EU reflection Process on Chronic Disease
Results of the Stakeholder Consultation

September 2012

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Executive summary

Broad participation in chronic disease consultation

This report contains a summary and analysis of a stakeholder consultation by the European Commission that is part of a reflection process launched by the EU and its Member States to respond to the growing challenge of chronic diseases. The consultation took place during the spring of 2012, ending April 15. Eighty stakeholders, mostly NGOs, from a wide range of different backgrounds, including patient organisations, disease-oriented charities, health care related organisations and from private industrial background and many others have responded to a series of questions from the Commissions. The responses have been summarised in this report that was tendered by the EAHC, the European Agency on Health and Consumer Affairs.

Apply a basic set of policy principles for health promotion and disease prevention

The European Union (EU) and the Member States (MS) governments are urged by stakeholders to implement a basic set of policy principles to attack the European chronic disease burden:

- Facilitate healthy choices in life for all citizens and strengthen health literacy
- Establish health promotion interventions for all preventable chronic diseases
- Integrate health in education programmes
- Develop and systematically apply analytical tools to determine cost-effectiveness of prevention
- Expand the science-based scope for early detection of chronic diseases
- Include health inequalities as important perspective in every policy action
- Strengthen prevention through implementing health in all policies
- Address health policies by a life-course approach

The EU and its Member States must attack the burden of chronic diseases in close collaboration with other international organisations, i.e. the World Health Organisation (WHO) and the Organisation for Economic Co-operation and Development (OECD).

Focus on a broad set of chronic conditions

Many stakeholders representing various patient groups have pointed at the need for the EU to broaden the definition and scope of its chronic disease approach to include other chronic disease besides addressing the ‘big four’, i.e. cancers, cardiovascular disease, diabetes and respiratory diseases.

Many of the recommendations that point at improving healthcare and aiming to lessen the burden of the ‘big four’ also apply to many other chronic disorders. For instance, mental health, musculoskeletal diseases, neurological conditions and genetic or rare diseases are other important chronic conditions in need of Europe wide attention, according to several stakeholders.

Health inequalities repeatedly emerge from this consultation as an issue of overarching and central importance; not just health inequalities within the Member States but also between the Member States.

Integrated action to combat major threats from chronic diseases

A fully committed, collaborative, integrated approach to deal with chronic diseases is widely recommended to be set in motion by the EU and its Member States. This must lessen the future increase in burden of chronic diseases for EU populations and decrease the pressure on healthcare systems. We need to prevent foreseen shortages of healthcare personnel and relief the threat that our health systems will lose their financial sustainability. Promoting Healthy Ageing is part of the solution.

Healthcare and prevention must be improved and better integrated, but this must be supported broadly by much more attention for Health in All Policies, for instance by actions in the educational, labour, environmental and social sectors.

The EU can play an important role by funding networks, that link practice (including patients/citizens) with policy and research.

Health in all policies

Stakeholders emphasize that Health in all policies (HiAP) is a precautionary principle for national governments: do no harm through policies or laws enacted in other governmental sectors. The EU and its Member States must put greater emphasis on the implementation of health in all policies, in accordance with the Lisbon Treaty.

Health in all policies rests on the serious involvement of other sectors such as the social and education sectors, the sectors of environment, work, food and agriculture, sports as well the social and transport sectors to address within their remits ways to contribute to better health outcomes, also in the area of chronic diseases.

Huge need and potential to improve healthcare quality

While the primary responsibility for the implementation and improvement of healthcare systems in the EU remains with the Member States, stakeholders suggest a wide array of potential measures, actions, research and exchanges of best practices that can be stimulated or supported by the European Union and its programmes. Such efforts must support health system improvements throughout the EU.

Stakeholders suggest some principal changes and improvements in national healthcare systems to better attack chronic diseases:

- Systematically introduce disease management approaches
- Introduce and promote effective self-care practices
- Strengthen primary care systems
- Systematically integrate prevention into care

- Support the development and implementation of innovations, i.e. in e-Technologies
- Improve information and data systems, including disease registries, to better communicate, organise, implement and evaluate the quality, effectiveness and patient-centeredness of national care systems
- Improve patient-involvement in all stages of care and strengthen informal care
- Increase the evidence base for interventions, treatments and early detection
- Exchange best practices, develop and exchange common standards and guidelines

Opportunities for research and improvement of prevention and early detection

Many opportunities and possible actions are highlighted to strengthen and improve national and European knowledge bases for prevention, screening and early detection. Focusing prevention research on cost-effectiveness and supporting the dissemination of best practices across the whole of the European Union are important recommendations from the respondents in this consultation.

Stakeholders advise to support research and development for a number of specific areas related to chronic diseases and their prevention, care and cure. A selection of the areas suggested: cost-effectiveness of disease management programmes, the implementation of self-care, the economic costs of chronic diseases to national economies, health systems and households, the social determinants of health, health technology assessment, aspects of malnutrition in healthcare settings, relevant aspects of genetics, furthermore pain and chronic pain, early detection and prevention of pre-term birth, how to improve informal care giving, primary care functioning and finally problems related to data protection legislation in the EU and its MS that may prohibit best use of data for public health. More research is also suggested for numerous individual chronic diseases and conditions and their early detection and treatment.

Better co-ordination and central support are important tools

Various recommendations point at the need to increase the coordinating capacity behind European research efforts to strengthen the fight against chronic diseases. This can be partly done by using either new or established structures and programmes, but also by expanding research collaborations outside the European Union. A selection of such recommendations:

- Establish or support a European centre of excellence for the study of chronic disease management, the development of disease management support tools, services and data management systems.
- Organise a European Institute on Ageing to act as clearing house for relevant information. Collect and disseminate research findings and offer opportunities to exchange good practice and relevant information among patients and clinicians.

- Use the approach taken in the so-called Joint Programming Initiatives. This has proven a potentially very relevant organisation form and can be used by the Commission in future work on chronic diseases.
- Make better use of existing coordinating initiatives such as the Innovative Medicine Initiative (IMI) and ESFRI, the European Strategy Forum on Research Infrastructures.
- Support the international collaboration of European researchers with others outside the European Union, i.e. the United States, Japan, China, Russia, with some priority for clinical trials and so increase the EU's competitiveness in global research as well.
- Invest in creating efficiencies in European cancer research by leveraging the expertise and intellectual potential of European institutes through increased collaboration.

Health data improvements to support better care and policymaking

Comparable information, both at national and at EU level, on the burden of chronic diseases is currently lacking. Stakeholders stress the value of using existing structures and activities for data collection. Information and Information Technology (IT) has useful application for data provisions, as well as for the delivery of individual patient care (eHealth, tele-monitoring, patient information), planning/management and for the organisation of health care services.

Respondents state that better data and IT-infrastructures in national healthcare systems can contribute to a better understanding of efficiency, effectiveness and the direct and indirect costs of interventions and policies. Better data and IT-infrastructure also contribute to benchmarking, patient safety, the facilitation of medical auditing, the enhancement of (effectiveness of) research, including research on new medication. This includes the need for common definitions, standards and classifications.

Stakeholders urge the EU Member States to further develop and improve their public health data collections to better support health policy making in the area of chronic diseases. The EU must, in close collaboration with WHO and OECD, support this much needed actions by facilitating central coordination of data harmonisation and collection and indicator development throughout Europe. Similarly, collection and analysis of harmonised data and information about healthcare systems must be strongly supported as well. Expanding the mandate of ECDC to cover monitoring and surveillance of chronic diseases and their prevention and care is an option recommended by several stakeholders as well. This is a way to put co-ordination and sustainable action in this area in place.

Member States and EU must join forces with stakeholders and patients

Many respondents emphasize the need for collaboration in the field of chronic diseases; between stakeholders, between MS, and between the EU and international organizations, e.g. the WHO and OECD. Respondents suggest a need for greater urgency, transparency and active involvement of the key stakeholders. The EU must engage in wider consultation procedures with relevant stakeholders and help set up and support stakeholder groups, e.g. by providing funding.

Innovative and cross-sectional partnerships are important in their view. Public Private Partnerships and multi- stakeholder collaborations are important as well, complemented with a governance structure including a strong and prominent role played by the Commission and authorities. Several respondents underline the importance of including patient representatives in multi-stakeholder consultations. Involving patients and experts from Central and Eastern European countries is a specific point of attention.

Conclusion and discussion

In summary this report is a reflection of a wide array of statements and opinions that come from a diverse set of stakeholders who have an interest in an efficient chronic disease policy in the European Union. The report, therefore, contains a broad scope of very relevant views, opinions and recommendations in the area of chronic diseases. It also includes concrete proposals for action by Member States and the EU. Based on the input from the stakeholders we answer the following questions
1) what are the major gaps?
2) what are the next steps?
3) what are the main actions to be undertaken at the EU, Member States and stakeholders level?

Major gaps

Some stakeholders feel that the scope of 'chronic disease' is too narrow. Stakeholders proposed to include mental health disorders, inherited diseases and (ultra)rare diseases. They feel that the questionnaire did not sufficiently focus on the differences between the different types of chronic diseases. Other fields that were missed in the consultation paper are 'health inequalities'. In this respect, stakeholders refer to certain migrant groups, health-illiterate people and gender issues. Furthermore, multimorbidity and comorbidity and rewarding informal carers are important issues to deal with in an ageing Europe

Presently, scientific collaboration in health lacks a strong strategic framework to tackle chronic diseases. Cross-fertilisation between clinical disciplines is vital, in order to accelerate the translation of basic science into clinical practice. Also knowledge on cost-effectivess, in prevention as well as in clinical settings is important.

Availability and comparability of data, at national and at EU level on disease incidence and prevalence of chronic diseases, is poor. A lot of developmental work is still needed to achieve this. Stakeholders also note that more action is needed to improve the stratification of data by socio-economic status and ethnic minorities. To obtain comparable information, it is important to use uniform methods, definitions and tools for data collection.

Next steps

Respondents mention that adopting integrated chronic disease strategies at both the national and European level would be an important step forward. An intersectoral approach to chronic diseases is key. Health in all policies (HiAP), developed by the Commission and Member States, for example in the field of agriculture and rural development, are highly relevant. Stakeholders see a combination of health promotion, disease prevention and medical care as integrated elements of any future effective approach to combat chronic diseases. However, prevention still needs systematic development in medical practice. Public Private Partnerships and multi-stakeholder collaboration, including involvement of patients, are important as well.

The current healthcare systems are not fully equipped for treating patients having several diseases at a time. Co-morbidity and multi-morbidity need much more attention as their occurrence will increase fast and their treatment requires a much more integrated approach to care than is delivered nowadays in most systems.

To obtain comparable information common health data collection methods across Europe and permanent co-ordination is needed. In relation to possible data sources for chronic diseases information, stakeholders propose the exploration of innovative and more efficient approaches to the development of information and data, in particular related to how data held within Electronic Health Records (EHR) can be reused to enhance clinical research processes in Europe.

Actions at the EU, Member State and stakeholder level

Action European Union

Most stakeholders mainly see a coordinating role for the European Commission. Various recommendations point at the need to increase the coordinating capacity behind European research efforts by using either new or established structures and to expand research collaborations outside the European Union as well. Stakeholders also proposed to build new structures such as a *European Institute on Ageing* to act as clearing house for relevant information. Also a European centre of excellence was brought forward, for the study of chronic disease management, the development of disease management support tools, services and data management systems.

Stakeholders urge the EU and the MS to closely collaborate with WHO in the area of NCDs as already agreed upon and follow and implement the various recommendations already made by WHO in the light of their European Strategy for the Prevention and Control of NCDs. It is also important to strengthen the links with OECD and with medical/scientific societies.

The EU can use legislative tools to promote health and behavioural change in daily practice and financial instruments to improve health promotion activities. Respondents see an explicit role for the EU in supporting Member States through exchange of information and good practices and through the development of information systems and guidelines. The EU can function as a catalyst for research undertaken at national level to improve chronic disease management, including the dissemination of research findings across Member States and the actual implementation of the research findings into daily practice of prevention and care. EU and Member States should support the evaluation of cost-effectiveness of programmes and projects.

Action Member States

In the field of comparable data there is potential for national level action in two specific areas. First, the stimulation of a universal, highly accessible Primary Health Care system as the starting point for information, documentation and exchange with input from patients. Second the need for national actors to embrace the benefits of strong, consistent, quality data sets in bringing about transparency and improvements in health care.

The respondents have also pointed at many opportunities for Member States to take a well-planned and programmatic approach to combating chronic diseases and strengthen the many opportunities to exchange best practices. The respondents also urge the MS to closely collaborate with WHO in the area of NCDs as already agreed upon and follow and implement the various recommendations already made by WHO.

Recognising that national governments in EU Member States have full competence of their health and social care systems highlights specific need for action at national level. National healthcare systems need a more integrated approach with a central role for the concept of chronic disease management.

Action stakeholders

Stakeholders unanimously welcomed the consultation by the Commission. They also expressed the hope that the Commission will continue to engage them in this matter. Stakeholders have offered their support for EU action in the area of chronic diseases by extending their usual commitment to health improvements in the form of advocacy, communicating and sharing information between patients and health care providers, participating in research and making their expertise and the expertise of their target groups available. Stakeholders can contribute through awareness raising, education, exchange of good practices, dissemination of scientific results, the implementation of innovative programs.

1 Introduction and methods

The European Commission and the European Union (EU) Member States (MS) have recently launched a reflection process to respond to the growing challenge of chronic diseases. This was called for in the Council Conclusions ‘Innovative approaches for chronic diseases in public health and healthcare systems’ [1]. In these Conclusions, the Council has invited the Member States and the Commission to ‘initiate a reflection process aiming to identify options to optimize the response to the challenges of chronic diseases, the cooperation between Member States and summarize its outcomes in a reflection paper by 2012’.

As part of this reflection process, in spring 2012 the Commission has invited stakeholders, including patient organisations, health professionals and healthcare providers working on chronic diseases to provide their views on options to optimize the response to the different challenges of chronic diseases, including the identification of priorities, gaps and shortcomings, and the need for future action. The stakeholder responses are summarised and analysed in the current report. The aim is to identify issues, gaps and suggestions for action to improve current policies and activities on chronic diseases, both at National and EU levels.

In its conclusions, the Council has also invited the Commission to integrate, where possible, chronic diseases as a priority in current and future European research and action programmes.
The Council identified scope for action in the following four areas:

- health promotion and prevention of chronic diseases
- health care
- research into chronic diseases
- comparable information at European level on the incidence, the prevalence, the risk factors and the outcomes concerning chronic diseases

This report is the second in a series of four reports to be prepared by the Dutch National Institute for Public Health and the Environment (RIVM) in 2012 in response to a call by DG SANCO (Directorate-General Health and Consumers). These reports should feed into DG SANCO’s work on chronic diseases and the reflection process described above.

The results of the stakeholder consultation will be reviewed in the Council Working Party on Public Health at Senior Level, in view of integrating elements and defining key points towards the preparation of a Commission report on the reflection process. That Commission report will summarize the main themes, issues, gaps and outcomes of the reflection process and provide realistic and concrete suggestions for possible future actions by different actors to address the chronic disease challenge effectively.

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[1] Council of the European Union. Council conclusions ‘Innovative approaches for chronic diseases in public health and healthcare systems’ (2011/C 74/03). Official Journal of the European Union 832011. 2011.

1.1 Outline of this report

This report summarises the input received from respondents of the stakeholder consultation divided into chapters as follows:

- What is the current situation on chronic diseases in the European Union?
- Health promotion and disease prevention: what more should be done?
- Healthcare
- Research
- Information, and information technology
- Roles of Member States, the EU and stakeholders
- Other areas for action

These chapters correspond to the action areas described in a discussion document provided by the Commission. This discussion document includes a series of specific questions and sub-question to be addressed by the stakeholders. The questions and main points from the discussion document are repeated in an introduction at the beginning of each chapter.

Each of the following chapters addresses one or more questions and sub-questions in an integrated way by means of a single narrative. This reports starts with a brief description of the methods used and ends with an overall discussion in which the following questions are answered: 1) how to use the information provided?; 2) what are the major gaps according to the stakeholders?; 3) what are the next steps?; 4) what are the main actions to be undertaken at the EU, Member States' and stakeholders' level?

1.2 Methods

The stakeholder consultation has taken place during the spring of 2012, ending on 15 April 2012. The Commission received 80 responses to their discussion document. Stakeholders include international lobby organisations in the health area, patient organisations, industry (in the field of health care, food, pharmaceuticals) and others

The authors constructed narratives for each chapter. No specific reference is included to individual stakeholders as various stakeholders often give more or less similar answers or answers that combine in a logical way. As stakeholders do not always clearly follow the structure of the sub-questions or provide answers to one question that can also partly answer another sub-question, the authors' narratives do not always directly reflect the structure of the questions and do not always follow a similar structure for each chapter.

The original answers have often been rephrased. The authors have rewritten the body of facts, statements, recommendations and priorities based on their knowledge and expertise in the area of public health and chronic diseases. The summarised recommendations, priorities and views are not necessarily those of the authors, however.

The original stakeholders' input that was used for this summary report is available in a tabular overview in a supplementary excel file.

