EU Reflection on Chronic Disease

European Chronic Disease Alliance input to the Reflection Process

The European Chronic Disease Alliance (ECDA) is an informal alliance representing over 100,000 health professionals who joined forces to put the case for immediate political action.
Our mission is to reverse the alarming rise in chronic diseases by providing concrete evidence-based policy recommendations.

Introduction

Chronic, non-communicable diseases are a challenge of epidemic proportions. At a global scale, non-communicable diseases are estimated to cost $47 trillion by 2030. Europe currently has the highest number of deaths and disability in the world due to these diseases.[1]

This paper represents the European Chronic Disease Alliance's (ECDA) collective input to policy makers in the frame of the European Union's reflection process on chronic disease, specifically called for in the Council conclusions of 7 December 2010 on "Innovative approaches for chronic diseases in public health and health care systems".[2] The ECDA would like to urge the European Commission and the Member States to include the recommendations provided herewith in any forthcoming strategy on chronic diseases.

For the purpose of this paper, the ECDA definition for "chronic diseases" is: *Chronic non-communicable disease or conditions that are of long duration and generally slow progression, linked by common risk factors such as tobacco, physical inactivity, nutrition, alcohol, environment, and are largely preventable.*

On the basis of these Council conclusions, this paper answers a number of questions addressed by the European Commission in the discussion document EU Reflection on Chronic Disease launched in March 2012 requesting initial input from stakeholders to the EU Reflection Process on Chronic Disease. Besides answering some of the Commission's questions, this paper recommends a number of concrete measures that can be taken by the European Commission and Member States to tackle chronic diseases effectively. First and foremost the ECDA calls for a coordinated EU-led strategy to tackle the enormous challenge to societies posed by chronic diseases.

WHAT IS CHRONIC DISEASE?
WHAT IS THE CURRENT SITUATION ON CHRONIC DISEASES IN THE EUROPEAN UNION?

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

Chronic non communicable diseases account for 86% of deaths in the WHO European Region. They include heart disease, stroke, hypertension, diabetes, kidney diseases, cancers, respiratory and liver disease.
Because most are treatable but not always curable, they generate an enormous financial burden due to treatment costs, care costs and loss of productivity. Four major health determinants – tobacco, poor diet, alcohol and lack of physical activity) account for most of chronic illness and death in Europe. All of them can be successfully addressed to prevent disease and promote the health of the European population.

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[1] Gaining Health – The European Strategy for Prevention and Control of Non-communicable diseases. WHO, 2006. http://www.euro.who.int/__data/assets/pdf_file/0008/76526/E89306.pdf

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

European data and improved cooperation at European level

- ECDA recommends expanding the mandate of the European Centre for Disease Prevention and Control (ECDC) to include the monitoring and surveillance of major NCDs.

- It is important for decision makers to understand the direct and indirect costs of preventable disease and benefits of health promotion to society. Comparable data at EU level on incidence, prevalence, risk factors and outcomes, is urgently needed. EU registries are clearly missing.

- 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.

- Cooperation with WHO in view of the Action Plan for a strategy on NCDs[3] and OECD and medical/scientific societies should be strengthened.[4]

What gets measured gets done

- We need to measure, monitor and report on action taken in the Member States and targets need to be set to facilitate monitoring and reporting of progress in this field.

HEALTH PROMOTION AND DISEASE PREVENTION. WHAT MORE SHOULD BE DONE?

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

How can existing actions on primary prevention be better focused and become more effective?

Many of the modern-day health problems and the complex nature of chronic diseases require "a systems perspective" which includes an understanding of the overall interdependencies and all stakeholder groups as well as of the social nature of risk, its equity dimensions and of individual motivations.

