

LIVING LONGER, BETTER

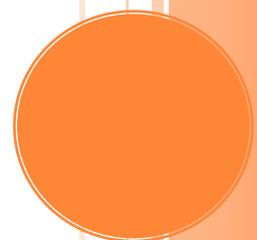
European Conference on chronic diseases

Brussels, 11 May 2012

An initiative of the European Heart Network, the European CanCer Organisation, the European Respiratory Society and the International Federation of Diabetes European Region, under the leadership of the European COPD Coalition.

All parties are members of the European Chronic Disease Alliance (ECDA).

European COPD Coalition
June 2012



Living Longer, Better

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On Friday the 11th of May 2012, the European COPD Coalition (ECC) organised, with the support of European Heart Network (EHN), the European CanCER Organisation (ECCO), the European Respiratory Society (ERS) and the International Diabetes Federation – European region (IDF - Europe), a European conference entitled “Living longer, better”. The purpose of the event was to actively input into the current Council reflection process on chronic diseases, addressing challenges, identifying solutions from the perspective of the disease burden.

Nick Fahy, moderator of the day welcomed the participants by underlining one of our main challenges: to find a way to work and put together clear common messages to feed into the process and bring about concrete changes for the benefit of those affected by chronic disease. The Conference is very opportune: chronic diseases are increasingly



on the political agendas, in particular with the Conclusions from the Council, initiatives undertaken at the global level (United Nations and World Health Organisation) and the recent European Council reflection process on chronic diseases. Mr Fahy pointed out the need to focus on the fact that chronic diseases are pertinent to other areas, such as transport, housing and agriculture. While the current priorities are related to growth, the health sector response in terms of prevention and treatment might be part of the answer. This could represent an economic contribution as well as a development relevant to citizens. Before introducing the first speaker, Mr Fahy raised the question about the opportunities offered in a European Union where health systems are a national competence.

Session 1 “Disease prevention and health promotion – Acting on risk factors: the “whats” and the “hows”

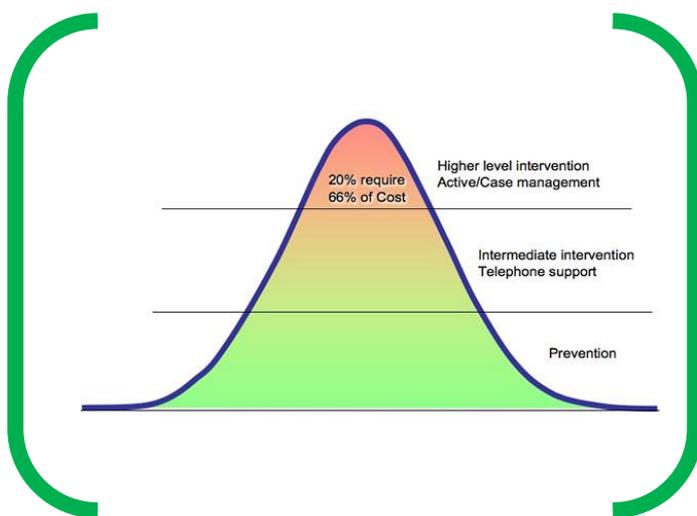
Dr. Usman Khan, Managing Director of Matrix Insight Ltd, in a presentation entitled “Making the best of best practice” talked about best practice available in management of diseases. Matrix Insight Ltd role is to review best practice and to maximise the potential impact of the interventions that are available for European governments to implement. Dr. Khan reminded the audience of one of the main challenges governments are facing: now that a considerable amount of data is

available, how to actually manage, choose and respond to this information? How to react to or act on the evidence showing that there is something wrong in the system?

Based on a graph showing the degree of certainty and the degree of agreement, Dr. Khan explained that in most of the cases, there is no certainty or consensus on the interventions available. The first question governments may have is on the evidence base itself. Dr. Khan mentioned that the increase in internet use is helping to disseminate good practice, which accelerates picking up information. He added that a level of evidence is needed to be sufficiently robust to face changing needs in public health, especially in the area of chronic diseases.



Dr. Khan then pointed out some of the constraints the policy-makers face, such as the reduction in public budgets, and the top-down cuts to public health expenditure in some countries. He also explored the return on investments, where savings could happen and what savings could be made through effective prevention. He gave the example of the Public Health England, linking evidence with cost effectiveness. Dr. Khan mentioned then the HEIDI WIKI approach, the importance of empowering



people, and the democratization of data. He emphasised the importance for people that hold the data to start taking ownership of it and make better use of it.