1.3 A reader's guide

When reading and interpreting the outcomes of this report one should keep the following in mind. First of all this report is a reflection of a wide array of statements and opinions that come from a very diverse set of stakeholders. Some are lobby organisations, some represent the food or pharmaceutical industry and others are large patient organisations or NGO and umbrella organisations. Others again are smaller organisations or work in the interest of people who suffer from a specific disease. Even individuals contributed to this consultation. All those stakeholders have responded from a different perspective and based on different interests. Some responses are coloured by a single interest, whereas others represent a broader view on chronic diseases.

Further, the character and content of the questions in the questionnaire provided by the Commission was rather open and unstructured. No limits were set to the stakeholder responses. This may have invited some stakeholders to come up with as many ideas as possible or sent large supplementary reports. While the Commission has succeeded in generating a huge response volume this way, it has proven rather difficult to summarise the large volume of responses in a balanced way. The main points are given in the key messages, more details are provided in the additional texts.

Some statements will appear at more than one place in the report, as for instance a proposal or recommendation may be relevant for 'healthcare' and 'research' at the same time.

The authors often write 'must' and 'will' instead of 'should' and 'would' as to best reflect the opinions and ambitions of the various stakeholders. We have not selected a single statement or opinion, whenever opposite views have appeared in the answers. As the origin of the statements is a wide selection of stakeholders with different interests and opinions, some statements or views expressed in the narrative may therefore be contradicting.

Taking all the above into consideration, we feel that this report contains a broad scope of very relevant views, opinions and recommendations in the area of chronic diseases. It includes many different perspectives, challenging ideas and concrete proposals for action by Member States and the EU. We hope therefore that this report can become a rich source of inspiration for the Commission in shaping future health policies that will improve the situation of chronically ill people in the European Union and provides useful input for the Commission report on the reflection process.

2 Current situation on chronic diseases in the EU

Key messages

- The definition chronic diseases should be broadened to chronic conditions
- Certain conditions need more attention, such as mental health problems, genetic disorders and rare diseases.
- Health inequalities remain an area that requires policy attention and a specific approach. In this respect, stakeholders refer to certain migrant groups (i.e. Roma), health-illiterate people and gender issues.
- There is a need to collect and analyse data selected via commonly agreed European criteria and indicators to assess and compare the situation on chronic disease in EU countries.
- There is much support from different type of stakeholders for such an improved standardised, comparable and transferable data on chronic diseases and related areas in the European Union.

2.1 Introduction

Chronic diseases are the greatest challenge to the goal that the EU has set itself of contributing to the achievement of an increase of two years in the number of years spent in good health by the EU population, by 2020.

Average EU death rates from many chronic diseases, including cardiovascular and respiratory diseases, have fallen over the last decade. However the number of people actually suffering from chronic diseases such as diabetes, depression, musculoskeletal disorders and some cancers is rising. This is contributing to increases in long-term disability and reductions in the average number of years spent in good health in many parts of the EU.

Between 2007 and 2009 the estimated numbers of years spent in good health across the EU declined for men from 61.5 years to 60.9 years and also reduced slightly for women from 62.3 years to 62.0 years. These average figures mask huge differences both within countries and between countries.

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

2.2 Defining chronic diseases: a point of discussion

Many respondents welcome the broad definition of chronic diseases in the discussion document for the reflection process that was prepared by DG SANCO. The generally accepted definition of non-communicable diseases (NCDs) only mentions four major chronic diseases: cardiovascular disease, cancer, diabetes, and chronic respiratory disease. Many stakeholders point to the fact that the area of reflection should actually be broadened to ‘chronic conditions’ rather than ‘chronic diseases’. The

World Health Organization report “Innovative Care for Chronic Conditions” (2002) favours the term “chronic conditions” stating that chronic conditions are “health problems that require ongoing management over a period of years or decades" and pointing to several common aspects shared by chronic conditions. Defining chronic diseases also means defining persons encompassed by this definition, and their rights.

It is acknowledged that although there are a huge number of different chronic diseases there are a number of issues which many chronic diseases share. These include the type and organisation of health services, risk factors such as smoking, diet or alcohol related harm, socio-economic or environmental factors, as well as information and research. The focus of the reflection process is therefore on these common factors rather than on particular diseases. A couple of stakeholders suggested inserting a section to illustrate the fact that ‘chronic’ does not mean ‘non-modifiable’ and certainly does not imply that these conditions are subject only to generational change.

Respondents explain the hope that the current strong initiatives within the EU should emerge stronger from this exercise: the leadership in tobacco control, the Health Examination Survey, the Partnership against Cancer, and the concern for diabetes, cardiovascular disease, chronic respiratory disease, and musculoskeletal disease among others.

2.3 Other diseases and conditions to be included by the EU

While recognising the heavy burden of the “big” chronic diseases, such as cardiovascular disease, diabetes, respiratory diseases and cancer, many stakeholders stress the significant burden of many other chronic diseases and conditions, individually and collectively, on patients, their families and society.

Table 1 contains the conditions that deserve more attention according to the stakeholders (not in any particular order).

Table 1. Conditions mentioned by stakeholders that need attention

- Mental health problems (schizophrenia, bipolar disorder, depression, psychosis and dependence related diseases)
- Brain diseases, Alzheimer's disease and dementia
- Epilepsy
- Musculo-skeletal disorders
- Rare and ultra-rare diseases (i.e. immunodeficiencies, metabolic disorders, chronic genetic disorders)
- Chronic conditions of the oral cavity (many associated with common chronic diseases or as a side-effect of their medication)
- Allergies
- Vitamin D deficiency (causes osteomalacia and rickets; mild or moderate Vitamin D deficiency also represents a risk factor for fractures and falls and influences the immune system, the cardiovascular/ metabolic system, cell proliferation and cancer)
- Pain and chronic pain, both in general and specifically affecting the pelvis and abdomen
- Viral hepatitis B and C; the awareness of the relation between liver disease and viral hepatitis is low
- Multimorbidity.
- Pulmonary Hypertension (PH, a group of several chronic diseases that affect the lungs and the heart)
- Incontinence
- Prostate cancer
- Obesity and associated co-morbidities.
- Chronic gastrointestinal diseases (Crohn's Disease, Ulcerative Colitis, and other inflammatory disorders such as Fibromyalgia)
- Disability due to chronic respiratory disease
- Hearing impairment, especially progressive forms
- Dizziness and unbalance which may become chronic

Many of the above chronic conditions and diseases also appear repeatedly in some of the other chapters as in need of more research, improved care or better data coverage.

In addition, respondents point at risk factors that may also not get enough attention, but are relevant for chronic diseases, i.e. air pollution, passive smoking (as risk for newborns and baby's), malnutrition and preterm birth.

2.4 Additional information needs

Stakeholders not only suggest including a number of disorders, diseases or conditions as part of the chronic disease problem, but they also mention other important aspects that deserve attention in relation to chronic diseases.

2.4.1 Health Inequalities, health literacy, gender issues

Many stakeholders point at the need for more and better information in the field of health inequalities. Inequalities in health and chronic diseases are not only relevant in terms of geographical location, but also in relation to various social factors such as gender, age and ethnicity. It is also useful to study them by comparing the health status of different social groups or specific population groups. In this way, gathering information from many fields can contribute to a better depiction of the situation and the design of better and more targeted policies, in order to tackle chronic diseases at European and national level. Health inequalities also appear in other chapters of this report in relation to needs for healthcare improvement, needs for research and information needs.

Information and evidence about migrants, Roma and ethnic minorities, other mobile, marginalized or hard-to reach populations is significantly lacking. Strategies addressing chronic diseases must take into account the epidemiological, social and cultural specificities of migrants, as well as their genetic predisposition and exposure to risk factors as these may differ from the general population. Migrants are particularly vulnerable to chronic diseases. They often undergo acculturation that can spur unhealthy lifestyle changes, as well as socio-economic inequalities, such as difficult living and working conditions. Moreover, lack of social integration and loss of social networks can also increase migrants' overall exposure to chronic disease risk factors, mainly: unhealthy diet, physical inactivity, tobacco use and harmful consumption of alcohol and other substances. Again, these areas of interest reappear in chapters on healthcare, research and information needs.

Health literacy is related to literacy in general and important for health. It is defined as people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course. The variation of health literacy varies considerably between different EU Member States. With this in mind, it is essential to include the perspectives of health literacy when facing the challenge of chronic diseases.

Gender-related aspects of chronic disease need addressing in any future programmes. This is especially so where it affects younger women in childbearing age, with respect to the effects of future chronic- illness management coupled with the burden of caring for young children and possibly older family members. These people will need additional support structures in community environments.

Health literacy and gender issues reappear as important issues in the chapters on health promotion and healthcare.

2.4.2 *Monitoring and stratified data needed*

Stakeholders frequently mention a number of key aspects of the chronic disease situation that national governments and the EU must address to support evidence-based policymaking. The expression “What gets measured gets done” is cited a couple of times, suggesting that in order for policies to become effective, the situation has to be measured and monitored in a careful and meaningful way.

This type of information includes the burden of disease for patients, the socio-economic burden related to chronic diseases, co-morbidities, direct and indirect costs, healthcare workforce education, productivity loss, and health gains and inequalities related to the provision of prevention, treatment and care.

All these aspects vary according to age, social status, and other criteria, and therefore it is important to have stratified data. Altogether, there is much support for improved standardised, comparable and transferable data on chronic diseases and related areas in the European Union.

There is a need to collect and analyse data selected via commonly agreed European criteria and indicators to assess and compare the situation on chronic disease in EU countries. A European framework for the collection and evaluation of relevant data needs to be established. Stakeholders suggest a set of indicators that can help to get a better view of the picture of chronic diseases in Europe (Table 2).

Table 2. Proposed indicator set for chronic disease monitoring

Demographic indicators and indicators of disease burden

- Prevalence and incidence of chronic disease and chronic disease risk and metabolic factors
- Mortality rate in the EU by country, region and community
- Mortality rate attributable to chronic disease risk and metabolic factors
- Premature mortality rate from chronic diseases
- HLY (healthy life years)
- LEwD (life expectancy with disabilities)
- DALYs (disability adjusted life years)
- QALYs (quality adjusted life years)
- Data on co-morbidity and multimorbidity

Indicators on healthcare facilities and human resources

- Geographical distribution of healthcare professionals and healthcare providers
- The number of healthcare orientated graduates in full-time university study

Indicators in the socio-economic area
and for human costs of chronic disease

- Total labour costs of population with chronic conditions and disease (employers short- and long-term disability costs, effects of absenteeism, hours worked)
- Labour productivity of population with chronic conditions and disease
- Improvements in recruitment and retention from healthier employees
- Percentage and costs of early retirement population due to chronic disease
- Financial impact on healthcare and social security systems
- Key performance indicators in health care
- The employability of family and other informal carers
- Consumption and savings patterns of individuals with chronic conditions and disease and their families
- Risk of poverty
- Social exclusion, discrimination and stigma

The suggested collection of comparable data must be performed in close collaboration with other international organisations, such as the World Health Organisation (WHO) and the Organisation for Economic Co-operation and Development (OECD). In this way the EU and the WHO should ensure that comparable data on prevalence, incidence and costs (direct and indirect) of chronic diseases and associated risk factors are aligned and published on a regular and foreseeable basis.

Other suggestions and priorities around data and data collections needed to support health policymaking by the EU and its MS appear in chapter 6 on Information and information technology.

2.4.3 *Proposals for a different approach to tackle the burden of chronic diseases*

Stakeholders provided many proposals and examples of good practices to help tackle the burden of chronic disease in the European Union. We mention:

- Seek co-operation with WHO in view of their Action Plan for a strategy on NCDs and strengthen the links with OECD and with medical/scientific societies as well.
- Measure, monitor and report on actions taken in Member States. It would be good to set up a framework for best practices.
- Set targets to facilitate monitoring and reporting of progress in this field.
- Further expand collaborative approaches such as the European Innovation Partnership on Active and Healthy Ageing to tackle demographic challenges from multiple approaches, within the immediate environment of the individual: workplace, social and care settings.

2.5 Discussion en conclusion

The first consultation question has triggered a wide variety of answers by stakeholders. Many different aspects were mentioned of which we reported the most frequently given ones. There were no contradicting suggestions, but of course all stakeholders represent their own interest in the best way they can. Part of the answers is a response to the way the Commission has formulated the subject of ‘chronic disease’ and deals with the fact that in the view of stakeholders a wide range of diseases and conditions are relevant when talking about chronic disease. Further, stakeholders point at a series of different aspects related to chronic diseases that are important in their view. Finally, many answers to the Consultation question point at data collection aspects and at ways to use these data for policy-making.

Most of the above remarks and recommendations also reappear, sometimes in a different form, in the following chapters and their narratives. We conclude that stakeholders interpret the question: *“What further information and evidence should be taken into account by National Governments and the EU regarding the chronic disease situation?”* in different ways.

One set of answers that could also have appeared under this heading is the desirability of a ‘health in all policies’ (HiAP) approach. Stakeholders, however, mention this issue mainly under the heading of ‘health promotion’. Therefore HiAP will be addressed in chapter 3.

3 Health promotion and disease prevention

Key messages

- The area of health promotion, disease prevention and early detection should be addressed in its broadest sense, also including the necessity of a 'Health in All Policies' approach.
- Facilitating healthy choices in life for all citizens, strengthen health literacy and a life course approach are important for combating chronic diseases.
- The EU and the Member States should establish effective health promotion interventions for all preventable chronic diseases. It is, therefore, important to develop and systematically apply analytical tools to determine the (cost-) effectiveness of interventions and early detection.
- Prevention and healthcare should be integrated in future policy approaches to chronic diseases at both the national and EU-level.
- Health inequalities should be included as important perspective in every policy action.

3.1 Introduction

This chapter addresses the question "what more needs to be done to enable more people to live longer without chronic disease and to enable more people with chronic disease live better?" One answer is better prevention to reduce exposure to key risk factors.

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 also play an important role.

However, there is a well known tension regarding the degree to which government regulation and other actions to influence the life style risk factors should compromise the individual's freedom to choose for themselves. Similar tensions exist regarding regulation and role of business.

Consultation questions

- *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 focussed and become more effective?*
- *What potential is there for broad based early detection action?*
- *In what areas is there a particular need for additional action at EU level?*

- *In what areas is there a particular need for action at national level?*
- *What will you/your organisation contribute to address this challenge?*

3.2 Healthy lifestyle, healthy choices

Stakeholders agree that tobacco use, an unhealthy diet, including high salt intake, low physical activity and harmful alcohol consumption are major preventable risk factors of the chronic disease burden in the European Union. Obesity is a major intervening and preventable risk factor. Next to genetic factors, socio-economic and environmental circumstances play a major role as well. A healthy behaviour is therefore central in the prevention of chronic diseases in the EU. Other policy areas besides healthcare and prevention can and must contribute as well.

Smoking and alcohol

Smoking remains the leading preventable cause of cancer. Implementing a much stricter Tobacco Products Directive (TPD) will better protect young people from starting to smoke. This includes larger warning signs on plain cigarette packets and further reductions in exposure to tobacco marketing, as well as increased regulations on additives and flavouring of tobacco products.

The EU can urge the Member States to follow the WHO Framework Convention on Tobacco Control (FCTC) that has been signed by nearly all Member States and fully implement all relevant measures proposed in the framework, such as smoke free public places, higher taxes and supporting people who try to quit smoking. The actual implementation by EU Member States of Council Recommendations on smoke free environments is unclear and needs monitoring.

Taxes on tobacco and alcohol need a further increase throughout the EU because they are major causes of chronic diseases. Change the social environment and de-normalize tobacco consumption. Non-smoking must become the social norm. Member States must prohibit internet sales of tobacco.

Long-term risks of alcohol consumption receive too little attention. A widespread understanding of information related to the risks of alcohol drinking across the EU is important and needs additional support.

A minimum price per unit of alcohol sold as well as minimum excise duty rates in all Member States to deter consumption as well as strengthening the control of sales to underage individuals with effective penalties will reduce the burden of alcohol. There is a proposal for the introduction of health warnings on alcoholic beverages in all Member States and for banning of marketing and advertising for alcohol.

The importance of a healthy liver can be the message to take to schools and universities by sustainable campaigns.

Surveillance systems to monitor the prevalence of alcohol-related liver disease and mortality are important for Member States.

Medical doctors, nurses, associated professionals, including social workers and teachers need education on the early recognition of alcohol misuse.

Promote healthy lifestyles within key institutions and settings. Primary care practice, schools and work settings can play a key role in this regard. The role of these organisations and institutions needs reinforcement by education of their professionals and incentives for their full involvement.

Diet, food and nutrition

The area of nutrition is huge and very complicated. Enormous differences exist within the EU in dietary habits, contents of food products, labelling and in many other aspects that are all relevant for health.

Population-wide dietary policies can be powerful and cost saving, if they include evidence-based interventions, such as reducing salt, saturated fat and sugars in food products and the full elimination of industrial transfats.

In addition, the full implementation of the Nutrition and Health Claims Regulation is proposed as it only allows the use of health claims when they are scientifically justified, are easy to understand and relevant to public health.

Having a healthy and balanced diet requires that adequately formulated calorie contents of food products are present on those products across Europe. Education campaigns at EU level to inform and educate consumers about how to achieve a balanced diet and adopt a health lifestyle are important as well.