The risk of a person developing diseases depends on interaction between the individual, his or her personal susceptibility and the wider environment. Many diseases, such as diabetes and asthma, have a complex pattern of inheritance. It is becoming increasingly clear that antenatal and early life

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[3] 2008-2013 Action plan for the global strategy for the prevention and control of non-communicable diseases http://www.who.int/nmh/publications/9789241597418/en/index.html

[4] Busse R, Blumel M, Scheller-Kreinsen D, Zentner A. Tackling chronic disease in Europe. **World Health Organization on behalf of** European Observatory on Health Systems and Policies (2010). Available from: http://www.euro.who.int/__data/assets/pdf_file/0008/96632/E93736.pdf

events are important factors in the risk of developing diseases such as cardiovascular, type2 diabetes and Chronic Obstructive Pulmonary Disease (COPD) in adulthood.

The evidence on the role of behavioural, social and environmental determinants of chronic diseases is growing. For example, indoor and outdoor air pollution increases the risk of asthma and other respiratory diseases, and fine particulate matter in the air increases the risk of cardiovascular disease and lung cancer significantly affecting life expectancy. Declining cardiovascular mortality after smoking is banned in public places is an example of rapid benefits for health of successful actions addressing the environmental determinants of health.

1. Health in all policies

A recent study by the Institute of Medicine (IOM)[5] suggests that Health in All Policies can be "seen as a manifestation of the precautionary principle: first do no harm to health through policies or laws enacted in other sectors of government." It cites California's Clean Air Act as an embodiment of this principle. We need not only see the precautionary principle evoked for environmental initiatives but also for health initiatives.

Turning the tide of diseases that have reached epidemic proportions requires fundamental changes in the social norms that regulate individual and collective behaviours. Such changes can only be triggered by wide ranging prevention strategies addressing multiple determinants of health. Tackling major risk factors for chronic diseases linked to behaviours that are highly prevalent in a population, requires multiple preventive interventions, which are both effective and broadly based. The *2010 WHO Global Status Report on non-communicable diseases* list best buys as an intervention that is not only highly cost-effective but also cheap, feasible and culturally acceptable to implement, see **Annex 2.**

Instead of seeing major diseases as a challenge to the health sector only, *health in all policies* highlights the fact that the risk factors of major diseases are modified by measures that are often managed by other government sectors as well as by other actors in society.[6] Education, employment and the environment influence the distribution of risk factors among population groups, thereby resulting in health inequalities. Focusing on *health in all policies* may shift the emphasis from primarily individual lifestyles and single diseases to societal factors and actions that shape our everyday living environments. It does not, however, imply that any other public health approaches, for example health education or disease prevention are undermined or treated as less important.

The EU must put greater emphasis on ensuring the implementation of *health in all policies*. In accordance with the Lisbon Treaty, the EU must ensure that policies that have an influence on the health of EU citizens must promote health and healthier lifestyles. Any balanced and sensible government policies must aim to influence not only the fields of health and research, but also areas

[5] Institute of Medicine of the National Academies. For the Public's Health: Revitalizing Law and Policy to Meet New Challenges (2011). The National Academies Press. Available from : http://www.iom.edu/Reports/2011/For-the-Publics-Health-Revitalizing-Law-and-Policy-to-Meet-New-Challenges.aspx

[6] http://ec.europa.eu/health/archive/ph_information/documents/health_in_all_policies.pdf

such as agriculture, transport and communication, environment, regional development and finance. Moreover, the European Union financial instruments including Structural Funds, European Agricultural Fund for Rural Development and EU-funded research should contribute to creating healthier European societies. These possibilities for health promotion must be explored further and implemented.

Examples of successful "Health in all policies" strategies:

- The EU public health project *TobTaxy* – bringing the health case to raise tobacco tax to the finance departments see: www.smokefreepartnership.eu

- European Public Health and Agriculture Consortium (EPHAC) – for a healthier more sustainable agriculture policy: http://www.healthyagriculture.eu/

2. Reducing health inequalities

People with higher socioeconomic position in society have a greater array of life chances and more opportunities to lead a flourishing life. They also have better health. The two are linked: the more favoured people are, socially and economically, the better their health.[7] Research on the factors influencing health is revealing the importance of health inequalities in determining the outcomes and distribution of health burden.[8] Health inequalities result from social inequalities. Action on health inequalities requires action across all the social determinants of health and will benefit society in many ways. It will have economic benefits in reducing losses from illness associated with health inequalities. These currently account for productivity losses, reduced tax revenue, higher welfare payments and increased treatment costs.[9]

There are major health inequalities within and between countries in Europe. A top priority for the Europe 2020 strategy is to emphasise that a major effort will be needed to combat poverty and social exclusion, and reduce health inequalities to ensure that everybody can benefit from growth. Health ministries have a vital role to play both in ensuring the contribution of the health system and in advocating for health equity in the development plans, policies and actions of players in other sectors**.** However, the health system alone cannot reduce health inequalities.