Dr. Khan concluded his intervention by reminding the room that evidence is not enough and that it could be as disempowering as empowering. The answer is to ensure we have processes in

place that bring the data to the policy makers and allows them to make the best choices for their context, as quickly as possible.

Luk Joossens, Advocacy Officer, Tobacco Control – European Cancer Leagues (ECL)/Belgian Cancer Foundation, presented the effectiveness of tobacco control measures. Mr. Joossens began his presentation by providing figures on the global burden of tobacco, such as the 100 million deaths worldwide in the 20th century caused by tobacco, while reminding the audience that tobacco control is an area where there is plenty of evidence for successful actions. Mr. Joossens presented examples of effective tobacco control policies such as “MPOWER”: Monitor tobacco use and prevention policies, Protect people from tobacco smoke, Offer help to quit tobacco use, Warn about the dangers of tobacco, Enforce bans on tobacco advertising, promotion and sponsorship and Raise taxes on tobacco.



Global tobacco control is underfunded, especially in the EU where it is far below the US funding. Generally, the money raised from tobacco taxation is 500 times higher than the money spent on tobacco control. Mr. Joossens presented a picture of the different tobacco control policies, rated according to their effectiveness¹. Pricing policies are top of the list (30 points), followed by smoking restrictions/bans (22 points), tobacco control funding (15 points), advertising ban (13 points), smoking cessation (10 points) and labeling/health warnings (10 points). Mr. Joossens highlighted that some policies were not mentioned such as education and selling to minors, because they are not as effective as those listed. The presentation ended with the following recommendations: comprehensive tobacco control policies, tobacco control spending (a minimum of 2 euros per capita per year), comprehensive smoke-free legislation, regular increases in tobacco taxes, large mandatory pictorial health warnings at the front and back of the pack of all tobacco products in combination with plain packaging. Finally, countries must address tobacco industry interference in public health policies.

Maureen Mulvihill from the Irish Heart Foundation presented the goals, policies and challenges for healthy eating to prevent cardiovascular diseases (CVDs) and other chronic diseases. She shared the European Heart Network (EHN) “Report on Diet, Physical Activity and CVDs” and reminded the audience that prevention is key in the reduction of the burden of chronic diseases, with interventions targeting the whole

¹ source: World Bank

population having the largest impact. She presented some of the intermediate and long term goals stated in the EHN report, i.e reduction in consumption levels of saturated fat, trans-fatty acids, increase in consumption of fruit and vegetables, reduction in consumption of salt, reduction in the consumption of alcohol, increasing levels of physical activity, etc. and stressed that many countries were very far from achieving these goals. Ms. Mulvihill raised the 4 Ps: Price (the use of fiscal measures), Product (reformulation efforts), Place (school, workplace etc), and Promotion (marketing: internet, TV, sponsorship, labelling, education, etc.). She then mentioned some of the key policy actions presented in the Report.



A question was raised from the floor asking whether it would be more effective if in policy activities there were to be a separation between diet and physical activity given that often, lack of physical inactivity is used as an argument to prevent effective action on tackling diet-related issues. Ms. Mulvihill acknowledged the suggestion, but pointed out that, however in CVD prevention diet and physical activity are intrinsically linked and are core part of the strategy to reduce the disease burden.



Dr. Arvid Nyberg from the Finnish Lung Association ended the series of presentations on disease prevention and health promotion sharing the Finnish experience of national plans for respiratory diseases and in particular Chronic Obstructive Pulmonary Disease (COPD). Dr. Nyberg opened his intervention presenting the structure of healthy lungs and of lungs with COPD: He pointed out some of the systematic consequences of COPD: lung cancer, muscle

wasting, CVD, depression, anxiety etc.

The Finnish COPD programme, its starting point and goals were then introduced to the audience. Amongst these goals were a decrease in the incidence of chronic bronchitis, in the proportion of severe and moderate COPD, in the number of bed-days of COPD patients (by 25%) and in the annual healthcare related costs per

patient. Multidisciplinary training is part of the implementation phase of the COPD national plan. It consisted of a series of COPD training for all healthcare (including primary healthcare) professionals, spirometry training (a medical device that measures breathing capacity) and training for smoking cessation for all healthcare professionals. Dr. Nyberg shared some of the achievements of the programme, including an improved knowledge of, and skills in COPD, a better attitude towards smokers and COPD patients and enhanced primary healthcare management of COPD in terms of resources and tools. As a conclusion, Dr. Nyberg outlined that COPD is now a relatively well known disease amongst the Finnish population, and amongst healthcare professionals. Attitudes towards, knowledge of and skills in COPD, spirometry and smoking cessation have improved and resources have increased. Combined with other efforts, the programme stopped the prevalence of COPD, reduced smoking rates, improved the quality of diagnosis, decreased medical and care costs and hospitalization for COPD patients.