Promoting measures to increase the affordability of healthy food choices may support a healthy lifestyle and this can include fiscal incentives such as taxes and subsidies. Access to healthier food choices is especially important among low-income groups.

The effectiveness of fiscal measures taken at national levels in some Member States that target foods that contain specific nutrients with the aim to reduce the obesity prevalence is questionable according to one stakeholder representing the industry, however. The relation between tax raising and changes in food consumption is in need of scientific validation and this stakeholder questions discerning between ‘added’ and ‘naturally occurring’ sugars and the effectiveness of taxes to be imposed on soft drinks as secondary effects will reduce the effectiveness of such measures.

One stakeholder proposes the introduction of Vitamin D supplementation for European elderly to reduce the risks, such as the increased risk of fractures caused by falls, as posed by Vitamin D deficiency. Under-nutrition of elderly people is of major concern as well.

Certain preventive European programmes in the nutrition area, such as the ‘school fruit scheme’ are important and must face further implementation as they have great potential to increase fruit and vegetable intake across Europe.

Obesity

As obesity is a major risk factor that contributes to increased risks of diabetes, osteoarthritis, cancer and cardiovascular diseases as well as chronic liver diseases such as ‘non-alcoholic fatty liver disease (NAFLD)’ the prevention of obesity needs attention urgently. NAFLD will become a major cause of chronic liver disease and liver transplantations in the not too far away future.

There is a need to increase the awareness that obesity can lead to increased risks for musculoskeletal problems and pain.

Healthy choices

Member States should facilitate healthy choices of their citizens. These are often inhibited by:

- *Information failures*: inadequate knowledge of or understanding of the long-term consequences of unhealthy behaviours
- *External factors*: social costs and benefits of certain forms of consumptions are not fully reflected in the private costs and benefits to individual consumers, e.g. in case of addictive substances and unhealthy foods
- *Failures of rationality*: preventing individuals from making choices in their own best interest

Nudging aims at prompting healthy behaviour by re-designing the basic structure, environment and perception of a choice-making situation. Nudging still needs further research, sharing of best practices and support for practical implementation across Europe as it can make the choices easier that enhance health, welfare and quality of life.

Research needs to focus on collecting evidence of the benefits of healthy choices made by older people with specific chronic diseases as well and in addition on the comparison of the effects of preventive interventions as compared with pharmaceutical preventive treatment.

It is important to develop guidelines on the optimal balance between investment in pharmaceuticals and lifestyle interventions in the prevention and management of chronic conditions, particularly for older adults.

There is an unused potential for primary care givers and health insurers to contribute to optimising health literacy.

3.3 Health promotion and disease prevention

Prevention is worth investing in

Respondents state that investment in community-based preventive health promotion programmes to increase physical activity, improve nutrition, improve mental health, reduce alcohol-related harm and put an end to tobacco consumption will significantly reduce healthcare costs. Programmes should cover the life course, lead to gains in worker productivity and quality of life across the whole population, including excluded and vulnerable groups.

At EU-level an overarching chronic disease framework must be developed that systematically addresses the major risk factors of chronic diseases. At Member State level this framework must turn into a strategy that includes evidence-based disease-specific approaches that are adapted to the national situations and priorities.

EU-wide campaigns such as ‘ex-smokers are unstoppable’ and the ’school fruit scheme’ are commended for their potential by the stakeholders.

Preventive interventions need to be evidence based with a clear view on cost-effectiveness.

The creation of databases that contain information on best practices in prevention and how to best disseminate them is needed at national and European levels together with support for implementation of best practices at a wider scale.

The use and reuse of healthcare data for identifying people at risk needs support by adequate legal instruments that both provide privacy protection and support the interests of public health.

Patient organisations can be important for health promotion and prevention through active participation in research and prevention efforts and by their advocacy. They provide opportunities to reach specific risk groups.

Prevention in medical practice

Stakeholders see a combination of health promotion, disease prevention and medical care as integrated elements of any future effective approach to combat chronic diseases.

Prevention still needs systematic development in medical practice. The care system must guide and coach people over a lifetime to improve their health behaviour. Effective technical and pharmaceutical support elements can assist to optimise this approach.

Men and women have different risk factors and chronic diseases affect them differently. To effectively target prevention and health promotion programmes, they need to be gender sensitive.

A major issue in current prevention is the fact that many interventions do not reach or are less effective in some of the groups that are highest at risk, including people with lower socio-economic positions.

Personal health management has preventive components. This can start with falls prevention as a first step in actions that prevent declines in functioning and frailty in elderly patients with chronic diseases.

Preventing inappropriate multiple prescription of drugs in elderly patients is becoming increasingly important.

A general lack of co-ordination between European and national preventive efforts is a major current problem in EU-wide prevention.

Investigate whether financial incentives for healthy and preventive behaviour can be effective instruments to enhance preventive lifestyles in people that are in contact with the healthcare system.

Still, not all chronic diseases are currently preventable, such as neurodegenerative, genetic and rare diseases, but delaying the onset or slowing the progression may become feasible in the future.

Vaccination and screening

Adult Immunisation Programmes that protect the elderly and enhance their quality of life need more attention. Coverage of influenza vaccination is not sufficient within the EU, for instance and a Health Council recommendation encourages MS to increase coverage to the WHO-targets of 75% by 2015. Coverage of pneumococcal vaccination is also amenable for improvement. The burden of pertussis in infants is increased by the reservoir of unprotected adults notwithstanding relatively high DTP vaccination rates in young children. Adolescents and adults at risk for severe complications after a pertussis infection are those with underlying chronic conditions such as asthma, COPD, cardiovascular diseases and immunodeficiency. Regular pertussis booster vaccination in preschool children and other relevant groups may be necessary.

For these and other reasons increased co-operation is needed in Europe in the area of vaccination strategy development.

Prenatal and neonatal screening

Screening programmes of newborns for treatable inherited diseases are not uniformly present throughout all Member States. Best practices and standards in this regard should be developed and disseminated to make such screening available for all newborns in all Member States.

3.4 Early detection of chronic disease

Early detection of disease is very advantageous, but often avoided, because of a belief that it will increase the use and costs of healthcare or if treatment is ineffective it will not lead to health gains. Early detection for brain disease will improve outcomes, however, as well as reduce costs of inappropriate referral and treatment.

The use and analysis of existing large healthcare data sets needs enhancement to improve the identification of early and predictive signs for chronic diseases and next approach patients with options for support in taking preventive action.

Such early detection necessitates optimal legal facilities for the use and reuse of such data, while simultaneously protecting patient and provider privacies, but serving the public (health) interest at the same time. In Member States, specific privacy commissions can serve to decide on the use and reuse of data.

A health professionals organisation in the field of respiratory diseases suggests that screening the general population for respiratory symptoms and lung function is an effective method for detecting subjects with a mild but persistently impaired lung function at an early but undetected stage of the disease. This stakeholder proposes regular monitoring of child and adolescent growth and development, including measurements of height, weight and lung capacity as well.

Early detection of COPD by spirometry improves the patient’s outcomes and makes the natural history of the disease less severe. Early detection is important for Alzheimer’s disease as well, but still requires good guidelines.

More and better training of primary healthcare professionals and community healthcare professionals can enhance their knowledge of risk factors and early detection of chronic diseases.

Extensive genetic data collections can support early detection of many chronic diseases. Their further specification and refinement needs further research in order to integrate these techniques into more effective preventive approaches and support reduction of the burden of chronic disease in the general population.

Routine nutritional screening for older patients who are at risk of malnutrition is necessary for early and timely intervention. European standards for the implementation of such screening in hospitals and care homes are important, while good screening tools already exist.

Early detection and screening programmes for people at risk need effective communication to those people with easy access for them. National sources or the national healthcare system must pay for it. International collaboration and joint development of novel tools to detect chronic diseases is important. Attention for the psychological implications for those labelled to be at risk is important. Over-emphasis on early detection can lead to medicalisation of non-medical conditions with an upward effect on healthcare utilization and costs.

Population- based screening for cancer is, according to several stakeholders, an effective and cost-effective measure. This can be expanded towards systematic screening for high-risk individuals for other diseases as well by looking at risk factors like age, smoking, waist circumference, family history, cardiovascular history and even gestational history. The exchange of knowledge, best practices and research evidence in this area needs European support.

3.5 Specific areas for additional attention at EU and MS level

Evaluation of prevention

Stakeholders point at the need for support of experimental implementation projects by supporting not only their implementation, but evaluation as well and support active promotion of those that are cost-effective.

There is a need to develop standardised evaluation programmes for the effectiveness of specific intervention strategies that address key risk factors in specific groups.

Best use must be made of recommendations and evidence already collected by international organisations, such as by WHO in their 2010 Global Status Report on non-communicable diseases.

Specific disease-oriented prevention

The rising incidence of type2 diabetes is an example of the increasing need for prevention. It is often diagnosed too late, however, and no longer amenable for prevention by lifestyle changes. Better identification of the risk factors for glaucoma is essential for improving its prevention. Allergies are put forward as a chronic condition, where early diagnosis and diagnosis of new rare forms is important.

Mental health is also a major cause of chronic illness, where an important factor is the lack of awareness about how to maintain one's mental well-being.

Life course approach

Life-course approaches are central to addressing the accumulation of exposure to the risk and consequences of chronic conditions. Investing in pre-conception and maternal care can help prevent chronic diseases. That includes investing in continuing professional education for pre-conception, maternal and perinatal care to improve awareness of underlying risks for chronic conditions during pregnancy. Working towards developing safer medication for newborns is one of the areas involved. Preterm birth can and must be prevented by better primary prevention.

Good maternal and newborn care is an important precondition for a healthy start in life and prevention of preterm delivery, for instance by early detection, is important and in need of more research.

Health in All Policies

Stakeholders emphasize that Health in All Policies (HiAP) is a precautionary principle for government: do no harm through policies or laws enacted in other governmental sectors. Policies in other sectors should also work to improve health. The EU and its Member States must put greater emphasis on the implementation of health in all policies, in accordance with the Lisbon Treaty.

Health in all policies rests on the serious involvement of other sectors such as the social and education sectors, the sectors of environment, work, food and agriculture, sports as well the social and transport sectors to address within their remits ways to contribute to better health outcomes.

Especially in the field of HiAP evidence on effects is still often lacking, however. A sustainable health survey system and repeated collection of comparable survey data that allow determination of trends may provide evidence for effects of health promotion and HiAP in the future.

We will discuss some examples below where stakeholders suggest that sectors can contribute to combating chronic diseases and improving health.

Environmental sector

Clean air, safe water, appropriate housing and availability of green areas are important for health. Indoor air pollution is a suggested important contributor to chronic disease development and reductions of emissions at the source remain important preventive measures. 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. Development of air cleaning and filtration technologies is essential to prevent these environmental exposures and chronic disease risks in many large buildings.

Global warming is an environment threat that can threaten health of the elderly and of people with chronic diseases by enhancing the risks of extreme heat and cold.

Supporting physical activity in the urban environment, at schools and in work places is recommended and urban planners and architects need to become partners in such an approach.

There is a proposal to use the European Structural Funds as a means to reduce the environment threat and improve access to clean drinking water and better housing and so prevent part of the chronic disease burden.

Education sector

Knowledge about health needs better integration into education. Healthy lifestyle recommendations must be an integrated element of education curricula in all school levels. This can increase the awareness at younger ages of what they can do to stay away from undesirable health risks. It was also suggested that stigmatisation of chronic disease patients is still a large problem in many chronic diseases, e.g. for epilepsy, and this could also be improved by better education about health.

Stakeholders propose to involve DG Health and Education in identifying measures to improve health education and health literacy in the EU and optimise the possibilities to receive sufficient years of schooling in all Member States. More years of formal schooling correlates strongly with enjoying better health.

Work sector

Health promotion and disease prevention at the workplace are important. Diminishing productivity loss and unemployment and improving early return to work are achievable goals. Improving health at work requires co-ordination and collaboration among the national health, social and work sectors.

A substantial amount of the burden of rheumatic and musculoskeletal chronic diseases is work-related and in need of preventive action at the workplace. A work-related musculoskeletal EU-directive can support the adaptation of working environments to prevent musculoskeletal problems further.

Social sector

Especially for chronic mental ill health the collaboration between the medical and social sectors is important in risk reduction and improvement of protecting factors. Homelessness and lack of adequate housing are important risks.

Another social as well as health issue is that of irregular migrants. In several EU Member States legislation attempts exist that restrict the access by this group to healthcare provision and treatment. This leaves chronic disease patients untreated and unreached by prevention.

Better indicators for health inequalities and exchange of best practices on health inequalities are important for prevention and care of chronic disease patients as well.

Public private partnerships

Respondents state that more collaboration with other sectors by means of more public private partnerships is important to aim at generating a whole of society approach in the areas of, for instance, diet and nutrition and physical activity.

3.6 Member State and EU action opportunities

Stakeholders suggest to use the financial instruments of the EU, including Structural Funds, European Agricultural Fund for Rural Development and EU-funded research as possible tools for health promotion that can contribute to creating healthier European societies.

The EU can use legislative tools such as advertising restrictions on unhealthy products and regulating salt and fat content in order to promote health and behavioural change in daily practice.

Given the wide range of health inequalities within and between EU Member States the reduction of these inequalities has to remain a top priority for the EU and this must include combating poverty and social exclusion.

The EU and the Member States must actively consider the extension of the mandate of the European Centre for Disease Control to cover the chronic disease epidemic.

Recognising that national governments in EU Member States have full competence of their health and social care systems highlights the need for action at national level, also in the area of health promotion and prevention.

National health ministries have a vital role to play in ensuring an equity-oriented contribution of the health system, in advocating for equity and health in policy proposals of other sectors.

European Union Member States must operate proactively and allocate more funding to preventive measures. They must prepare national progress reviews in the NCD-area and present these at the next UN Summit in 2014.

3.7 Stakeholder contributions

Stakeholders mention awareness raising of the burden of certain chronic diseases among the general public and health professionals and advocacy at UN, EU and national level. Stakeholder contributions also include education of patients, health professionals and informal carers, knowledge sharing through website and preparing independent patient information leaflets, and activities to empower patients and to advance health literacy. Many stakeholders mention the exchange of good practice and experience, e.g. trough the production and exchange of European clinical practice or care guidelines.

Stakeholders often work together in partnerships, e.g. with the European Parliament, Commission and Council central and local governments, NGOs and other stakeholders. Several stakeholders from the industry as well as health professionals mention that they contribute to the EIPAHA or are involved in platforms and forums such as the EU Alcohol and Health Forum and the EU Platform on Diet, Physical Activity and Health. Several stakeholders (industry and health insurance funds) also mention that they can contribute to the implementation of innovative disease management programs.

Several stakeholders contribute to supporting evidence-based policy. Activities in this area include developing the knowledge base through participation in research, collection of scientific evidence (including information on the cost-effectiveness of prevention), the collection of up to date and comparable data (on country and EU-wide level), and collecting data on clinical practice in registries. Stakeholders also engage in the dissemination of scientific results to policymakers, health care professionals, other researchers and the general public. For example by organising or supporting scientific conference and providing recommendations to policymakers.

3.8 Discussion and conclusion

Stakeholders identify many important actions and developments as important in preventing chronic diseases and suggest numerous approaches that can help focus existing actions to become more focused and effective. We have tried to distillate the most relevant remarks that were frequently mentioned by different stakeholders.

Stakeholders point at the importance of approaching health promotion by enhancing healthy living and healthy choices as a major element of combating chronic diseases. Important elements of such an approach are monitoring of the actual implementation of tobacco control measures, fiscal measures, nudging, health literacy, (cost)-effective interventions, integration of health into educational programmes and awareness raising of the risk of alcohol consumption. However, respondent argue under the heading of health promotion that some chronic conditions are not easily amenable to prevention. These diseases, such as depression, Parkinson’s and Alzheimer’s disease, as well as many others, also need inclusion in a future, fully integrated European chronic disease strategy.

Many stakeholders elaborate on the necessary integration of prevention and healthcare in future policy approaches to chronic diseases at both the national and EU-level. As they also point at the need to integrate research and data recommendations, there is overlap between this narrative on health promotion and disease prevention and other chapters, e.g. those on healthcare and research. Next, looking at disease prevention and early detection, we find issues related to settings, and cost-effectiveness that stakeholders felt are important. Specific areas for additional attention at EU and Member State level include supporting the implementation and evaluation of experimental implementation projects and a lifecourse approach.

Stakeholders address the area of health promotion, disease prevention and early detection in its broadest sense, also including the necessity of a ‘Health in All Policies’ approach. The need to work at health in all policies, as well as including health inequalities as important perspective in every policy action are important element in the stakeholders’ views.

Recognising that national governments in EU Member States have full competence of their health and social care systems highlights the need for action at national level. The EU can use legislative tools to promote health and behavioural change in daily practice and financial instruments to improve health promotion activities. Stakeholder can contribute through awareness raising, education, exchange of good practices, dissemination of scientific results, and the implementation of innovative programs.