The health of a baby is crucially affected by the health and well-being of their mother. Maternal health, including stress, diet, drug, alcohol and tobacco use during pregnancy, has significant influence on fetal and early brain development. Low birth weight in particular is associated with poorer long-term health and educational outcomes. Socially graded inequalities are present prenatally and increase in early childhood. The biological effects of birth weight on brain development interact with other influences associated with social position to influence cognitive development. Member States need to recognise the issue of maternal, newborn care and aftercare as a public health priority, particularly the health of preterm infants and infants with illnesses.

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[7] Marmot M. Fair Society, Healthy Lives. The Marmot Review. Strategic Review of Health Inequalities in England post-2010 (2010). Available from: http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review

[8] Marmot M. Fair Society, Healthy Lives. The Marmot Review. Strategic Review of Health Inequalities in England post-2010 (2010). Available from: http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review

[9] Ibid

Member States should develop educational programmes specifically targeting mothers in deprived situations to address health inequalities in maternal and newborn care within all EU Member States.[10]

3. Facilitating healthy choices

There are many reasons why Member States should intervene to facilitate healthy choices for all citizens. Some of these reasons are:

(1) Information failures, which may contribute to the adoption of unhealthy behaviours and lifestyles through an inadequate knowledge or understanding of the long-term consequences of such behaviours;
(2) External factors, resulting in the social costs and benefits of certain forms of consumption not being fully reflected in their private costs and benefits to individual consumers e.g. negative external factors in the case of addictive substances or unhealthy foods;
(3) Failures of rationality, which prevent individuals from making choices in their own best interest.

Information is critical to enable citizens to make rational and efficient choices. People have to be fully informed about the characteristics and quality of the products they consume, the benefits they will derive from consumption, but also the costs they will incur.

In the case of health-related consumption behaviours, information is often lacking on the nature and the magnitude of the associated health risks. Information may be lacking because it does not exist; because it is concealed or communicated in ways that are confusing people by parties that have a vested interest e.g. misleading or irrelevant health claims used by the food industry; or because it is complex and not easily accessible to the lay person e.g. information on the health risks involved in the consumption of different types of fats.

The importance of information in forming health-related beliefs is shown, for instance, in a study of the determinants of higher smoking rates in Europe compared to the USA[11]. The authors reach the conclusion that beliefs were changed in the US when substantial information about the harms of smoking was made available to the public. The same information appears to have been communicated less effectively in Europe.

Much more discussion at EU and national level is needed about cost-effective ways to influence behaviour.

The European Commission has a unique legislative opportunity to bridge this gap in effective communication through a robust and strong revision of the Tobacco Products Directive. Introducing

[10] Caring for tomorrow, The EFCNI White Paper on Maternal and Newborn Health and Aftercare services, 2011. Available from: http://www.efcni.org/index.php?id=1888

[11] Cutler D, Glaeser E. Why do Europeans smoke more than Americans? National Bureau of Economic Research. Working Paper 12124. 2006 Available from: http://www.nber.org/papers/w12124.pdf

large mandatory pictorial warnings (front and back), and standardised packaging, would substantially increase the provision of information to European citizens on the disastrous consequences of tobacco use. We fully endorse the position of the European Parliament which has emphasised the need for an immediate, effective revision of the Tobacco Products Directive.[12]

Equally, the European Commission has immediate opportunities for facilitating better food choices by merely allowing health claims that are easy to understand and relevant to public health and proposing a nutrient profiling system to allow claims only on healthier options.