Take home messages:

- *change is possible,*
- *we need to agree clear goals,*
- *we need to have strong public health organisations supporting the implementation of the plan and objectives, to ensure the sustainability of the interventions,*
- *smoking prevention should be the basis and*
- *there is no need to re-invent the wheel but rather, be inspired by other successful experiences.*

Session 2: Health care and the health system: what next?

Irina Odnoletkova presented the payers' perspective on chronic care. Ms Odnoletkova briefly presented the organisation she represents, the **International Association of Mutual Benefit Societies (AIM)**, implemented in 28 countries, covering 170 million people. She shared general concerns on such matters as the economic crisis, the ageing population, the increase of healthcare expenditure, the growth of out of pocket contributions from citizens, quality of care and the lack of long-term vision (funding based on short term budgets).

She focused her presentation on the Chronic Care Model, used worldwide to introduce innovations in chronic care. Amongst the important elements of the model is delivery system re-design, self-management support, decision support based on the guidelines, clinical information systems, community resources and policies and health systems focused on developing a performance-oriented culture. In Europe, Member States respond differently to the chronic care model. While comprehensive approaches are



implemented in Slovakia, Poland, Scotland and France, disease-management programmes are followed in Germany, the Netherlands, Denmark, Finland, Italy, Spain and Sweden. An inadequate coordination of care between health services, a lack of (self) management, a lack of preventive care and increasing costs of chronic care are some of the potential threats to this model. In order to counter these, global innovation and new care models need to be introduced step by step, and should be complemented by a new health delivery model, a new distribution of roles between healthcare professionals, new financing and incentive models and especially a long term vision and long term budget planning.



40% of the population in Europe above the age of 15 is reported to have a chronic disease¹.

Ms. Odnoletkova then presented the COACH Programme, the evidence-based telephone delivered coaching service for patients with chronic diseases. She presented the chain of self-management support that runs from patient behaviour, disease control, health outcomes, patients' satisfaction to lower overall costs. To conclude, Ms. Odnoletkova said that the development of new delivery model requires political will,

organisational efforts and a new culture of dialogue between caregivers, patients, payers, industry and authorities based on the principles of transparency and common values.

Stijn Deceukelier representing the Flemish Diabetes Association gave a presentation on shifting from a healthcare system designed for acute care towards one for chronic disease management.



Taking the example of diabetes, Mr. Deceukelier explained why this shift is paramount: the 2007 United Nations Resolution on World Diabetes Day, the European Parliament Resolution on addressing the EU diabetes epidemic, the EU reflection process on chronic diseases are some of the indicators that there is an urgent need to refocus care systems. He presented a set of actions that could be implemented using the healthcare system as a tool:

reduction in exposure to risk factors, facilitation of improved and healthy lifestyles and adaptation of the physical environment (enabling patients to live better with chronic conditions).

Belgium was used as a concrete example where there are many good elements in place: pilot projects such as “Sweet Pregnancy” aim to prevent pregnant women developing gestational diabetes and are moving in the right direction. A series of potential pitfalls were presented such as a reimbursement system oriented towards acute care, the lack of coordination between existing projects, the different competence level for prevention and care and the lack of an approach that would put patients in the centre of care. Mr. Deceukelier presented potential solutions to tackle these problems. Using a horizontal approach, introducing generic models for chronic diseases, focusing on policy for several diseases (vertical approach) and involving patients in decision making would help redress the status quo. Concluding his presentation, Mr. Deceukelier emphasised the need to act now.



Francesca Avolio from the Committee of the Regions Inter-regional Group on Health (representing the Puglia Region, Italy) presented on “Empowering patients for health sustainability”. Ms. Avolio outlined the new healthcare model in the region to foster healthy ageing following a substantial cut in regional health budgets in recent years. The pillars of the model include new group practices of general practitioners (GPs), leverage on the trust between GPs and patients, accurate design of clinical pathways for each disease problem, empowerment of patients and the healthcare plan as a focused target. The model can be divided into different steps from the identification of a patient, consensus and enrolment of the patient, data collection, intervention plan set up, implementation of the plan and its monitoring/evaluation. The model puts patients, considered as the

true managers of their well-being, in its centre and in order to achieve this objective several conditions have to be fulfilled:

“knowing how and when to call the doctor, learning about the condition and setting treatment goals, taking medicines correctly, getting recommended tests and services, acting to keep the condition on good control, making lifestyle changes and reducing risks, building on strengths and overcoming obstacles and following-up with specialists and appointments”.