4 Healthcare

Key messages

- Stakeholders agree that the rising burden of chronic disease is a major threat to the sustainability of EU health systems.
- National healthcare systems need a more integrated approach with a central role for the concept of chronic disease management.
- Healthcare improvements are necessary as well for a large number of chronic diseases that are not mentioned among the 'big four' chronic diseases (cancer, diabetes, cardiovascular and respiratory diseases), for example rare and ultra-rare diseases, Alzheimer's disease, and mental ill health.
- Innovations in E-technology are feasible and desirable but the introduction of such new technologies must take place with full involvement of patients.
- Patients with comorbidities and the effects of informal care are two areas that should get more attention.
- The health care system is the major collector of comparable data and information on chronic diseases, but improvements in this area are needed. Integration of different databases is one means to achieve this. E-health technology also has huge potential in this area.
- Other policy areas such as employment, environment, agriculture and education are also important in tackling chronic diseases (Health in All Policies).
- EU and Member States should support the evaluation of cost-effectiveness of programmes and projects and the exchange of best practices.

4.1 Introduction

The healthcare system is central to chronic disease prevention, treatment and care. In nearly all EU Member States the cost of health care continues to rise driven by a combination of increasing chronic disease levels, rising expectations from patients and professionals and improved availability of treatments. Attempts to reduce costs by improving efficiency in health care have met with limited success.

The role of the health care system as a supporter of patients to manage their own illness is one which is becoming increasingly important. Innovation in healthcare can be important to almost every aspect of prevention and treatment of chronic diseases.

Consultation questions

- *What changes could be made to enable health care systems to respond better to the challenges of prevention, treatment and care of chronic diseases?*
- *What changes could be important to better address the chronic disease challenge in areas such as: financing and planning; training of the health workforce;*

nature and location of health infrastructure; better management of the care across chronic diseases?

- *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?*
- *In what areas is there a particular need for additional action at EU level?*
- *In what areas is there a particular need for additional action at national level?*
- *What will you/your organisation contribute to address this challenge?*

4.2 Growing burden on healthcare by chronic diseases

Stakeholders agree that the rising burden of chronic disease is a major threat to the sustainability of EU health systems by endangering the supply and affordability of sufficient and adequate healthcare for an ageing population. Shortage of healthcare professionals is a major future threat. Ageing is an important driver as well as increased expectations by patients and the growing availability of better but more expensive medication and technological solutions. Improved treatment outcomes in a way increase the prevalence of chronic patients as well.

Given possible disparities in the availability and quality of prevention and care for chronic disease patients throughout the EU the fear is put forward that this could lead to people moving abroad to receive more adequate treatment in other countries or even health-related migration.

A combination of autonomous demographic and socio-economic developments contributes to increasing shortages of informal caregivers and increasing pressures on those who currently give informal care. Not only the ageing of our populations plus lower birth rates, but also the trend towards smaller families, an increasing mobility, leading to greater physical distances between relatives, as well as a rising number of women entering the labour market in addition to a prolonging working life by a delayed retirement age all contribute to enhanced pressures on informal care. Across the European Union spouses, relatives and friends provide about 80% of care for chronic patients. Informal care and carers therefore need a proper place in any future initiatives on chronic diseases.

Using available knowledge and information that is present at the Member State and European level is essential. Many relevant reports have already appeared that contain information about NCDs and related healthcare in Europe. Their conclusions should be turned into action. One example is the Men’s health report.

EU Member States will have to remain fully responsible for their national healthcare systems under the EU principal of subsidiarity. The need to develop a EU-wide chronic disease strategy is not challenged, however, but under the explicit notion that this strategy shall be developed in synergy and close collaboration with the NCD-strategy being developed for Europe as a whole by WHO’s office for the European Region in Copenhagen.

4.3 Change of focus in healthcare systems

Stakeholders repeatedly note that in most areas of health systems changes could and should be made, including in financing and planning, in the nature and location of the health infrastructure, in training of the health workforce and especially in better management of care across chronic diseases and by laying emphasis on the further development of innovations, including eHealth.

Several times stakeholders judge current national healthcare systems in a very critical way. In their view, the current systems mainly focus on short-term interventions and on the more acute episodes. Most current systems are not fully integrated yet as they do not adequately interlink primary, secondary and tertiary care sectors, they often lack integration with the social care system and lack a systematic approach to prevention. Current overuse of very costly specialized care and emergency care must get less.

Systems should also become better capable of delivering care across the EU-borders without loss of information, quality and effectiveness. Stakeholders suggest the possibility to define an overall European chronic disease management plan, implemented country by country and by disease after disease, including prevention, early diagnosis and disease management.

Shifts from fee-for-service to pay-for-performance were among the suggested solutions for changes into more cost-effective healthcare delivery with greater attention for prevention and early detection. The use of financial incentives is a good instrument to stimulate innovation and improve co-ordination between providers and to stimulate integrated care. Safety, quality and sustainability need to be the major drivers of decisions in healthcare changes.

Prioritisation of care budgets has been proposed on the basis of economic reassessments of disease burdens at regional level and to be repeated over time as the chronic disease burden can and possibly will change over time. Health needs assessment could be a strategy to reshape and redirect health systems. Having networks of chronic disease nurses is also a possible healthcare improvement.

The current healthcare systems are not fully ready for patients having several diseases at one moment as well. Co-morbidity and multi-morbidity need much more attention as their occurrence will increase fast and their treatment requires a much more integrated approach to care than is delivered nowadays in most systems. Chronic pain is also a crosscutting issue among multiple chronic diseases that will require more and more appropriate attention in any future healthcare system.

In any future healthcare system the professional autonomy of physicians is of paramount importance for the provision of adequate care. Decisions on treatment need to be within the medical interests of the patient and these decisions need to be taken by doctors who are free from conflicts of interest of any type and of any administrative or financial pressures.

The adequate involvement of patients and their representative organisations in healthcare design and delivery is an essential element of the renewal of any healthcare system that aims to better deal with chronic diseases. It is important to evaluate the contribution of patient’s and exchange the encountered best practices. Pro-active involvement of patients in decision-making processes at the national and

European level is an important prerequisite for reshaping European healthcare systems as well.

4.4 Need for more integrated care

Different types of stakeholders (from industry, NGOs/umbrella organisations, patient organisations as well as organisations representing health professionals) suggested a more integrated approach to healthcare, as well as the need for introduction of disease management schemes and the wider use of chronic care models. This approach puts the patient more central in the healthcare system and empowers patients to take responsibility for their own health, while remaining more often at their own home. They will be having better control, e.g. via self-management. Enhancing and integrating self-care into healthcare practice appears an essential prerequisite for future care arrangements. Autonomy and quality of life are central elements in such an approach.

Cost-effectiveness of new care arrangements is a desirable and feasible outcome of the proposed healthcare changes. Models of payment, insurance and healthcare contracting must be reshaped according to the needs of patients, while optimising cost-effectiveness. Enhancing informal care can reduce costs as well, if properly organised and if maintained in a sustainable way. Equal access to diagnosis, care and treatment remain essential for any healthcare system renewal, however.

Sufficient attention for prevention must become an integrated part of any healthcare system changes that were repeatedly proposed. Renewals will have to be organised in close collaboration between healthcare providers, payers and/or insurers, and with patients and important informal caregivers and other persons who act in support of the patient. More attention for must be paid to a further specification of those target groups that will benefit most from preventive efforts and to develop screening methods to allow such better focused prevention.

Learning from best practices should be central, especially when disease management and case management related innovations in Member States have coincided with being less expensive.

Strengthening primary care and outpatient facilities are important elements of many of the suggested future healthcare changes. With increased home-based and outpatient care provision the need for technological support increases as well. Improved and expanded provision of primary care can offer high quality care and simultaneously reduce hospital costs and it is therefore recommendable for various countries to invest in primary care as a means towards more people-centred care and lower costs. Still, for some chronic diseases like COPD and asthma primary care physicians may require more training to recognise exacerbations and to treat patients according to guidelines that will take disease severity into account.

Healthcare professionals need training in the delivery of new care arrangements together with the people that provide social care or informal care to chronic disease patients.

More effective specialised care networks for chronic diseases may emerge with support from long-term financial and legal arrangements. This necessitates increased attention for change management in healthcare systems and for the development and implementation of new and more generic workflow systems. Considering the implementation of new business models for healthcare may assist necessary system changes.

Central place for disease management approaches

Stakeholders frequently put the concept of chronic disease management central in their views of the future. They define chronic disease management in the clinical setting as an organized, proactive, multi- component, patient-centered approach to healthcare delivery that involves all members of a defined population, who have a specific disease entity, or belong to a subpopulation with specific risk factors. Care focuses on and integrated approach across the entire spectrum of the disease and its complications, as well as on the prevention of co-morbid conditions, and relevant aspects of the delivery system. Essential components include identification of the population, implementation of clinical practice guidelines or other decision-making tools, implementation of additional patient-, provider-, or healthcare system-focused interventions, the use of clinical information systems, and the measurement and management of outcomes. In this approach, self-care is a significant element.

Guidelines are important tools for clinical management of chronic diseases. A wide collection of national guidelines already exists, but there is a need for constant renewal. Prevention and health promotion must become an integrated part of any new healthcare system, with adequate compensation schemes and evaluation procedures.

Integrated care for chronic patients also necessitates adequate palliative and end-of-life care, to be supported by specialist nurses and specialist palliative care teams, which are scarce or non-existent in many countries still. Adequate approaches to chronic pain treatment, as delivered by specialized outpatient services, are needed, but often still lacking, as is the availability of sufficient adequately trained professionals.

Half of people aged over 65 years of age suffer from three chronic diseases and 20% even have more than five. Patients that take over 10 different drugs are not an uncommon event. This leads to undesirable interactions and even additional medical consumption. Despite the fact that an increasing number of chronically ill suffers from co-morbidities, disease-management programmes often still constitute of a single-disease approach and tend to neglect co-morbidities. In addition, it should be realised that most evidence is collected in single disease trials that exclude patients with co-morbidity.

4.5 Innovations in E-technology are feasible and desirable

Innovations, e.g. in e-Health and technologies, are important with the caveat that they should not result in greater inequalities in health and will maintain the human dimension for the patients involved. The introduction of new technology must therefore take place with full involvement of patients and his or her surrounding informal caregivers and with the professionals involved. Promoting innovation simultaneously with reducing inequalities by taking into account both dimensions simultaneously is among the proposed strategies for innovation. An adequate implementation will only be successful if the outcome is added value for all parties.

One stakeholder (individual) suggested to combat fraud and abuse in European healthcare systems by giving people at national level direct access to an electronic system where they can declare these healthcare burdens, while assuring their full privacy protection.

The increased use of assistive technologies is very promising for patients with increasing cognitive impairments and suffering from a chronic disease, including specialised reminder systems, location systems and patient monitoring systems. Still, ethical issues need consideration in this area. Medical training must include teaching the best use of e-Health technologies in healthcare.

E-technology such as Personal Connected Health and Telehealth can help in improving patient-caregiver as well as caregiver-caregiver communications in many ways. This will improve the chances to deliver adequate care at the patient's home, empower the patient and facilitate integrated care among several caregivers. Improving the exchange and use of data is essential for this to become optimally effective. This will be especially beneficial for paediatric and geriatric patients. Overdependence of elderly patients on remote telemonitoring is to be avoided, however, for instance by introducing callcenter back-up and better trained healthcare professionals. Using e-technology in clinical trials is a promising venue.

In general E-health innovations include multiple possible applications including communication, screening and risk prediction, follow up for interventions that relate to both prevention and treatment, enable remote monitoring and optimise the organisation and delivery of healthcare in hospitals. Improved access in remote geographical area's, reduced waiting times and improved access to data by clinicians are among the examples of areas where E-technology will contribute to better healthcare. This will enhance quality of care, improve working conditions for physicians and increase productivity of the health system, next to providing less patient discomfort by reduced travel and waiting times.

E-health platforms containing patient data, disease information and communication facilities to exchange information between patients and caregivers are seen as promising future elements of integrated care.

Random EU investment in a multitude of e-Health and m-Health (mobile health) projects for healthcare must be avoided in the future. There must be a focus on low-cost models with patient-involvement in the development of such healthcare management models.

Health Technology Assessment is an instrument to be more widely used in assessing the effectiveness of new E-technologies in healthcare.

4.6 Action for specific chronic diseases

As in some of the other chapters of this report, stakeholders state with regard to the questions about healthcare and chronic diseases that healthcare improvements are necessary as well for a large number of chronic diseases that are not mentioned among the 'big four' chronic diseases (cancer, diabetes, cardiovascular and respiratory diseases).

For rare and ultra-rare diseases it must be guaranteed that new medicines will be developed and made equally accessible for all patients in Europe. For other diseases, such as glaucoma, epilepsy and brain disorders, and Alzheimer's disease, but also for mental ill health and for rheumatic disease improvements of our healthcare systems are necessary as well. In this sense other chronic diseases have also been called to attention, such as Parkinson's disease, multiple sclerosis, sleeping disorders, other respiratory diseases than COPD such as chronic pulmonary hypertension and rheumatic diseases such as osteoarthritis and other musculoskeletal diseases, including osteoporosis.

Yet, respondents mention other chronic conditions as being in need of improved healthcare systems as well: obesity, heart failure, chronic kidney disease, schizophrenia and xerostomia. In relation to nutrition they recall other important chronic diseases such as irritable and inflammatory bowel disease and Crohn's disease as well as the food-sensitive rare disease phenylketonuria.

Respondents suggest the development of national centres of expertise for some of the less frequently occurring chronic diseases. Genetically determined and life-threatening plasma-related disorders are very expensive to treat and currently approached by a variety of ill-comparable care standards across Europe. Pre-diabetes is according to some stakeholders an under-diagnosed chronic condition as well.

For some chronic diseases, such as cancers, early diagnosis, including effective screening programmes, followed by adequate treatment, are still lacking in many EU Member States. Their introduction promises increased survival. Better awareness of signs and symptoms is also important in that regard and this is still open for improvement throughout the European Union as well.

An information gap exists in Europe with regard to data on co-morbidity and on MCC, multiple chronic conditions. There are no clinical guidelines to address these conditions effectively in spite of knowing that co-morbidity may deeply affect the outcomes of treatment.

Further facilitation and encouragement of organ donation and transplants is an important healthcare issue that also relates to some of the chronic diseases with a high individual disease burden.

The potential importance of oral ill health as a risk factor for increased occurrence of severity of several chronic diseases and their prevention and care is in the responses as well.

Homeopathic and anthroposophic medicinal products are suggested by one stakeholder as being a relevant patient-chosen element of disease therapy, but without suggesting any special application for the area of chronic diseases, except for the importance of freedom of choice as a central element in integrated healthcare.

4.7 Health care system as major collector of comparable data

In this stakeholder consultation on healthcare and chronic diseases it is also mentioned repeatedly that the healthcare system will have to function much better than it does now as being the major collector of comparable data and information on chronic diseases. This will allow for a better focus on new priorities, enable better monitoring of changes and improvement and also allow for a better evaluation of the quality and outcomes of new approaches in the care for chronic disease patients. Knowing the problem and knowing how it will develop in the future is essential for any strategic decision making in the chronic disease area.

Integration of different databases and health registries is put forward as a means to achieve a better overall picture of how health systems respond to patient needs. Introducing European wide standardized electronic health records is a means to get better national and internationally comparable data on chronic disease occurrence and treatment quicker.

Paying for data delivery by healthcare providers is a possible measure to take into consideration when considering changing financing strategies in new chronic disease oriented healthcare systems.

The huge potential of e-Health technology to improve the essential increased exchange of personal health data for identifying, managing, and evaluating healthcare decisions is mentioned repeatedly. In order for information to be relevant and exchangeable at the level of the European Union it is essential to develop common standards and adequate ways to secure and protect privacy sensitive information, however, without increasing existing inequalities.

4.8 Other policies also important for tackling chronic diseases

Stakeholders mention the importance of aspects of nutrition for health and healthcare repeatedly. Healthy diets prevent an important part of the chronic disease burden and that goes already for children. Adequate nutrition of elderly patients with chronic diseases is a relevant issue as undernourishment occurs in general much more often than is recognised by healthcare workers and it is linked to increased co-morbidity and other adverse reactions. The awareness of under-nutrition in care settings needs increasing. Healthcare professionals need more training in this area as well as better screening tools.

The relation between work and chronic disease is, according to stakeholders, complex but relevant. Many interventions have been under investigation in EU Member States and can possibly be implemented wider that improve the health of people at working age. Similarly, some of these interventions can help to prevent chronic disease, or support return to work of those with a chronic disease and so combat the loss of economic output by the burden of chronic diseases of those at working ages.

The environmental aspects of the prevention of chronic diseases need to become part of a chronic disease strategy, among others because there is the explicit need to protect children against environmental risks.

The healthcare system can be further unburdened of chronic diseases by increasing the attack on smoking and alcohol abuse by enhanced taxation policies, agricultural policies and better education of future doctors.

Cultural competency is an essential part of any new healthcare system that treats chronic disease patients with different cultural backgrounds. Reaching marginalized populations and combating discrimination remain essential. Future healthcare systems must foster the integration and participation of migrants and develop in a migrant friendly way.

4.9 Member States’ and EU action opportunities

Stakeholders make various suggestions about increasing the exchange of best practices and about other actions by the EC that can support making progress in the chronic disease area across the European Union. Several times respondents mention that adopting integrated chronic disease strategies at both the national and European level would be an important step forward.