Member States also have an obligation to address the information failure and provide more default healthy options. We provide many suggestions of such options throughout this paper.

4. Health promotion and communication

The Ottawa Charter for Health Promotion defines health promotion as the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social wellbeing, an individual or group must be able to identify and to realise aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasising social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy lifestyles to wellbeing.

Investing in the early years is key to preventing ill health later in life. An increased investment in public health promotion is important to increasing efficiency in the health service. A small shift in resource towards public health promotion activity would offer significant short, medium and long term savings to the service and to the taxpayer. Effective and evidence-based health promotion programmes should be implemented. The European Commission is in a unique position to promote such activities and to take on a long-term and visionary approach.

Public health campaigns when well-orchestrated have been proven to change the level of knowledge and awareness. They are particularly useful where awareness is the main goal, wide exposure is achieved, long-term follow up is possible, and when the behavioral goal is simple.

The “ex-smokers are unstoppable” campaign of the European Commission is innovative and should be commended. The “school fruit scheme” is also to be commended for its great potential to increase fruit and vegetable intake across Europe.

The importance of prevention and health promotion is recognised at EU-level in the Lisbon Treaty, in the EU Health Strategy and the European Innovation Partnership on Active and Healthy Ageing (EIP-AHA). Article 168 of the Treaty recognises their importance and encourages sharing of best practice and benchmarking between Member States.

[12] http://www.europarl.europa.eu/sides/getDoc.do?type=TA&reference=P7-TA-2011-0390&language=EN

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.

5. Health in education

[The European Parliament] emphasises the need to step up the provision of education about healthy dietary and physical-activity habits in schools; notes that, globally, adequate resources should be made available for such educational work; European Parliament resolution on NCDs 15 September 2011[13]

Education deserves special consideration because of the evidence of an important causal link with health and lifestyles. Individuals who have poor education are significantly more likely to adopt unhealthy lifestyles and to be in poor health.

DG Education and Culture could be involved in identifying measures to improve health education and health literacy in the EU, e.g. health promoting schools.

More educated individuals are able to obtain greater health outputs from given amounts of inputs, but they are also able to select more appropriate mixes of inputs, for instance by making healthier consumption choices. Years of formal schooling completed have a strong effect on health outcomes, whether these are measured in terms of mortality, self-reported health status and physiological indicators of health.

What potential is there for broad based early detection action?

The European Parliament emphasises the importance of the early identification of individuals who are at high risk of contracting or dying from these diseases or are suffering from pre-existing dispositions, chronic and severe illnesses and risk factors that aggravate NCDs - European Parliament resolution on NCDs, 15 September 2011[14]

It cannot be over-emphasised that early detection and diagnosis, greater international collaboration, implementation of 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 at Member State level.

The scope for efficacious and reliable early detection and screening varies depending on the specific disease in question. For disease specific recommendations, please see **Annex 3** on early detection, and **Annex 4** on screening and early interventions.

[13] http://www.europarl.europa.eu/sides/getDoc.do?type=TA&reference=P7-TA-2011-0390&language=EN

[14] http://www.europarl.europa.eu/sides/getDoc.do?type=TA&reference=P7-TA-2011-0390&language=EN

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

- The Member States and the European Commission need to be proactive in preparing for a progress review to be presented at the next UN Summit in 2014. Europe, with the highest burden of non-communicable diseases (NCDs), needs to be the leader.

- The ECDA urges the European Commission and EU Member States to allocate more funding to preventive measures. In the current financial turmoil, many European countries have adopted drastic measures that have seriously affected access to care for chronic non-communicable disease patients. Yet, the economic crisis should be used as an opportunity to explore new and innovative ways of tackling chronic diseases.

- 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. The "ex-smokers are unstoppable" campaign of the European Commission is innovative and should be commended. The "school fruit scheme" is also to be commended for its great potential to increase fruit and vegetable intake across Europe.

- 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.