Ms Avolio insisted on the fact that general practice is the most suitable place to promote patient empowerment and self-management, and that family medicine, considering its particular relationship with patients and their family, can ensure the empowerment reaches well into the community.

Ms Avolio emphasised the situation in Puglia and its specificities. Over the past months, money was invested in the reorganization of the healthcare services towards the integrated care model, professionals were trained in this direction and ICT were largely introduced for the management of COPD notably. The Strategic project on COPD began with gathering information on the environment, gender and the socio-economic conditions of people with COPD as well as information related to the epidemiological and natural history of the disease in order to have a clearer picture of the situation. Ms Avolio presented then some of the objectives and tools of the project (using electronic clinical questionnaire, telespirometry as a screening tool and training professionals in performing spirometry tests in order to achieve a reorganized healthcare model based on ICT tools allowing improved diagnosis and management, continued care and quality of care. Ms Avolio ended his presentation with the next steps of the projects.

Session 3: The value of research

Julio Celis, Board member of the European Cancer Organisation (ECCO) and President of the European Association for Cancer Research (EACR)

presented his views on the future of health research and innovation in Europe.

Dr. Celis began his intervention by referring to some of the societal challenges Europe is facing today: an ageing population, the growing prevalence of chronic diseases, a declining labour force and a rise in healthcare costs. In order to meet these challenges, better biomedical research and a coherent and strategic European action engaging all relevant stakeholders on health research are needed. However, a fragmented community of potential innovators and the complexity of the innovation cycle are some of the obstacles to the effectiveness of European research. Horizon2020, the future EU programme for



research, as it stands will not solve the challenges we face today. A change in the culture is strongly needed, stressed Dr. Celis. Research funding could be better used and allocated, research could be better linked to societal challenges, collaboration beyond borders could be strengthened as well as with ministries. Working towards a scientific priority-setting, monitoring strategic planning and programme-setting, stimulating the exchange of information, promoting an innovation-friendly environment while addressing the regulatory legislative challenges framing it and creating a forum for exchange of best practices on research coordination are part of the solution. Dr. Celis presented then the Alliance for Biomedical Research in Europe and its proposed response to the challenges: a European Council for Health Research. Dr. Celis ended his presentation by encouraging participants to disseminate the concept of the European Council for Health Research, build political support at the European and national level and be active in the pilot projects of the European Partnership for Action Against Cancer (EPAAC).

Dorota Sienkewicz Policy Coordinator for Health Equity at the European Public Health Alliance (EPHA) presentation was entitled “Research on social determinants of health, a public health must”. Ms. Sienkewicz presented an overview of the social determinants of health (SOH) as well



as the existing research on the issue and underlined that many important social determinants of health (SDOH) as well as their governing policies remain largely unexplored. Citing figures on the burden of chronic diseases, she pointed out that further research on SDOH would benefit patients but also protect healthy people from developing disease in the first place. To the question “How to do it” she responded with the “health in all policies” approach and the need to strengthen research on the policies and political choices that have a direct or indirect impact on the SDOH. She also highlighted the need to expand the scope on wider SDOH to include areas such as agriculture and food production, the quality of physical and social environments, transport, energy etc. and finally the importance of applying a life course dimension “from cradle to grave”.

In order to achieve this, partnership between civil society and academic institutions should be strengthened as well as the involvement of user organisations who know best what their needs are.



Marc McCarthy, researcher for the European Public Health Association, focused his presentation on how public health research fits in the EU agenda. Professor McCarthy pointed out, from the beginning,

the need to think about people that are healthy, calling them the “silent minority”,

and not only on patients. He then presented figures related to the allocation of health-related EU funds comparing notably the EU research funding instrument, the Seventh Framework Programme (FP7) and future programme, Horizon2020. Very often, funding is diverted to the digital field, genomics as well as research on industry. He thus insisted on the fact that public health research should have as much funding as biomedical research, the current level of which is only at 5%. Professor McCarthy concluded his presentation by emphasising the need to engage civil society as much as industry and demonstrated that research has an impact on health systems.

Time was then devoted to questions and answers. One of the points raised was that ministries of health do not work with ministries of research. The final points made were the importance of having a single voice and the need to increase available resources and for that Member States involvement should be strengthened.

Session 4: Information and IT: more and better?

Robert Johnstone presented the European Patients Forum perspective on the role of the patient in the design of eHealth tools and services.

Mr. Johnstone mentioned that while health systems have been organised to respond to acute interventions, a change is needed in order to adapt to the challenges of chronic conditions. When speaking about eHealth technologies, patients have a key role to play in identifying issues, problems and solutions. Therefore it is important to engage them in health policy making as they reflect patient needs and expectations, better than anybody else.