Evaluation of effectiveness and exchange of best practices

National governments must put appropriate measurement systems into place that allow the prioritization, implementation and assessment of national preventive efforts. This includes screening programmes and the provision of adequate financing strategies that adequately reimburse such preventive actions.

The outcomes of innovative healthcare projects that have been executed in Member States of the European Union and that have proven cost-effective, can be disseminated as best practices to other countries and this can be supported at EU-level.

EU-support for the evaluation of the cost effectiveness of chronic disease prevention programmes is important from the prevention perspective of NCDs. Quick and effective ways of dissemination of the results from relevant clinical trials and health services research are essential to steer our health systems by best evidence. In certain areas of care, i.e. those dealing with multi-morbidity, chronic care and end-of-life care, the exchange of new approaches, forms of organisation and proven best practices among Member States need stimulation by the EU.

Exchanges of best practices and good examples for chronic disease guidelines among Member States and relevant national NGOs and governmental institutions could work to improve and sharpen existing national guidelines with sufficient attention for the actual implementation of such guidelines.

Sharing best practices in new forms of co-ordinated care that have arisen in EU Member States for specific chronic diseases such as Parkinson’s disease or multiple sclerosis could be evaluated and shared within the European Union with support from the EU.

Support adoption of new technologies

Incentives can be created at national and EU-level that support and drive the adoption of new technologies. This includes incentives that maximise the efforts that were already developed and aim to improve interoperability of healthcare systems in order to optimise widespread adoption of e-health technologies.

The promotion of age-friendly, and even ‘dementia-friendly’, communities is important for future elderly with chronic diseases and the exchange of innovative or best practices in this area between Member States provides a good opportunity for EU support.

Health inequalities

An important issue of EU-level dimension is the problem of inequalities in health and healthcare. The occurrence of healthcare inequalities between MS and within the MS can further increase in our national healthcare systems that bend under increasing financial burdens. Such socio-economic differences are undesirable and EU-support, if possible, for their reduction is important.

Health inequalities are often disease specific and they may originate from treatment differences that can arise from a lack of standards of care. It is important to map, compare and assess standards from EU Member States in order to arrive at common and equal ways of treatment for chronic disease patients.

Other areas

The reflection process on sustainable health systems that runs in parallel to the chronic disease consultation of Member States and stakeholders is important. Stakeholders propose that the EU flagship initiatives also support the EU action strategy to fight the chronic disease burden. They must focus on improving quality of live and for instance support the development of new job skills that bridge the existing gap in healthcare needs better.

Little research has until now been executed in the area of informal care. Again, looking at existing practices, supporting arrangements, negative and positive external influences and effects of this informal care and informal caregivers to chronic disease patients is important to identify and exchange best practices among EU Member States.

Smoking is one of the major risk factors that causes various chronic diseases and it is therefore one of the major elements to be tackled in an integrated care approach to chronic diseases. EU-support to reduce smoking effectively therefore remains extremely valuable. Similarly, healthy diets and adequate physical activity deserve continuing attention within future healthcare settings.

It is feasible and relevant that an organisation is set up at EU-level to support and coach national primary care organizations about their chronic disease management approach. This parallel with support for e-Health system development at the level of primary care practices throughout Europe.

4.10 Stakeholder contributions

Stakeholders basically mention the same things as presented under this heading in chapter 3 Health promotion. Stakeholders participate in EU-funded projects, support research, organise conferences, identify and share best practices through the development of good practices database, develop evidence-based guidelines, and raise awareness, for example about e-health solutions among health professionals.

They express willingness to work together with EU institutions and Member State governments and with different other partners to improve the entire system of care. Stakeholders participate in new initiatives, from the research phase to the improvement of the quality of life of people with a chronic disease. Some stakeholders mention that they participate in the EIP-AHA.

4.11 Discussion and conclusion

Stakeholders mentioned many different aspects. We have tried however to distillate the most relevant remarks that were frequently mentioned by different stakeholders. Stakeholders also raised some issue related to the important role of the healthcare system for data collection. Therefore, there is overlap between this narrative on healthcare and the chapter on information and information technology.

Keeping in mind that the primary responsibility for the implementation and improvement of healthcare systems in the EU remains with the Member States, stakeholders suggest a wide array of potential measures, actions, research and exchanges of best practices that can be stimulated or supported by the European Union and its programmes. Such efforts must support health system improvements throughout the EU.

Regarding national healthcare systems, stakeholders repeatedly suggest some principal changes and improvements that are necessary to better attack chronic diseases:

- Systematically introduce disease management approaches
- Introduce and promote effective self-care practices
- Strengthen primary care systems
- Systematically integrate prevention into care
- Support the development and implementation of innovations, i.e. in e-Technologies
- Improve information and data systems, including disease registries, to better communicate, organise, implement and evaluate the quality, effectiveness and patient-centeredness of national care systems
- Improve patient-involvement in all stages of care and strengthen informal care
- Increase the evidence base for interventions, treatments and early detection
- Exchange best practices, develop and exchange common standards and guidelines

5 Research

Key messages

- Research on chronic diseases should be expanded, improved and programmed in an integrated and coordinated way.
- There is an unbalance between the high EU investments in biomedical research and the rather low investments in public health research.
- The focus of chronic disease research in the EU must be on improving health, well-being and quality of life of patients, as well as on enhancing cost-effectiveness of prevention and treatments and so contribute to reducing the increase in national health expenditures in Member States.
- Monitoring the occurrence of diseases, risk factors and their trends in Member States is an essential and important prerequisite for the assessment and evaluation of the developing burden of chronic disease in European countries and regions.
- The EU can function as a catalyst for research undertaken at national level to improve chronic disease management, including the dissemination of research findings across Member States and the actual implementation of the research findings into daily practice of prevention and care.
- The mechanisms that lead to socio-economic inequalities in chronic diseases both within and between countries and the question of how to reduce them remain among the most important issues for further study.

5.1 Introduction

Bio medical and public health research contributing directly or indirectly to chronic disease prevention and treatment are some of the most important research areas. One important issue is how to ensure that the best research knowledge is actually used in practice. Another is to identify existing gaps in research. There is also a need to enhance research cooperation in order to ensure that the research supported by the EU level and by national governments complements each other.

Some research could benefit from better use of existing initiatives, such as the Innovative Medicine Initiative (IMI) and the European Strategy Forum on Research Infrastructures (ESFRI), which includes research infrastructures for clinical trials and bio medical research which could pave the way for a more harmonised European framework.

Consultation questions

- *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?*
- *In what areas is there a particular need for additional action at national level?*
- *What will you/your organisation contribute to address this challenge?*

5.2 General directions for research priorities

Stakeholders recommend targeting of future research towards optimising knowledge-based, predictive, patient-centred and personalised healthcare strategies that integrate with effective preventive approaches. Such research must be outcomes oriented. This will include improving integrated care models for chronic disease management and for optimal self-care and this includes opportunities for newly added IT-systems, for instance to support patient monitoring. Patient-centered, personalised healthcare is a major focus of future research.

Better educational tools for prevention and health promotion and for the optimisation of health literacy are desired outcomes of an integrated approach to the programming of chronic disease research in Europe. Research outcomes should improve national, regional and local health policy making and support effective new initiatives.

Unravelling the mechanisms and causes of chronic diseases remains essential to improve early diagnosis and support better prevention as well as to develop new therapies that improve the quality of life of patients. Stakeholders advise more research on ‘health in all policies’ and the social determinants of health. Population health approaches and not individual risk factor approaches would need to be studied also addressing health inequalities.

The mechanisms that lead to socio-economic inequalities in chronic diseases both within and between countries and the question of how to reduce them remain among the most important issues for further study. It would therefore be necessary to foster the development of national surveillance systems of chronic diseases that include migrant and mobility specific indicators.

Societal issues enhance the increasing chronic disease burden or threaten the sustainability of the care system and are in need of research. A growing trend towards activities that create self-harm that can also have chronic sequelae is important in this regard. The suggestion arises to further study the roots of such risk taking behaviour, including drug abuse, and its possible prevention. Violence has been mentioned in this regard as well, including its increasing occurrence in healthcare settings.

Several times stakeholders mention the need for large-scale, highly multidisciplinary, multinational research efforts in the area of chronic disease in the future, given the complexity of the issues involved.

5.3 More specific areas for research

Stakeholders advise to support research and studies on a number of specific areas related to chronic diseases and their prevention, care and cure. This would include research on:

Self-care

- the feasibility and effectiveness of self-care, including new forms of self-care and their possible imbedding in current regulatory and financing frameworks, including a search for effective ways of dissemination of proven best practices.

Cost-effectiveness/disease management/economic costs

- cost-effectiveness of programmes focusing on health promotion, disease prevention and disease management for chronic diseases
- economic costs of chronic diseases to national economies, health systems and households.

Social determinants of health

- social determinants of health, taking into account other emerging factors, e.g. environmental determinants of health.

Patient involvement and behaviour

- attitudes, preference, behaviour and outcomes of the use of homeopathy and anthroposophic medicine by chronic disease patients in addition to other forms of healthcare
- involvement of patients in health technology assessment studies in order to enhance the role of patient-centered priorities in evaluating the outcomes of new healthcare technologies and treatments

Health technology assessment

- how to develop innovative HTA type models that focus on quality of life end type measures, including evaluation of healthcare management programs by this approach

Nutrition

- unintended and possible negative effects of dietary recommendations
- possibilities to coordinate among the multitude of ongoing research efforts in the nutrition area

Genetics

- nutrigenomics, functional genomics, epigenetics, metabolomics and proteomics are indicated as important areas for research on chronic diseases
- learn more about the combination of genetics, lifestyle factors, including nutrition and health

Pain

- ways to support the formation of networks of specialists on a single specific chronic disease with pain specialists
- implementation and evaluation of the best treatment options for chronic disease patients and how to work towards clear clinical pathways for the treatment and management of chronic pain, also within an integrated healthcare environment
- pelvic pain as it is an important type of pain that is still insufficiently studied

Pre-term birth

- the prevention of premature birth as this is associated with much higher risks of life-long chronic disease and handicaps

Screening in the nutrition area

- *how to* develop *the most appropriate forms of screening and follow-up of elderly persons living independently, including for overweight, obesity and the occurrence and risk of under-nutrition*
- *what is the* impact *of disease related malnutrition across Europe, including in healthcare settings*

Informal care giving

- informal care giving, as these carers can be very important for chronic disease patients and contribute to their quality of life, while increasing, however, the psychological stress for these carers themselves. Very little research exists on informal care at the European level.

Primary care

- how to develop frameworks for evaluating primary care including comparative research of primary care systems within the European Union.
- how to support the necessary increase in research capacity on primary care in Member States where such a research capacity is still lacking, with sufficient attention for prevention and for the good relation with secondary care as this is essential for a healthcare system as a whole.

Data and information

- the impact and problems related to data protection legislation in the EU and its MS, with a focus on the benefits and harms for people with a chronic disease, require monitoring and evaluation

5.4 Disease specific areas of research

This includes suggestions for research on:

Ultra-rare diseases

- the development and delivery of life-changing therapies for ultra-rare disease patients

Screening-related genetic disease

- how will ageing affect patients that have been identified by screening for genetic diseases

Dementia

- further support for the Joint Programming of Research in Neurodegenerative Diseases (JPND)
- the quantification, cost-effectiveness and health gains from different support strategies (day care, home care, respite care) for people with dementia
- the genetics of dementia
- methods to better identify individuals at risk, improve early diagnosis and the timely provision of appropriate care for people with dementia
- how to develop guidelines for quality assurance in dementia screening and diagnosis as well as to define a European system for accreditation of specialist dementia units

Muculoskeletal disorders

- how to reduce the burden of musculoskeletal diseases as a major chronic disease that causes loss of quality of life as well as major economic costs in the working age group in Europe; including unused opportunities for prevention and opportunities for early diagnosis and intervention

Osteoporosis

- how to improve the treatment of osteoporosis by developing new and better drugs
- study the interaction of frailty of elderly, falling prevention and bone fragility

Improved diagnosis or treatment for selected and often rare diseases and conditions

- develop more and better treatment options for: pulmonary hypertension, plasma-related disorders, oral health problems
- improve early diagnoses of impaired glucose tolerance

Mental health

- the intrinsic and important relationships and interactions between physical health and mental health and invest in research on the prevention of mental ill health

Link between chronic and infectious disease

- the link between chronic diseases and infectious diseases (e.g. viral hepatitis and liver cancer), especially on co-morbidities that may lead to undesirable drug interactions.

Multi-morbidity, co-morbidity

- how to focus much more than in the past on aspects of co-morbidity and multi-morbidity as there is a high and increasing prevalence of co-morbidity and multiple co-morbidity among the average chronic disease patient
- how to design, evaluate and improve effective long term care programmes for elderly people with multiple chronic diseases
- organise a European network on multi-morbidity research to exchange available expertise and best research practices

5.5 Improve the prioritisation and coordination of EU research

Stakeholders mention the need to improve communication about existing funding opportunities and rules for research applications for EU funding, especially towards academia and NGOs. Both experts and stakeholders must be more closely involved in the development of the EU research strategy on chronic disease and on the identification of priority research needs. Given the scarceness of research funds it is suggested that research priorities must be set on the basis of unmet needs, including patient impact, public health burden and productivity losses to society. Current EU research financing cycles of 3-5 year often lead, according to some stakeholders, to breaking up of excellent research partnerships before innovative cycles, which generally take about 10 years, have been finished. According to a number of stakeholders there is a problem of fragmentation and duplication of research going on in the European research area that focuses on health.

Various recommendations point at the need to increase the coordinating capacity behind European research efforts by using either new or established structures and to expand research collaborations outside the European Union as well.

Several of the recommendations and suggestions below are valid at the levels of both the EU and the Member States. MS must try to spend a minimum of 3% of their GDP to research.

The European Commission must take on board relevant recommendations from the WHO report on *“Prioritized Research Agenda for Prevention and Control of Noncommunicable Diseases”.*

A summary of these recommendations points at the need to:

- Establish or support a **European centre of excellence** for the study of chronic disease management, the development of disease management support tools, services and data management systems.

- Organise a **European Institute on Ageing** to act as clearing house for relevant information. Collect and disseminate research findings and offer opportunities to exchange good practice and relevant information among patients and clinicians.

- Use the approach taken in the so-called **Joint Programming Initiatives.** This has proven a potentially very relevant organisation form and can be used by the Commission in future work on chronic diseases.

- Make better use of existing coordinating initiatives such as the **Innovative Medicine Initiative (IMI)** and **ESFRI, the European Strategy Forum on Research Infrastructures.**

- Support the **international collaboration** of European researchers with others outside the European Union, i.e. the United States, Japan, China, Russia, with some priority for clinical trials and so increase the EU’s competitiveness in global research as well.

- Invest in **creating efficiencies in European cancer research** by leveraging the expertise and intellectual potential of European institutes through increased collaboration.

In addition, stakeholders suggest a **European Council for Health Research** as an instrument to provide optimal strategic scientific leadership for EU programmes in health research. According to others a new health-related clinical research infrastructure can also be an important instrument for chronic disease strategy development in Europe. This kind of structure could take the form, as The Commission has suggested, of a **Knowledge and Innovation Community (KIC)** under the Horizon 2020 strategy with the aim to improve quality of life and well-being of citizens of all ages.

Next, stakeholders repeatedly mention an urgent need to ensure that national research programmes and European research programmes compliment each other better than is currently the case.

The EU may support R&D in the area of chronic disease by implementing ‘smart regulations’ in areas such as the Clinical Trial Directive and the Data Protection Regulation as these may give the opportunity to lower the administrative burden for R&D and support the maintenance of the current level of R&D in Europe.

5.6 Food and nutrition research in need of coordination

Stakeholders from the area of food and nutrition consider this one of the most essential elements in chronic disease causation and point at a major need to be able to get a thorough overview of the multitude of research projects that is ongoing in the food and nutrition area under different programmes and actions at EU level.

Such knowledge gathering and transfer has to include reporting on progress towards shared objectives and recommendations for future research programming. A **Coordinating Research Agency for Food** must coordinate the research and overlook any funding by European DGs in the areas of Research, Agriculture and Health. As new agencies are not politically feasible the alternative would be to build the necessary coordination on existing structures such as the European Forum on Food and Health Research, the national Food Safety Authorities, and collaboration between the Commission and national research agencies.

5.7 Improve the dissemination of research findings

A widely shared vision among stakeholders is that research outcomes must get as quickly as possible to the patients who need them, which is currently very problematic. Sufficient information is a key for successful treatment. Availability of the latest scientific knowledge and best practices for a care provider is just one example. Well-educated patients can better comply with their treatments and can more adequately pay sufficient attention to their individual preventive activities. There is still a gap between research innovations and their implementation in daily practice by a lack of adequate knowledge translation and transfer into clinical research. Suggestions to improve this are:

- Facilitate the sharing of European research outcomes in the area of chronic diseases, for instance by dedicated mailings to relevant NGO’s and other organisations.

- Use the existing **European Patients Forum** as an organisation by which relevant research findings can be translated into the policy environment and ensure dissemination to relevant patient organisations.

5.8 Better data collection in health care to support research

Within and between EU Member States there is often still a lack of good comparable data, even for the most common chronic diseases. Increasing the availability of comparable national health databases and registries is central to improving research opportunities, policy evaluation and future priority setting. It is still essential to promote the use of international data standards, such as ICD, ICPC and others across Europe. For international clinical trials or international comparisons among clinical registries it is of the highest importance that health record systems are interoperable within Europe. This is for reasons of efficiency and quality and for reaching scientific rigor.