- The EU must put greater emphasis on ensuring the implementation of *health in all policies*. In accordance with the Lisbon Treaty, the EU must ensure that policies that have an influence on the health of EU citizens must promote health and healthier lifestyles. Any balanced and sensible government policies must aim to influence not only the fields of health and research, but also areas such as agriculture, transport and communication, environment, regional development and finance. Moreover, the European Union financial instruments including Structural Funds, European Agricultural Fund for Rural Development and EU-funded research should contribute to creating healthier European societies. These possibilities for health promotion must be explored further and implemented.

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- In the **Annex 1** of the document attached, Recommendations for action at EU level are mentioned for each individual risk factor: tobacco, unhealthy nutrition, alcohol and physical inactivity.

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

- Several Council Conclusions address health inequalities.[15,16] Member States should now implement them. Simple steps include improved access to good quality air, water, food, sporting, recreational and cultural facilities and green space. They all contribute to reducing inequalities as well as helping to create sustainable communities. Improvements in housing conditions have been shown to have a number of positive impacts on health, including lower rates of mortality. Adequate heating systems improve asthma symptoms and reduce the number of days off school.[17] The European Commission can aid this process by facilitating exchange of best practice.

- Government policies should also aim to devolve more power at the local level and thereby empower individuals and communities to define the problems and develop community solutions. The Committee of the Regions / Eurocities and other relevant actors should be engaged in such actions.

- Early detection and diagnosis, greater international collaboration, implementation of 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 at Member State level.

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HEALTHCARE

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

Importance of prevention

ECDA emphasizes the importance of prevention. Having a simple screening tool, adapted to primary care setting, that would detect diseases in early stages would reduce the number of patient referrals. This would result in fewer later stage cases of disease and consequently, better quality of life for patients, and result in savings for the health care system.

Addressing co-morbidities

The major innovation for further improving care will be the implementation of a coordinated and strategic cooperation between team members and among different units in the development of

[15] http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lsa/114994.pdf

[16] http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lsa/126524.pdf

[17] Howden-Chapman P, Pierse N, Nicholls S et al. (2008) Effects of improved home heating on asthma in community dwelling children: Randomised controlled trial. BMJ 337: a1411.

diagnostic and clinical management strategies. Further development of multidisciplinary care teams is crucial.

The care of many chronic diseases is increasingly complex. It not only relies on the talents of highly coordinated multidisciplinary teams but requires shared responsibilities across a continuum of longitudinal care involving numerous specialties and departments. A better integration between primary care physicians and other health care specialists is crucial in the care of chronic disease patients.

Guidelines are an important tool for clinical management that should be subjected to a comprehensive evidence-based approach. A proper guideline programme leads to optimal management of chronic disease, with improved outcomes and a reduction in health inequalities across Europe and globally. An important goal for the future will be the production of truly multidisciplinary guidelines, which is particularly important in patients (especially the elderly) with multiple chronic conditions. Guidelines need to be inclusive and produced in collaboration with the relevant stakeholders, such as patients and their organisations. In view of the growing complexity of guidelines it is crucial to, in future guidelines, include sections with summaries for lay people, discuss the role of new technology, and ensure guidelines answer clinicians' questions.

Periodically reviewed and adapted guidelines are an essential part of the treatment strategy and progress of clinical, especially medical oncology, where systemic treatment possibilities constantly evolve and change with the ongoing development of drug research by pharmaceutical companies and cancer research trial groups. In almost all European countries national guidelines, increasingly evidence based for most cancers, have been developed and are constantly amenable for adaptation.

Affordability & accessibility of health care

There is increasing inequality in access to health care in Europe resulting from factors such as service design, accessibility, acceptability, affordability and financing mechanisms. As inequalities in health care have been associated with inequality in health within high-income countries, it may well also contribute to inequalities in health within countries in central and Eastern Europe. Unless urgent action is taken now, these gaps between and within countries will increase.

Care for chronic diseases will necessitate new modes of approach such as integrated care, multidisciplinary care, clinical pathways, self-management, teleconsulting, telemonitoring and rehabilitation. For the latter four modalities, there is evidence of an effect on outcomes, but access to these services remains dismal. It is estimated that less than 5% of the eligible patients actually have access to rehabilitation.[18] Member States must endeavour to improve accessibility for all.

