

EXECUTIVE SUMMARY

EU reflection Process on Chronic Disease

Results of the Stakeholder Consultation

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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-effectiveness, 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.