A stronger collaboration with WHO in this area is proposed to support research that will give policy makers a clearer view of their national situations and provide them with instruments to target their approaches and evaluate implemented strategies.

Increased monitoring of chronic disease occurrence is important, but should also be taken up by linking this information to geographical monitoring of pollutants and human bio-monitoring. It is also mentioned that there is no fully operational way to register all types of cancer in all Member States yet.

5.9 Stakeholder contributions

Advocacy and communication with relevant partners, identifying national and European research needs, participating and collaborating in relevant research activities, exploring possibilities to organise centres of excellence, organising conferences, interconnecting of researchers from different disciplines are among the stakeholder contributions mentioned.

Several stakeholders, both industry as well as non-profit type organisations mention that they are part of a network with other leading institutes, universities and biotech companies, sometimes even worldwide (public-private partnerships). In this way major collaborations are established for clinical cohorts, knowledge transfer and development of new technologies. Stakeholders express the opinion that research in this field would benefit from the EU's support.

5.10 Discussion and conclusion

In their answers to the above consultation questions many stakeholders have reacted by proposing priorities for research, both in a general and a more specific way. Most stakeholders agree on the need to expand, improve and programme research on chronic diseases in a highly integrated and coordinated way. They point at the large and increasing burden of these chronic diseases and not only to the future premature loss of life years and immense loss of quality of life, but also to its huge economic costs and social implications.

While a major part of the chronic disease burden is amenable to public health action, i.e. to prevention and health promotion, a clear unbalance is noted several times between the high EU investments in biomedical research against the rather low investments in public health research. Furthermore, there appears to be an imbalance between what is called 'non-profit' versus 'commercial' research in the area of public health research as well.

Both biomedical and public health research approaches, however, can contribute directly or indirectly to chronic disease prevention and treatment and to alleviating its burden. A major question for both approaches is still how to optimise and quicken the actual implementation of the research findings into daily practice of prevention and care. How to effectively decrease or abolish the practice of smoking are still major questions for European chronic disease prevention.

Stakeholders emphasize that the focus of chronic disease research in the EU must be on improving health, well-being and quality of life of patients, as well as on enhancing cost-effectiveness of prevention and treatments and so contribute to reducing the increase in national health expenditures in Member States. Searching for effective awareness campaigns focusing on elderly care can contribute to better management of chronic diseases.

Monitoring the occurrence of diseases, risk factors and their trends in Member States is an essential and important prerequisite for the assessment and evaluation of the developing burden of chronic disease in European countries and regions. Member States can assess the performance and effectiveness of their health systems with such data. This can include assessments of the effects of preventive action and the performance and expenditure of healthcare systems. Social determinants, inequalities and environmental influences on health must be studied, as well as genetic and behavioural determinants of health. Monitoring the effects of health in all policies has to be included.

The EU can function as a catalyst for research undertaken at national level to improve chronic disease management, including the dissemination of research findings across Member States.

The suggestions and recommendations given to the questions on research point at the need for a European wide strategic action to create a stronger and more systematic research cycle in the European Union. This would include a programmatic process starting at defining priorities, followed by designing strategies to involve the best available expertise, via implementation of the actual research, while constantly evaluating the outcomes and refining the priorities, towards the dissemination of results and implementing the findings in daily practice or industrial production. Stakeholders advise to make better use of existing structures such as the Innovative Medicine Initiative (IMI) and the European Strategy Forum on Research Infrastructures (ESFRI). But several stakeholders also recommend establishing a European centre of excellence for the study of chronic disease management, the development of disease management support tools, services and data management systems.

Several public-private partnerships and the European Innovation Partnership on Active and Healthy Ageing have been mentioned as good examples regarding research development. At some points the answers overlap with those given for other areas, i.e. healthcare or health promotion.

6 Information, and information technology

Key messages

- Both at national and at EU level, comparable information, on incidence, prevalence, risk factors and outcomes of chronic diseases is currently lacking.
- Making use of existing structures and activities for data collection is important.
- Information Technology (IT) is especially useful for the delivery of individual patient care (eHealth, tele-monitoring, patient information).
- Information Technology can also play an important role in data provision, e.g. through using IT in the development of patient registries.
- Europe needs mechanisms for safeguarding, providing and strengthening data linkage in the face of privacy and data protection concerns.
- To obtain comparable information common health data collection methods across Europe and permanent co-ordination is needed.
- To make sure that data and information can actually be used by policy makers and by experts, not only a good data infrastructure is important, but high quality dissemination and reporting activities as well.

6.1 Introduction

Information systems on chronic diseases are important to support individual patient care, to plan and manage health services and to develop and modernise policies for prevention. The European Health Interview Survey, the European Health Examination Survey, the development of morbidity statistics by Eurostat and other bodies and EU actions in areas such as cross-border mobility, e-health and active ageing are relevant in this context. There may be scope for additional action on comparable information at national and European levels on burden of chronic diseases. to enable benchmarking and evidence-based policy.

Consultation questions

- *What more needs to be done on the development of information and data on chronic disease?*
- *In what areas is there a particular need for additional action at EU level?*
- *In what areas is there a particular need for additional action at national level?*
- *What will you/your organisation contribute to address this challenge?*

6.2 Many useful applications of information and IT

Respondents identify numerous useful applications of information and Information Technology (IT) in the field of chronic diseases. For many of these, they state that they could and should be stimulated. Most importantly, the usefulness of IT for the delivery of individual patient care (eHealth, tele-monitoring, patient information) is stressed. Related to this, facilitation of communication and education aimed at implementing preventive action is a valuable asset. Furthermore, the role of IT in data provision is important and emphasized, e.g. through using IT in the development of patient registries.

Information and IT are also useful for planning/management and for the organisation of health care services, e.g. through the application of Electronic patient records (EHRs) in general practices. Information and IT can also be of benefit for carers, supporting them through e.g. networking possibilities via internet providing practical advice and psychological support.

At a more general level, respondents state that information and IT can contribute to the understanding of efficiency, effectiveness and direct and indirect costs of interventions and policies, benchmarking, reducing inequalities across Europe, the improvement of patient safety and the facilitation of medical auditing, and the enhancement of (effectiveness of) research, including research on new medication.

6.3 Additional data and information needs

General needs related to data and information

Respondents mention several general needs related to chronic diseases information, starting with the need for a commonly agreed definition of the term ‘chronic diseases’. Moreover, the development of a commonly agreed set of key indicators is important. Many respondents state that comparable information, both at national and at EU level, on incidence, prevalence, risk factors and outcomes of chronic diseases is currently lacking. To obtain comparable information, we need uniform methods, definitions and tools for data collection. One respondent (representing the health professionals) explicitly states that these should be agreed upon with the support of the medical profession.

In relation to possible data sources for chronic diseases information, stakeholders propose the exploration of innovative and more efficient approaches to the development of information and data, in particular related to how data held within Electronic Health Records (EHR) can be reused to enhance clinical research processes in Europe.

Europe needs mechanisms for safeguarding, providing and strengthening data linkage in the face of privacy and data protection concerns. Respondents also see a need for providing good and practical information to the public in an accessible and user-friendly way. This will help to improve citizens’ health literacy.

Finally, one stakeholder (representing the health professionals) pointed at the need to inform people about the fact that over-emphasis on prevention can lead to medicalisation of non-medical conditions and this will lead to an upward effect on utilization of health care and costs.

Specific topics related to data and information

Respondents mention several specific diseases, conditions and topic areas, for which (better) data must be developed (listed below). For these areas, we need various types of information, such as epidemiological information, economical information, information on disease impact, and good practice examples. Respondents also mention various means to develop such data. These range from (online) registries, conditions-related reference centres, observatories and dedicated institutes to research activities such as repeated Joint Actions and Eurobarometer studies.

Furthermore, expanding the mandate of the European Centre for Disease Prevention and Control (ECDC) to include the monitoring and surveillance of major NCDs is a proposed part of the solution, as well as the stimulation of tools enabling the collection of data from health records and claims systems.

Diseases/conditions for which more data is needed:

- Brain diseases
- Dementia
- Diabetes
- Epilepsy
- Malnutrition
- Musculoskeletal diseases
- Oral health
- Pelvic pain and dysmenorrhoea
- Rare and ultra-rare diseases, including Primary Immuno-Deficiencies (PID)
- Vitamin D deficiency

Other areas for which more data is needed:

- Access to good quality care
- Effectiveness of prevention strategies and treatments
- Good practice examples of integrated care
- Health care abroad
- Health services utilization
- Healthy ageing
- Patient experiences with health care services, patient perspective
- Patient involvement and empowerment
- Public attitudes to research and outcomes that are improved as a result of this work
- (Benchmarking of) Quality in pain management
- Safety and quality of care
- Work force

6.4 Member States' and EU action opportunities

Availability and comparability of data; what data do we need?

Many comments and suggestions relate to actions needed to improve the availability and quality of chronic diseases information. This relates to data on incidence, prevalence, risk factors and outcomes (including economic impact) of chronic diseases. Moreover, we need more action to improve the stratification of data by Socio-Economic Status and ethnic minorities (such as Roma), as well. In addition, we need to have better information on social determinants of health in general.

Other topics for which respondents state that additional action is needed are:

- linking of epidemiological data with geographic monitoring data of pollutants (especially for children) and improved Human Bio monitoring,
- information on effectiveness of interventions and of education policies,
- information on public knowledge, attitudes and beliefs, and
- information on the situation of people with special needs and on disadvantaged groups.

Advice to make use of existing structures and activities for data collection

Respondents state that action at both the EU and the Member State level is required. Such action needs to take into account the differences between health systems in Member States as well as existing EU activities such as the European Health Interview Survey, the European Health Examination Survey, the development of morbidity statistics by Eurostat and other bodies, as well as registries and other sources.

EU actions in areas such as cross-border mobility, e-health and active ageing are also relevant in this context. Current EU activities such as EHIS, EHES, ECHIM and the Eurostat work on morbidity statistics are promising developments. Their sustainability (in terms of coordination, quality assurance and standardization activities) is not guaranteed, however, and that goes especially for the work on morbidity statistics, where a lot of methodological development is still needed. This requires the involvement and close collaboration of experts in public health as well as in health statistics.

The European Health Surveys Information Database (the HIS/HES Database) is an important element of the European Health Survey System. Stakeholders recommend that in order to keep the information on surveys as sources of data for monitoring the prevalence and determinants of chronic diseases up-to-date, the EU must ensure the future of this database.

Common methods and more co-ordination needed

Different types of stakeholders (representing health professionals, industry, international organisations and NGO and umbrella organisations) express the urgent need to develop and promote the adoption of common health data collection standards – including common definitions, classifications (and their relations), quantification of response rates - across Europe. The EU needs to take the lead in the development of such common standards. Related to this, respondents also identified the need for centralisation of data at EU level, ensuring coordination of data collection, access to existing data as well as the coordinated development of new indicators.

Such central coordinating activities should be the task of a permanent capacity, which could take various forms, for instance as a decentralised - yet permanent – network of experts, or by strengthening of health monitoring capacities for chronic diseases within the Commission, or it can be implemented by existing EU agencies or by a new EU body. Another option is implementation as a combined effort by the EU and organizations like WHO-EURO.

More specifically, one of the respondents suggests a potential role for such a central institution in the field of quality management. Another respondent identifies the need for the creation of new capacity for better defining the social determinants of health.

Improving the interoperability of data and legislative issues

Several respondents point at the need for improvement of the interoperability and transferability of data at the European level. Respondents see interoperability of health data on chronic diseases as an important factor to be able 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 in general.

Obstacles in the collection of data and indicators, including accessibility of data and legislative (data protection) problems, must be dealt with. The introduction, at EU level, of a unique patient identification number will overcome many of the current obstacles to data transfer.

Recommendations for indicators

Member States are asked to deliver health indicators in a comparable way and the ECHI indicator set is the guiding structure for this activity (Regulation on “Community statistics on public health and health and safety at work” Regulation (EC) No 1338/2008).

Respondents state in this respect that the Commission must take care that the basic ECHI indicator selection, which includes a lot of information on chronic diseases (morbidity, health interventions), is to be followed up by the Member States. One respondent suggests moving from population level rates to include summary measures of population health such as HALE, Health gaps and Disease burden, as recommended by WHO as well.

Information on policies and regulations

There is a need for information on the current state of relevant policies, regulations and laws. Respondents suggest that the EU will develop a monitoring criteria process to assess the effective implementation of national plans and guidelines on chronic diseases and risk factors. The EU needs to take the lead in exchange of best practices.

International cooperation in the field of health information

Respondents point at the need for increased cooperation between the EU and other international organisations, such as the WHO and the OECD. There is a pre-eminent need for the development of integrated monitoring systems. It is proposed to work towards reconciling international monitoring systems and to further standardize data collection among agencies. More specifically, stakeholders suggest the EU to cooperate with WHO in view of the Action Plan for a strategy on NCDs as well as with the OECD. One respondent stresses the need to broaden the scope beyond Europe and strengthen worldwide health statistics.

Need for research on chronic diseases

Europe must co-ordinate and consolidate EU-funded research on patients suffering from different diseases, in different care settings and in different Member States as well as research outputs in the area of chronic disease monitoring and management. The EU can play an important role by funding networks, that link practice including patients/citizens with policy and research. National and EU authorities must invest in long-term evaluation programmes.

More specifically, respondents have pointed at the need, both at the national and the EU-level, to promote research in primary care, and to promote evaluation (i.e. cost effectiveness) research and measuring the impact of initiatives aimed at improving outcomes in patients with multi-morbidity.

Specific potential for action at the EU level

Next to the coordinating role related to the harmonization and collection of data mentioned above, the respondents proposed several other topics, where the EU can contribute specifically. A good example is the need to develop a strategy for information to patients and citizens at EU level.

In addition, the EU could pay more attention to basic health systems, emphasising the need for horizontal systems with focus on multi-morbidity and societal issues instead of having a disease orientation with separate campaigns for cancer, diabetes, obesity, mental health, etc.

Other issues are the role of the EU with regard to the inclusion of relevant data and information in the HEIDI wiki of DG SANCO. Next, the inclusion of relevant questions and tests in the EHIS and EHES surveys as well as the need for the development of a European database on health-care organisation for chronic conditions, and finally the need for strengthening cooperation with medical and scientific societies. Furthermore, stakeholders suggest developing targets that facilitate monitoring and reporting of actions taken in Member States.

Specific potential for action at the national level

In many of the necessary actions, described above, respondents see a role for both the EU and the Member States. There is specific potential for national level action in two areas. First, the stimulation of a universal, highly accessible Primary Health Care system as the starting point for information, documentation and exchange with input from patients. Second the need for national actors to embrace the benefits of strong, consistent, quality data sets in bringing about improvement in health and health care.

Not only data are important, but dissemination and reporting as well

To make sure that data and information can actually be taken into account by policy makers and by experts, for instance to develop guidelines and identify good practice for chronic disease prevention and management, we need high quality dissemination and reporting activities. Several respondents have made recommendations to give this priority. In this respect, one respondent regards the fact that the Commission has developed the HEIDI wiki as a major source of information, while it is depending on volunteer contributions without a proper quality insurance system in place, as problematic.

6.5 Stakeholder contributions

Many respondents state that they intend to make expertise available, for instance for setting up registries, developing common standards and guidelines, position papers, and best practice examples, support the development of strategies and action plans, and assist in developing indicators.

In addition, the stakeholders suggest possible contributions to research and other projects, both financially and by collaboration in practice. Moreover, many respondents will contribute through networking and dissemination activities, such as moderating consensus procedures between multiple stakeholders, and organizing multi-stakeholder workshops, meetings, conferences, and events (e.g. for encouraging best practice sharing).

Respondents also mention the dissemination of information on future actions resulting from this consultation process and of other relevant information through websites, social media, international journals and interactive tools several times.

Possible contributions to data collection and evidence gathering

Respondents state that they could contribute to specific data collections, for example on patients' direct experiences and certain diseases. Next, they suggest possible contributions to gathering and summarizing broader evidence bases, as well as contributions to exercises aimed at identifying data gaps.

Finally, two other types of contribution are important, namely first raising awareness of the need for better data at European level, particularly in countries with the greatest inequalities in critical care outcomes. Second support for relevant EU and WHO initiatives in the field of oral health data.

6.6 Discussion and conclusion

Respondents mention many different aspects in response to the questions on the development of information and data on chronic diseases. We mentioned the remarks that are frequently put forward by numerous stakeholders and several striking remarks from single stakeholders that we think are specifically relevant for the question on data and information on chronic diseases.

Respondents identify numerous useful applications of information and Information Technology (IT) for the delivery of individual patient care (eHealth, tele-monitoring, patient information), data provision, planning/management and for the organisation of health care services. Many respondents state that comparable data, both at national and at EU level, on the burden of chronic diseases is currently lacking. Therefore, many comments and suggestions relate to actions needed to improve the availability and quality of chronic diseases information.

Respondents mention several specific diseases, conditions and topic areas, for which (better) data must be developed. Respondents also mention that different types of information are needed and different means to develop such data. However, several stakeholders stress the value of using existing structures and activities for data collection. In particular, the exploration of innovative and more efficient approaches to reuse data in Electronic Health Records deserves attention.