Palliative care

The development of palliative care as a specialty in its own right has led to great improvements in the care of patients with end-stage disease. A great inequality in access to services currently exists between patients dying with malignant and non-malignant respiratory disease. This is in part due to lack of resources, which constrains the wider availability of palliative care programmes in the health

[18] Brooks D, Sottana R, Bell B, et al. Characterization of pulmonary rehabilitation programs in Canada in 2005. Can Respir J 2007; 14: 87–92.

care system. A study by Gore *et al.* showed that COPD patients were generally better provided for in terms of aids and appliances, but very few had received counseling and none had received help from specialist palliative care services. [19]

Across Europe and the developed world, most people with chronic respiratory disease die in hospital although it is known that few would make this choice. There is a need to change our practice to allow both curative care and palliative care to run side by side, and for patients with non-malignant disease to be referred to specialist palliative care services at a time when specialist palliative care teams can still be of help.

Besides palliative efforts in patients with chronic pulmonary diseases, the palliative care approach is probably most developed in adult oncology, where the majority of patients, once their disease has spread and becomes treatment-resistant, will need some form of palliative symptom control (pain, digestive troubles, depressive symptoms, neurological impairment, etc.). The development of somatic and spiritual palliative care in oncology across Europe, having started and greatly been promoted by pilot centres in the UK some decades ago, is probably one of the most rewarding and useful patient-oriented developments in modern clinical medicine, represented today by the European Society of Palliative Care and its very active research and educational programme.

Adequate measures should be taken and promoted across the health continuum to improve access to end-of-life care. Greater support for specialist nurses and specialist palliative care teams is required.

What changes could be important to better address the chronic disease challenge in areas such as: financing and planning; training of the health workforce; nature and location of health infrastructure; better management of the care across chronic diseases?

The gains from prevention cannot be overestimated – a few simple steps to improve early diagnosis, detection and screening will go a long way to addressing our NCD crisis. However, 97% of health expenses are currently spent on treatment, only 3% being invested in prevention. The ECDA outlines steps that can be taken for the specific diseases in detail in **Annex 3 and 4**.

The economic crisis in particular has given European health policy a new push. Member States have agreed on a new EU-level economic governance, 'European Semester', which helps coordinate their macroeconomic, budgetary and structural reform policies. This coordination started with a Commission Communication on the Annual Growth Survey (AGS) and recommendations to the Member States. The macroeconomic report which accompanied the Communication, noted that "Health care systems need to be rigorously monitored and, where needed, reformed to ensure

[19] Gore JM, Brophy CJ, Greenstone MA. How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. Thorax 2000; 55: 1000–1006.

greater cost-efficiency and sustainability, especially in regard to demographic ageing"[24]. Such cost-efficiency can be brought about by implementing the recommendations outlined in this paper.

In addition, reimbursement rarely covers prevention and health promotion and this is an area where Member States should continue to exchange information.

The management of co-morbidities is a major challenge often overlooked by evidence-based diagnosis and treatment using disease-specific clinical guidelines.

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

Home care services benefit patients with chronic diseases, especially paediatric and geriatric patients. Telemedicine can be considered as an extension of home care as it allows the patient to stay at home while remaining connected with health care professionals to ensure adequate monitoring of their condition. Telemedicine has shown some promising effects for monitoring COPD and asthma patients, or in cardiology, for heart failure patients and, of course, diabetes patients.

In the next decade there is a potential to increase and improve the use of home care and telemedicine to form a part of the disease management process. When introducing new technologies, appropriate training for health care workers is necessary. This has been recognized by the Council of the European Union under the Hungarian presidency and the conference declaration on European Cooperation on e-health adopted 15/03/2010.

Specialist consultation clinics should be considered in order to improve both the self-management of chronic conditions and the communication between the health professional and the empowered patient. These models will include increased patient involvement in directing treatment, greater use of patient-reported outcomes, and evaluations of efficacy of treatment by patient reports via internet, mobile phones etc.
However, ECDA acknowledges a strong need for more research and evidence, including large scale clinical trials, economic analysis and models for preventive and predictive care.

