffinengo	NGOs and umbrella organisations
76	WHO	WHO Europe	15 APR	<a href="mailto:LME@euro.who.int">LME@euro.who.int</a>	Meulenbergs, Leen	International Organisation
77	WW	Weight Watchers	13 APR	<a href="mailto:maddalena.colombi@interel.eu">maddalena.colombi@interel.eu</a>	Maddalena Colombi	Industry
78	Private		28 MARCH	<a href="mailto:Ewa.Raglan@gosh.nhs.uk">Ewa.Raglan@gosh.nhs.uk</a>	Ewa Raglan	Individuals
79	Private		16 APR	<a href="mailto:alainpservaes@gmail.com">alainpservaes@gmail.com</a>	Alain Servaes	Individuals
80	Private		22 MARCH	<a href="mailto:kristyvoug@0070.syzefxis.gov.gr">kristyvoug@0070.syzefxis.gov.gr</a>	Kristy Vougiouklaki	Individuals