Stakeholders urge the EU Member States to further develop and improve their public health data collections to better support health policy making in the area of chronic diseases. The EU must, in close collaboration with WHO and OECD, support this much needed actions by facilitating central coordination of data harmonisation and collection and indicator development throughout Europe. Similarly, collection and analysis of harmonised data and information about healthcare systems must be strongly supported as well. Expanding the mandate of ECDC to cover monitoring and surveillance of chronic diseases and their prevention and care is an option recommended by several stakeholders as well. To make sure that data and information can actually be used by policy makers and by experts, not only a good data infrastructure is important, but also high quality dissemination and reporting activities to ensure a correct interpretation of the data.

7 Roles of Member States, the EU and stakeholders

Key messages

- Broad intersectoral collaboration is needed to ensure a comprehensive, joint approach towards tackling chronic diseases. Efforts coming from sectors such as healthcare, housing, industry, education, technology and social services need integration.
- Collaboration is needed between different actors (stakeholders, between MS, between the EU and international organizations and Public Private Partnerships) and between different sectors (e.g. healthcare, housing, employment, industry, education, technology).
- As many common factors play a role in most MS that relate to chronic diseases and their determinants and treatment, chronic diseases is a very suitable topic for international cooperation, and MS should work together on the key challenges. The EU should collaborate with the WHO and OECD in the field of health information.
- The EU must engage in wider consultation procedures. It is important to include patient representatives in multi-stakeholder consultations.
- Participation and involvement of stakeholders from the very beginning to the implementation phase of EU actions on chronic diseases should be strengthened.
- Involving patients and experts from Central and Eastern European countries is a specific point of attention.

7.1 Introduction

EU Member States are responsible for the definition of their own health policy and for the organisation and delivery of health services and medical care. The EU can support Member States through exchange of information and good practice, the development of information systems and guidelines. EU can provide funding for projects, joint actions and stakeholders working in the area of chronic diseases. Stakeholders include patients and health professionals but also employers and businesses involved in activities which are directly or indirectly related to chronic disease.

Consultation questions

- *What additional activities on chronic disease beyond the four areas described above should be considered at EU level?*
- *How can the EU engage stakeholders more effectively in addressing chronic diseases?*
- *How can EU Member States engage stakeholders more effectively in addressing chronic diseases?*

7.2 Need for broad collaboration in the field of chronic diseases

Many respondents emphasize the need for collaboration in the field of chronic diseases: between stakeholders, between MS, and between the EU and international organizations.

One stakeholder remarks that the reflection process' consultation document of the European Commission does not make sufficient reference to either the basis for action nor to the political will that has been declared at the highest levels committed to act in this area. This respondent then points at: the Treaty on the Functioning of the European Union, the UN political declaration on non-communicable diseases, the EU Council's conclusions, the European Parliament's resolution, Members States action plans, nor the WHO declarations and action plans on this topic. Any reflection on chronic diseases must recall these elements. Moreover, the sense of urgency expressed by both heads of government and Commissioner Dalli must be central to this reflection process and referred to accordingly.

The Member States, the European Union and stakeholders must work together to ensure a comprehensive, joint approach towards tackling chronic diseases. As many common factors play a role in most MS that relate to chronic diseases and their determinants and treatment, chronic diseases is a very suitable topic for international cooperation, and MS should work together on the key challenges.

It is also important for the EU to collaborate with the WHO, especially to work towards a single European health information system, as agreed by the EU and WHO-Euro, and to seek synergies with existing or new international policies, such as Health 2020. The EU should also collaborate with the OECD in the field of health information. The United Nations High Level Meeting in 2011 has produced a Political Declaration that provides both an immediate and a long-term agenda for such collaboration between the EU and WHO.

Respondents offer their support

Many respondents offered their support to the EU and MS in their initiatives to address chronic diseases. Specific types of support offered included advocacy, expertise, help with formulation of actions and guidelines, be the link with pharmaceutical industry, contribute to research, support others with evidence based information and self-management, and provide a platform function.

7.3 Possible additional activities

Necessary elements of EU and national policy frameworks

Many respondents mention the need for an intersectoral approach to chronic diseases. Efforts coming from sectors such as healthcare, housing, industry, education, technology and social services need integration. Other EU policies, such as cohesion, agriculture and rural development, research and innovation, are highly relevant as well. The impact on health of decisions taken in other fields needs systematic consideration (see also paragraphs 3.5 and 4.8) . A European chronic diseases strategy must follow a similar legal and policy structure as the EU action on Rare Diseases (e.g. Commission Communication, Task Force on Chronic Diseases, European Network, prioritised research and monitoring and surveillance of chronic diseases).

Health inequalities, health literacy/information, and accommodating patients with chronic diseases in the workplace must become integral elements of an EU Strategy on chronic diseases. The EU can have a significant impact on rights based issues as well, and address discrimination and equity uncertainties. Therefore, prevention and promotion programmes must become gender-sensitive.

In addition, one respondent states that an EU strategy on chronic diseases should reflect the central role that nurses and health visitors play in preventing and managing chronic diseases, and make links to the work force implications of the epidemiological development of chronic diseases.

Respondents see a role for the EU in supporting and coordinating MS activities in the development of national policies for tackling chronic diseases, e.g. the alignment of existing guidelines for action, and the development of criteria to assess the implementation of national plans and guidelines. Some stakeholders suggest that the EU should evaluate national chronic disease initiatives, e.g. how MS implement various recommendations produced by different EU initiatives.

Prevention and treatment and the exchange of best practices

Several comments regard existing interventions in the field of chronic diseases and the need to exchange best practices. Related to preventive interventions, one suggestion was to dedicate funding to the evaluation of interventions and create a database of interventions including effectiveness and efficiency information.

Developing early prevention programmes that aim at employees, communities, and children in particular are priority issues according to some respondents. The implementation of Community based initiatives must be stimulated, as well, as these are effective. Related to treatments for chronic diseases, the promotion of the use of personalized disease management models, such as the cyclic Personalized Diabetes Management Model, is recommendable, as well as the promotion and development of E-Health solutions. Similarly, the development, use and exchange of decision tools and algorithms to support physicians when taking clinical decisions must be stimulated.

Partnerships between public and private sectors, as well as governmental and civil society groups, need fostering to overcome barriers to chronic diseases treatment and care faced by vulnerable groups such as migrants. In those cases where treatment is available, policy makers should ensure a timely access, especially in the field of chronic diseases. Respondents see an explicit role for the EU in supporting Member States through exchange of information and good practices.

7.4 Suggestions and recommendations for EU contribution

Respondents have made several suggestions and recommendations for activities the EU could engage in while working on tackling chronic diseases.

The EU can support and fund the important advocacy efforts undertaken by stakeholders to raise awareness of chronic diseases. One mean approach to raise awareness is by educational campaigns addressing the general public. Government agencies, the EU, media, civil society, patient groups and professional societies must work together here.

One respondent recommends that the European Commission will include in its definition of chronic conditions also those conditions caused by a genetic defect.

Another suggestion is for the EU to support adequate training and support for all nurses to better deal with chronic diseases, and dedicate resources to combating chronic diseases by stimulating innovation.

In relation to the current EU focus on Healthy Ageing, the suggestion arose that this should run parallel to initiatives focusing on the management of chronic diseases. One idea by stakeholders is to explore opportunities in the priority areas set by the European Innovation Partnership on Active and Healthy Ageing, such as establishing an action group addressing age-related malnutrition. Other issues mentioned are the need to ensure effective implementation of actions against smoking (FCTC Article 5.3 and its guidelines), and to avoid commercialization of the chronic diseases issue. Finally, respondents see an explicit role for the EU in supporting Member States through the development of information systems and guidelines.

Specific topics in need of attention

Respondents point at several specific diseases, conditions and topic areas, that need (more) funding, support, research and/or attention:

- Allergies and asthma (the role of the micro-biome and of specific germs)
- Employment
- Environmental factors
- Epilepsy
- Indoor air quality
- Inequalities
- Nutrition (prevention focused on nutrition and the priorities defined in the 2011 Polish Presidency declaration)
- Oral disease
- Patient perspective and preferences
- Place of work
- Prevention (primary but also secondary and tertiary)
- Primary health care services and their role in improving overall physical and mental health and well-being through tackling social determinants of health
- Rare and ultra-rare chronic diseases
- Social organisation and its impact on health
- Socio-economic factors

Central coordination of health information and research

Respondents (representing health professionals, NGOs/umbrella organisations, researchers) mention repeatedly the need for a new body whose main responsibility will be the monitoring and reporting on the situation in chronic diseases. The EU can play a more active role in the collection of comparable data on chronic conditions and disease to allow better planning, priority setting and evaluation across the EU. Comparable data at European level on incidence, prevalence, risk factors and monitoring and evaluation outcomes, are needed urgently (see also chapter 6 Information and Information Technology).

As a possible organizational form for such a body, stakeholders (health professionals, NGOs/umbrella organisations) suggest to consider extending the mandate of the European Centre for Disease Control (ECDC) to cover the chronic non-communicable epidemic. Tasks of that body could include cross-referencing and coordination between research-funding agencies as well as data harmonising efforts. The EU can take a coordinating role here via the formation of a European governance mechanism to coordinate across the wide stakeholder base.

With regard to the need for coordination of research activities, stakeholders point at a need to implement an overarching coordination between the different European initiatives, in particular for the coordination of the research programmes financed through the Joint Programming Initiative (JPI) and Horizon 2020. An integral European research programme is necessary.

One respondent recommends the creation of an “EC inter service group” on food and health issues, gathering programme owners from DG Research and Innovation, DG Agriculture, DG SANCO, and possibly other DGs, and establishing close relationships with the Management Board of the Joint Programming Initiative on healthy diet. Another respondent recommends the creation of a European Research Network on chronic diseases. Also in the field of health information, specific suggestions and proposals point at the need to enhance coordination. The role of the Commission in this area is seen by stakeholders as to set policy priorities at EU level, lead the way in data and indicator harmonization efforts, and safeguard the sustainability of key EU level data collections, such as EHIS and EHES, and other key indicator sets that these data feed into, such as ECHI. While doing this, the Commission must make sure that outcomes of earlier EU-funded projects, networks and activities are taken into account, to prevent double work and reinventing the wheel.

Finally in the information area, the Commission must make sure, together with the MS, that the new European data-protection legislation will allow for necessary data collection and safe and efficient use of routinely collected, personal health data for public health monitoring.

7.5 How can the EU engage stakeholders more effectively?

Suggested formats for stakeholder involvement and consultation

Respondents suggest that the EU engages in consultation procedures with relevant stakeholders, and helps set up and support stakeholder groups, e.g. by providing funding. Several respondents underline the importance of including patient representatives in multi-stakeholder consultations. Involving patients and experts from Central and Eastern European countries is a specific point of attention. One respondent suggests that the EU must oblige the MS to contact patient organizations and carers. Another suggests that it should also be possible to include individual patients in consultation processes, even children or impaired people.

Respondents suggest a need for greater urgency, transparency and active involvement of the key stakeholders. Innovative and cross-sectional partnerships are important in their view. Public Private Partnerships and multi-stakeholder collaboration are important as well, complemented with a governance structure including a strong and prominent role played by the Commission and authorities.

The European Innovation Partnership model seems to be an effective way to tackle health challenges in cooperation and to identify specific and targeted actions that may have a measurable effect. It can be useful to replicate such wide partnerships in the future and steer them towards achieving public health benefits. Since several commercial interests were involved, steering the partnership towards patient-effective outcomes needs to become a priority.

Other suggestions for stakeholder engagement

Respondents made several other suggestions for how the EU can engage stakeholders more effectively. These include providing funding for (research) projects and Joint Actions, and providing support for preventive programmes and education. Other suggestions were to stimulate collaboration and European networks as vital parts of Europe's plan against the increase of chronic diseases, and to work together with the EUnetHTA network. Several respondents mentioned the development of international best practice sharing mechanisms as a good way to involve stakeholders. The existing system of independent Scientific Committees, managed by DG SANCO that provides scientific rationale for evidence-based policymaking is a good practice example. This approach could also cover non-food issues.

Another suggestion was to nominate an EU representative responsible for EU health, employment, and social affairs policies, who could serve as an ambassador for integrated decision-making. Finally, respondents suggested that the EU should focus on specific topics (e.g. chronic pain), and develop an EU strategy on chronic disease management by using one chronic disease as a case study.

7.6 How can MS engage stakeholders more effectively?

Broad stakeholder consultation and provision of information are important issues

Respondents call on the MS to promote and enhance dialogue and cooperation between all stakeholders, e.g. their respective national organisations and foundations that represent health professionals, public health professionals, primary care organisations, specialist organisations, patient representatives for the major chronic diseases e.g. national heart and lung institutes, foundations etc. One concrete suggestion was to organize a multi-stakeholder national conference.

Participation and involvement of stakeholders from the very beginning to the implementation phase of EU actions on chronic diseases should be strengthened. Also at the national level patient involvement should be stimulated, e.g. through funding. It is important to establish concrete commitment from stakeholders.

National governments need to work together and identify models, tools and solutions, which can be shared across borders and between stakeholders. A concrete example mentioned was to build small and efficient chronic disease management committees representing different chronic diseases, composed of representatives from the stakeholder community, following the EUCERD (European Union Committee of Experts on Rare Diseases) model.

Other suggestions for MS are to work on full information for and education of stakeholders about the dimensions of the problem and its importance, and to nominate a national ministry representative for health and work, who can help bridge the gap between the two areas and increase cross-governmental discussions.

Finally, respondents mentioned that MS should further the evidence base. The role of the MS here is to ensure high quality, sustainable health information systems at national and/or regional level, and work together with the European Commission and other MS on harmonization of data and indicators.

7.7 How can EU and MS engage stakeholders more effectively?

Both EU and MS should make effective use of expertise and experience stakeholders

Many respondents make suggestions for how to improve stakeholder involvement and apply this at both EU and MS level. Respondents state that the EU and MS should put the experience and expertise of stakeholder groups in use, e.g. through setting up a multi-stakeholder Task Force on Chronic Diseases, or through partnerships between scientific societies and healthcare professionals, patients and industry, aimed at developing shared agendas and acting as a single point of contact for their area. When consulting stakeholders, the invitation lists needs updating to include newcomers and other stakeholders who have developed their activities over time.

Respondents suggest exclusion of the tobacco industry from any engagement in addressing chronic and other diseases, and public health in general, thus respecting the Article 5.3 from the WHO FCTC (Framework Convention on Tobacco Control) that the MS and EU have ratified.

The EU and the MS should focus on supporting stakeholders' initiatives that truly deliver the expected health benefits to consumers, based on European scientific opinions. Other suggestions include having a wide consultation on the use of new technologies, organizing a communication platform, and ensuring that patient organisations are involved from the onset in the setting of objectives and targets, in concrete actions and initiatives, and in monitoring and evaluation. Finally, respondents recommend to focus on specific topics in parallel and simultaneous programmes rather than to put all chronic diseases in one program, and to include both the societal and healthcare perspective in HTA studies in the field of chronic disease.

7.8 Discussion and conclusion

The question on additional activities on chronic disease invoked a wide range of answers. Several aspects mentioned frequently by stakeholders, such as the need for an intersectoral approach, health inequalities, health literacy, evaluation of effectiveness of interventions, the exchange of best practices, and the need for central coordination of health information activities and research overlap with aspects mentioned in response to the questions on health promotion, health care, research and information. Therefore, there is overlap between this narrative on the role of MS, the EU and stakeholders and other chapters. Not all stakeholder organisations have responded to the questions that related to the role of MS, the EU and stakeholders. Several of those who did, moreover, did not address all sub-questions or did not address the sub-questions specifically.

Many respondents emphasize the need for collaboration in the field of chronic diseases: between stakeholders, between MS, and between the EU and international organizations, e.g. the WHO and OECD. Respondents suggest a need for greater urgency, transparency and active involvement of the key stakeholders. The EU must engage in wider consultation procedures with relevant stakeholders and help set up and support stakeholder groups, e.g. by providing funding.

Innovative and cross-sectional partnerships are important in their view. Public Private Partnerships and multi- stakeholder collaborations are important as well, complemented with a governance structure including a strong and prominent role played by the Commission and authorities. Several respondents underline the importance of including patient representatives in multi-stakeholder consultations. Involving patients and experts from Central and Eastern European countries is a specific point of attention. Patient organisations should be involved from the onset in the setting of objectives and targets, in concrete actions and initiatives, and in monitoring and evaluation.

8 Other areas

Key messages

- Informal carers must be recognised and supported across all levels of EU action and initiatives.
- At both a national government level as well as EU level, chronic pain needs far higher prioritisation by both healthcare policy makers and relevant government departments.
- The professional autonomy of doctors, good working conditions, including reduction in the red-tape obligations set on doctors, and proper remuneration are essential elements that positively affect the quality of healthcare services.
- The consultation document mentions the role of health care professionals and the health care system in supporting patients but does not highlight the critical role of the patient.
- European and National policy and decision makers should help ensuring readily available, accessible and affordable information, counselling services and quality care for all European citizens through an integrative approach.
- Geriatric medicine is relevant for all areas of the chronic conditions reflection process. Therefore, geriatricians can take a leading role in the development of new clinical and practice guidelines.