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

ECDA calls on the EU to help Member States transform their health systems to make prevention and health promotion an integral part of health services. Even if health policy and provision of health care is a Member State responsibility, the EU should take an active role to aid this transformation. Member States share similar challenges, from demographic change to increasing health care costs, and common solutions are needed.

In the area of e-health, the European Commission needs to strengthen current efforts in e-health solution deployment and research.

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

Specific efforts are needed at Member State level for the deployment of existing, cost effective e-health solutions and other innovative measures applicable to chronic diseases e.g. phone-based SOPHIA project that supports people living with diabetes in France and that has proven to have a very positive effect on health outcomes. There is also a strong need for more research and evidence, including large scale clinical trials, economic analyses, models for preventive and predictive care. DG Information Society needs to strengthen current efforts in e-health solution deployment and research.

In addition, reimbursement rarely covers prevention and health promotion and this is an area where Member States should continue to exchange information.

Member States should also share best practices in empowering health personnel to deliver health. For example, educating and training staff in health promotion on topics such as the importance of smoking cessation, nutrition, and physical activity, would help them provide practical advice to patients during routine checks. Health personnel can also help identify high-risk groups for chronic diseases by using validated risk assessment tools.

What will you/your organisation contribute to address this challenge?

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.
It can engage in working with the European Institutions and member states in identifying and implementing best practice.
Members of the European Chronic Disease Alliance recently put forward a funding application as part of the European Community Health Programme 2012 on cost effectiveness of chronic diseases prevention programmes. The project entitled “Economics of Chronic Diseases” proposes to examine the cost-effectiveness of integrated approaches to chronic disease prevention with a particular focus on diabetes, cardiovascular diseases and respiratory diseases. It will result in a demonstration model for differential effects of interventions on various population sub groups.

RESEARCH

How should research priorities change to better meet the challenges of chronic disease? In what areas is there a particular need for additional action at EU level?

"[Invites the Commission to] integrate, where possible, chronic diseases as a priority in current and future European research and action programmes and take into account the outcome of the reflection process into the implementation of the EU 2020 initiative – Council conclusions, 7th December 2010.

Research makes a direct contribution to the prevention and treatment of chronic diseases and leads to dramatic increases in the quality of life for European citizens. Success in biomedical research requires a long-term investment as well as sustainable infrastructures. It is estimated that three-quarters of its return on investment of medical research come from its "spill over" effects and value creation to the broader economy.[20] The cumulative economic benefit comes from the increased contributions of a healthy population as well as the wealth generated by the health care sector. Furthermore, the Innovation Union Strategy 2020 identified "health and ageing" as one of the major societal challenges of the 21st century.[21]

There is a crucial need to boost biomedical research with appropriate resourcing at the EU level for dedicated European funding for European-wide studies – many of the biomedical challenges will only be better understood through highly multidisciplinary and large-scale / multinational research. For this to happen, common European-wide strategic planning of biomedical research is essential. Tackling the enormous medical costs and loss of labour in the forthcoming decades requires action now. The return on investment in medical research is significant, and can be up to 39% according to the analysis presented for cardiovascular diseases in the UK.[22]

With regard to European biomedical research, it is crucial that the funding strategy and priorities are defined together with the biomedical community. Only if experts are actively involved in the development of the research strategy and the identification of research needs can it truly address the challenges faced by science and society.

Today at EU level however health and research are separate policy areas. To overcome the existing fragmentation and duplication of research in Europe in the health field, human health must be at the core. 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.

In addition more research is needed on e.g. the 'health in all policies' approach to health and health promotion. More case studies are needed about the factors that influence individual behaviour and social norms. The search for common solutions must build on strong research cooperation across Member States. The Council of the European Union should also introduce regular meetings between health and research ministries.

[20] http://www.nature.com/news/2010/100609/pdf/465682a.pdf
[21] http://ec.europa.eu/health/ph_overview/Documents/health_economy_en.pdf
[22] http://www.wellcome.ac.uk/stellent/groups/corporatesite/@sitestudioobjects/documents/web_document/wtx052110.pdf

INFORMATION, AND INFORMATION TECHNOLOGY

What more needs to be done on the development of information and data on chronic disease?

[The European Parliament] emphasises the need to establish priorities for centralised data collection with a view to obtaining comparable data that will make better planning and recommendations possible across the EU - European Parliament resolution on NCDs, 15 September 2011[23]

It is important for decision makers to understand the direct and indirect costs of preventable disease and benefits of health promotion to society. Comparable data at European level on incidence, prevalence, risk factors and outcomes, is urgently needed. There is a need for developing more unified, robust, cost-effective methods at EU-level. Registries at European level are clearly missing and the way information is collected differs widely. Many projects are on-going, but all using different methodologies, which again renders the data incomparable.

Beyond the need for collection of standardized data on chronic diseases and their risk factors, which is acknowledged in this discussion paper, there is a need for coordination. ECDA recommends expanding the mandate of the European Centre for Disease Prevention and Control (ECDC) to include the monitoring and surveillance of major NCDs.
ECDA also reckons that it is important for decision makers to understand the direct and indirect costs of preventable disease and benefits of health promotion to society.

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

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.
Cooperation with WHO in view of the Action Plan for a strategy on NCDs[24] and OECD and medical/scientific societies should be strengthened.[25]

One major obstacle at European level is the interoperability of data. Although efforts are being made, in particular with the implementation of the cross-border health care directive, much remains to be done for all health data to be easily transferred between different operators.

The introduction, at EU level, of a unique patient identification number would overcome many of the current obstacles to data transfer. It must comply with personal data protection provisions.

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[23] http://www.europarl.europa.eu/sides/getDoc.do?type=TA&reference=P7-TA-2011-0390&language=EN

[24] 2008-2013 Action plan for the global strategy for the prevention and control of non-communicable diseases http://www.who.int/nmh/publications/9789241597418/en/index.html

[25] Busse R, Blumel M, Scheller-Kreinsen D, Zentner A. Tackling chronic disease in Europe. World Health Organization on behalf of European Observatory on Health Systems and Policies (2010). Available from: http://www.euro.who.int/__data/assets/pdf_file/0008/96632/E93736.pdf

Stakeholders involved in health data collection tend to focus either on clinical data, on registries or on epidemiology data. In some cases, the information collected is duplicated. Bridging the types of information would not only avoid duplication but result in a real life vision of the health status, in particular in terms of prevalence and incidence of the diseases.

[The European Parliament] calls on the Commission to continuously monitor and report on progress across the EU as regards the Member States' implementation of their national NCD plans, particularly on the four most common NCDs, with a focus on progress made in terms of prevention, early detection, disease management and research – European Parliament resolution on NCDs, 15 September 2011[26]

We need to measure, monitor and report on action taken in the Member States. To facilitate monitoring and reporting of progress a number of targets could be set. The ECDA proposed targets for chronic diseases are:

- 25% reduction in mortality by 2025
- Reducing tobacco use to less than 5% by 2040;
- Reducing salt intake to less than 5g per person per day by 2025;
- Reducing saturated fat intake to less than 10% energy per person per day by 2025;
- Eliminating the intake of industrial trans-fatty acids by 2025;
- Halving the intake of refined sugars in processed foods and beverages by 2025;
- Introduction of health warnings on all alcoholic beverages
- Reducing alcoholic liver disease and alcohol consumption and sales by 10% by 2025
- Providing affordable, safe, effective, quality-assured medicines (including for palliative care), vaccines and technologies to people with, and at high risk of, NCDs;
- By 2030, reduce the rate of increase in the prevalence of diabetes in adults from the predicted level of 9.5% to zero.

"*What gets measured, gets done*" – Margaret Chan, Director-General, World Health Organization, UN High-Level Meeting on NCDs, September 2011.

[26] http://www.europarl.europa.eu/sides/getDoc.do?type=TA&reference=P7-TA-2011-0390&language=EN

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