8.1 Introduction

The consultation paper identified a few of the areas that are important when considering chronic disease. Many other issues are also relevant.

Consultation questions

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

8.2 Informal carers in need of recognition and support

Several respondents emphasize the importance of informal carers, as they are the largest contributors to the sustainability of health and social security and they are a population prone to chronic diseases themselves. Informal carers, such as carers for people with dementia, need to be an integral part of a comprehensive EU chronic disease strategy, taking into account prevention, health promotion and health care provision – both formal as well as informal.

Informal carers must be recognised and supported across all levels of EU action and initiatives. Different types of support are required, such as measures that provide support to carers in their day to day caring responsibilities (e.g. eHealth, respite care, training), measures that facilitate combining work and family life, and protection of pension eligibility and entitlements while caring fulltime. In addition, measures are needed that improve the recognition by formal care service providers of the central role of informal carers as this will facilitate their reciprocal integration.

8.3 Chronic pain needs more attention

A couple of stakeholders argue that at both a national government level as well as EU level, chronic pain needs far higher prioritisation by both healthcare policy makers and relevant government departments. The EU needs to ask stakeholders, organized at the European level, to develop common definitions of chronic pain and its direct and indirect costs. This will create clarity for all stakeholders and provide the basis for a benchmarking tool for application across all European countries. An inclusion of the right to receive pain management into a European policy paper will benefit all patients who suffer from acute or chronic pain. Human Rights Watch has already demanded such action.

8.4 More attention for working conditions and workforce

The professional autonomy of doctors, good working conditions, including reduction in the red-tape obligations set on doctors, and proper remuneration are essential elements that positively affect the quality of healthcare services. This also supports recommendations for a more equitable distribution of human resources for health. Additionally, an area of further investigation concerns the wider impact of task shifting within the health care system.

In addition, it is recommended that future proposals for an EU strategy considers the workforce implications of managing chronic disease (in relation to specialist nursing, and the wider community nursing workforce), and linking this initiative with the Joint Action on workforce planning. Related to workforce developments, the current economic pressure on health care systems and its negative impact on health care services is an area that needs attention as well. We need a broad debate on the long-term implications of this trend, and efforts are needed to ensure short and medium term resource allocation decisions do not obscure longer-term objectives of reducing the burden of chronic conditions.

8.5 Role of patients and inherited diseases are missing

One of the respondents states that the consultation document lacks the importance of chronic disease self-management, patient empowerment and patient health literacy. Health promotion, prevention and chronic disease self-management must integrate around the process of empowerment. Additionally, a critical gap in the consultation document exists in the health care section, actually negating the many good experiences and relationships the EU has with patient organisations throughout Europe.

The consultation document mentions the role of health care professionals and the health care system in supporting patients but does not highlight the critical role of the patient. Furthermore, the stakeholder questionnaire aims at prevention and treatment of chronic diseases originating from lifestyle and environmental issues, and does not pay enough attention to inherited disorders. These can however be chronic and they require life-long management and care as well. People living with a rare disease may need additional or different support than people with more common diseases, such as diabetes.

8.6 Need for coordinated action

One respondent recommends extending the targeted population of policy response to chronic conditions and diseases to newborn infants. Another recommends an EU-wide co-ordinated approach on newborn screening practises as a tool to optimize early and accurate diagnosis of treatable rare conditions and maximize access to timely and efficient treatment for patients.

More respondents mention the need for cooperation and co-ordinated action; the Joint Programming initiatives, such as in the field of Neurodegenerative Disease Research, are suggested as a good model for coordinated actions across EU (see also paragraph 5.4 and 5.5).

In addition, the European Commission and Member States have much to learn from sharing experience of national policies in areas of common interest. This will contribute to advancement in areas that are widely acknowledged as effective policy options.

8.7 Commitment and integrated action at MS and EU level

Respondents state that health is a fundamental human right, not a privilege. In reality, there is still an urgent need to work towards ensuring readily available, accessible and affordable information, counselling services and quality care for all European citizens. It is the responsibility and obligation of European and National policy and decision makers to enable this, and it is time for the European Commission and MS to step up the actions and become more committed and action driven.

Respondents emphasize the importance of integrative approaches. For example, they state that a chronic diseases strategy must link directly to a funding programme with long-term commitment of national funding agencies around an agreed set of priorities that are clear, realistic and measurable. In addition, the improvement of multi-sector policies is necessary, through the adoption of the principles of equity and accessibility to promote the exercise of human rights. Finally, a Code of Conduct and Ethical Framework is vital to help protect the integrity of, and to ensure transparency in, public policy decision-making at all levels of government, by safeguarding against, and identifying and managing conflicts of interest.

8.8 WHO and EU can develop ambitious policies and targets

One of the respondents elaborates on the link with WHO action in the field of NCD. NCDs must be integrated into national goals as well as into the Millennium Development Goals (MDGs) and into any successor framework after 2015 when the MDGs expire. The EU and its MS should ask WHO to reinstate the original ten targets on NCDs related to the UN Political Declaration on NCDs, which were reduced to five, of which two were made less ambitious. They also call on the EU and its Member States to invest time and resources into this and invite civil society into this process. Respondents also call upon the EU to take forward bold proposals for alcohol and food pricing, similar to the legislation on tobacco advertising and food labelling.

8.9 Stakeholders offer their support and expertise

Geriatric medicine is relevant for all areas of the chronic conditions reflection process. It has a role to play in prevention, screening and early diagnosis, treatment, care, maintaining quality of life and independent living. Research has shown that integrated health care systems, which regularly implement comprehensive geriatric assessment, can significantly reduce disability, morbidity and health care costs in the older population. Therefore, geriatricians can take a leading role in the development of new clinical and practice guidelines.

Furthermore, respondents offer to contribute to the further development of the EU strategy through providing information and expertise, for example in the field of chronic diseases self-management programmes, concerning both implementation and evaluation.

8.10 Discussion and conclusion

In their answers to the above consultation questions the stakeholders have reacted in a variety of ways. Not all stakeholders answered this question. Those that did point at topics that in their view have not received enough attention in Commission documents or proposals. They also pointed at additional feasible and desirable policy actions at European and national levels. The answers occasionally overlap with those given for other areas, i.e. healthcare or health promotion.

9 Discussion and conclusions

9.1 Potential ways to use the stakeholder information

This report is a reflection of a wide array of statements and opinions that come from a diverse set of stakeholders who have an interest in an efficient chronic disease policy in the European Union. Some are lobby organisations, some represent the food or pharmaceutical industry and others are large patient organisations. Some of them again are smaller organisations or work in the interest of people who suffer from a specific disease. Even some individuals contributed to this consultation. All those stakeholders have responded from a different perspective and based on different interests. The report, therefore, contains a broad scope of very relevant views, opinions and recommendations in the area of chronic diseases. It also includes concrete proposals for action by Member States and the EU. We highlighted those that were mentioned frequently by different stakeholders, but also some opinions or proposals from single stakeholders that we felt were specifically relevant for the area of chronic diseases and the questions to be answered in this stakeholder consultation. In this way the report has become a rich source of inspiration for the Commission in shaping future health policies that will improve the situation of chronically ill people in the European Union.

The open character of the consultation questions yielded a lot of responses, which came in long and short versions and in many different formats. It is obvious that the time and energy devoted by stakeholders to answering the questions differed as well. Therefore, we considered it impossible to report exact numbers of answers per type of organisation. Finally, it should be noted that almost all stakeholders express their gratefulness to have been consulted in this matter (sometimes noting that time to respond was too short). They also hope that the Commission will continue to engage them in this matter.

9.2 Major gaps

Almost all stakeholders say they agree on the diseases and the health determinants that are described by DG SANCO in their consultation document. However, many of them would add conditions that they feel need more attention than they currently receive. Also, certain aspects and approaches to tackle the problem of chronic diseases are mentioned. It has been stated several times that the scope of ‘chronic disease’ is too narrow. Chronic diseases can have its origins in for example lifestyle (smoking, nutrition, physical activity) as well as in environmental issues (pollution, work-life etc.). “The questionnaire is obviously aimed at prevention and treatment of such chronic diseases.” Stakeholders representing patients with mental health disorders, inherited diseases or (ultra)rare diseases argue that these disorders may not be prevented, but patients still need optimal care to prevent negative outcomes. These conditions are often chronic and require life-long management and care. They feel that the questionnaire did not sufficiently focus on the differences between the different types of chronic diseases.

Another field that was missed in the consultation paper is ‘health inequalities’. In this respect, stakeholders refer to certain migrant groups (i.e. Roma), health-illiterate people and gender issues.

Multimorbidity and comorbidity are two of the most important problems to deal with in an ageing Europe. Their treatment requires a much more integrated approach to care, leading to the need of efficient collaboration between different sectors. For example, care providers have to exchange patient information and medicines should be carefully prescribed in order to prevent harmful interactions.

Informal care is another area that needs more attention. Informal carers should be valued and rewarded for their work much more than currently is the case. Due to the pressure on human resources in health care and in order to contain costs in general, informal carers are very much needed in the future. Self-management is another issue that becomes more and more important. One stakeholder put the shift of focus as follows: "…A shift from hospital-centred medicine to home care, from physician care to nurse care and from nurse care to self-management will be inevitable. The EU must prepare for this shift."

Presently, scientific collaboration in health lacks a strong strategic framework to tackle chronic diseases. National research programmes and European research programmes should compliment each other better than is currently the case. Cross-fertilisation between clinical disciplines is also vital, in order to accelerate the translation of basic science into clinical practice. If promoted by the EU and Member States this would result in significant cost savings and the more efficient use of research funding in Europe. Another area for potential cost-saving is knowledge on cost-effectivess, in prevention as well as in clinical settings. Exchanging information between countries and within professional networks is key here.

Availability and comparability of data, at national and at EU level on disease incidence and prevalence, as well as on the prevalence of determinants of chronic diseases, is poor. To obtain comparable information, it is important to use uniform methods, definitions and tools for data collection. Stakeholders also note that more action is needed to improve the stratification of data by socio-economic status and ethnic minorities. To be able to have sound evidence-informed policy making in the field of chronic diseases, the evidence base needs to be strengthened. A lot of developmental work is still needed to achieve this. The Commission should take care that the basic indicator selection (ECHI), which includes a lot of information on chronic diseases, is followed up not only in terms of displaying data but also in a regular reporting and dissemination structure in order to support European policy makers and initiatives in the area of chronic disease prevention and management.

9.3 Next steps

Several times respondents mention that adopting integrated chronic disease strategies at both the national and European level would be an important step forward. Many respondents mention the need for an intersectoral approach to chronic diseases. Efforts coming from sectors such as healthcare, housing, industry, education, technology and social services need integration. Health in all policies (HiAP), developed by the Commission and Member States, for example in the field of agriculture and rural development, research and innovation, are highly relevant. The impact on health of decisions taken in other fields needs systematic consideration. Other policy areas such as employment, environment and agriculture are also important in tackling chronic diseases.

Stakeholders see a combination of health promotion, disease prevention and medical care as integrated elements of any future effective approach to combat chronic diseases. However, prevention still needs systematic development in medical

practice. In addition, the evidence base for preventive interventions, treatments and early detection should be increased. The outcomes of innovative projects that have been executed in Member States of the European Union and that have proven cost-effective, should be disseminated as best practices to other countries.
Broad intersectoral collaboration should not only involve different sectors but also different actors, e.g. collaboration between different stakeholders, between MS, between the EU and international organizations. Public Private Partnerships and multi-stakeholder collaboration, including involvement of patients, are important as well.

The current healthcare systems are not fully equipped for treating patients having several diseases at a time, as already mentioned. Their treatment requires a much more integrated approach to care than is delivered nowadays in most systems. The adequate involvement of patients and their representative organisations in healthcare design and delivery is an essential element of the renewal of any healthcare system that aims to better deal with chronic diseases.

To obtain comparable information common health data collection methods across Europe and permanent co-ordination is needed. Action related to data needs to take into account the differences between health systems in Member States as well as existing EU activities such as the European Health Interview Survey, the European Health Examination Survey, the development of morbidity statistics by Eurostat and other bodies, as well as registries and other sources. In relation to possible data sources for chronic diseases information, stakeholders propose the exploration of innovative and more efficient approaches to the development of information and data, in particular related to how data held within Electronic Health Records (EHR) can be reused to enhance clinical research processes in Europe. Information Technology can play an important role in data provision.

9.4 Actions at the EU, Member State and stakeholder level

9.4.1 Action European Union

Stakeholders have provided many suggestions about the way the EU should continue its work to tackle the problem of chronic diseases. Most stakeholders mainly see a coordinating role for the European Commission. Various recommendations point at the need to increase the coordinating capacity behind European research efforts by using either new or established structures and to expand research collaborations outside the European Union as well. Examples of existing structures include the Innovative Medicine Initiative (IMI) and the European Strategy Forum on Research Infrastructures (ESFRI). Stakeholders also proposed to build new structures such as a *European Institute on Ageing* to act as clearing house for relevant information. Also a European centre of excellence was brought forward, for the study of chronic disease management, the development of disease management support tools, services and data management systems. These recommendations come from the WHO report on "*Prioritized Research Agenda for Prevention and Control of Noncommunicable Diseases".* The European Commission should take on board relevant recommendations from this report.

Stakeholders urge the EU and the MS to closely collaborate with WHO in the area of NCDs as already agreed upon and follow and implement the various recommendations already made by WHO in the light of their European Strategy for the Prevention and Control of NCDs. It is also important to strengthen the links with OECD and with medical/scientific societies.

The EU must engage in wider consultation procedures. It is important to include patient representatives in multi-stakeholder consultations. Participation and involvement of stakeholders from the very beginning to the implementation phase of EU actions on chronic diseases should be strengthened. The European Innovation Partnership model seems to be an effective way to tackle health challenges in cooperation and to identify specific and targeted actions that may have a measurable effect. It can be useful to replicate such wide partnerships in the future and steer them towards achieving public health benefits.

The EU can use legislative tools to promote health and behavioural change in daily practice and financial instruments to improve health promotion activities. Respondents see an explicit role for the EU in supporting Member States through exchange of information and good practices and through the development of information systems and guidelines. The EU can function as a catalyst for research undertaken at national level to improve chronic disease management, including the dissemination of research findings across Member States and the actual implementation of the research findings into daily practice of prevention and care. EU and Member States should support the evaluation of cost-effectiveness of programmes and projects.

Respondents mention repeatedly the need for a new body whose main responsibility will be the monitoring and reporting on the situation in chronic diseases. The EU can play a more active role in the collection of comparable data on chronic conditions and disease to allow better planning, priority setting and evaluation across the EU. As a possible organizational form for such a body, stakeholders suggest to consider extending the mandate of the European Centre for Disease Control (ECDC) to cover the chronic non-communicable epidemic. Tasks of that body could include cross-referencing and coordination between research-funding agencies as well as data harmonising efforts.

Also in the field of health information respondents point at the need for increased cooperation between the EU and other international organisations, such as the WHO and/or the OECD. Finally, the Commission must make sure, together with the MS, that the new European data-protection legislation will allow for necessary data collection and safe and efficient use of routinely collected, personal health data for public health monitoring.

9.4.2 *Action Member States*

In many of the actions, described above, respondents see a role for both the EU and the Member States. Recognising that national governments in EU Member States have full competence of their health and social care systems highlights specific need for action at national level. National healthcare systems need a more integrated approach with a central role for the concept of chronic disease management. Member Stats should share best practices in new forms of co-ordinated care and good examples for chronic disease guidelines among each other.

In the field of comparable data there is potential for national level action in two specific areas. First, the stimulation of a universal, highly accessible Primary Health

Care system as the starting point for information, documentation and exchange with input from patients. Second the need for national actors to embrace the benefits of strong, consistent, quality data sets in bringing about transparency and improvements in health care.

The respondents have also pointed at many opportunities for Member States to take a well-planned and programmatic approach to combating chronic diseases and strengthen the many opportunities to exchange best practices. The respondents also urge the MS to closely collaborate with WHO in the area of NCDs as already agreed upon and follow and implement the various recommendations already made by WHO.

Finally, respondents suggest exclusion of the tobacco industry from any engagement in addressing chronic and other diseases, and public health in general, thus respecting the Article 5.3 from the WHO FCTC (Framework Convention on Tobacco Control) that the MS and EU have ratified.

9.4.3 Action stakeholders

Stakeholders have offered their support for EU action in the area of chronic diseases by extending their usual commitment to health improvements in the form of advocacy, communicating and sharing information between patients and health care providers, participating in research and making their expertise and the expertise of their target groups available. Stakeholders can contribute through awareness raising, education, exchange of good practices, dissemination of scientific results, the implementation of innovative programs.

Many respondents make suggestions for how to improve stakeholder involvement and apply this at both EU and MS level. Respondents state that the EU and MS should put the experience and expertise of stakeholder groups in use, e.g. through setting up a multi-stakeholder Task Force on Chronic Diseases, or through partnerships between scientific societies and healthcare professionals, patients and industry, aimed at developing shared agendas and acting as a single point of contact for their area. When consulting stakeholders, the invitation lists needs updating to include newcomers and other stakeholders who have developed their activities over time.