Mr. Johnstone then pointed out the existing barriers to the achievement of truly integrated care such as the need to have a coordination done by one trusted healthcare professional and for patients to be considered as a whole, including in their cultural and psycho-social aspects. His presentation focused then on eHealth and user acceptance that tends to be overlooked by developers and decision-makers trying to convince patients why they should actually engage with them to understand their attitudes, requirements, preferences and constraints. This is essential to fully realise eHealth potentials.

User acceptance should be positioned at the very centre and this should be integrated in the eHealth approach. Later, Mr Johnstone insisted on the fact that health literacy is key to the future of healthcare, as well as patient empowerment. Collaborative approaches are needed but also innovative forms of care, access to high quality information and skills to use it. Mr. Johnstone shared some patients



organisations' initiatives before concluding his intervention with a series of key recommendations amongst which the need to have a multi-pronged approach encompassing patients centred chronic disease management, primary and secondary prevention and health promotion, the importance for the EU and Member States to support concrete actions and targeted programmes related to health literacy and finally the need to support civil society organisations including patients' organisations. Patients are part of the solution.

Dr Ivo Smeele, member of the COPD Asthma PC Expert Group Dutch College of GPs, Lung Alliance Netherlands, Care Group DOH Eindhoven and Engelsbergen Practice Eindhoven presented on chronic diseases and the added value of information. He



began his presentation by explaining the Dutch health system in order for participants to understand the way different stakeholders interact. He pointed out that in The Netherlands they have indicators for the quality of care for chronic diseases. His presentation focused then on COPD management and the need to improve data on the prevalence of the disease as in 29% of the cases it is not correctly diagnosed and in 38% of the cases over-treated. Dr. Smeele presented the results from studies aiming at improving data on prevalence and the quality of diagnosis and care for COPD but also for asthma, diabetes and cardiovascular diseases. Dr. Smeele pointed out the relation between chronic diseases and comorbidities as well as solutions that can represent a care group, i.e. common pathway for diabetes and cardiovascular diseases or common pathway for COPD and osteoporosis.

Dr. Smeele shared data on COPD and asthma, targeting treatment medication and hospital admissions, from experiences from Sweden and Germany. He pointed out that information makes the evaluation of strategies possible and will help make choices in a future with an increased demand, reduced budget and not enough healthcare professionals. He concluded his presentation by emphasising some of the preconditions for success: the organisation of care givers, national data sets that are exchangeable internationally, indicators for national quality of care, data centres and trusted third parties to analyse the feedbacks, best practices exchange. All these should result in improving process and outcome of care, targeting treatment on individual patient profiles, setting up pathways addressing patients' needs and cost-effective care.

Evert Jan Hoijtink (Commodity 12 EU Project) made a presentation entitled presented on "How does eHealth improve the management of chronic disease". The presentation began with an introduction to the project itself, its vision: to "design, build, and validate an intelligent system for the analysis of multi-parametric medical data. It will uptake the existing cutting-edge technologies and extend these technologies by combining state-of-the-art networks, software interoperation, and

artificial intelligence techniques in order to realise the concept of translational medicine by means of a Personal Health System.” Mr Hoijtink followed on with an introduction to disease management and a pilot project in the management of diabetes in The Netherlands specifically. He denounced the fact that there are still many health professionals that resist working in a disease management system despite general enthusiasm from patients.



To the question “Why health IT is the solution here?”, he responded by emphasising the efficiency of the system,

i.e. experts can provide advice from anywhere, inconsistent data is checked, as well as the effectiveness of the system, i.e. better treatment through the use of decision support and help towards decreasing the number of secondary complications. Mr Jan Hoijtink concluded with elements to further improve the quality of medical decisions: having more information regarding the patient and applying all available medical knowledge to the individual patient will lead to improved and more personalised treatment plans for patients.

Doctor Catherine Bismuth representing la Caisse Nationale d’Assurance Maladie (France) shared with the audience the French disease management pilot programme “Sophia” dedicated to disease management with a focus on diabetes. The programme

was developed in a context of an increasing emphasis put on prevention (since 2005), with the aim to implement an adequate environment for therapeutic education and disease management and extended financial coverage for patients with chronic diseases. A change in the political and legal framework in France created the opportunity to develop a strategy that focused on the patient, targeting vulnerable groups in particular. The



objectives, for the first pilot project on diabetes, were to improve the health status and quality of life in patients with diabetes and to reduce the complications, comorbidity frequency and healthcare expenditures.

The GPs support and help was a key success factor, they are an important part of the programme.

The programme focuses on maintaining a link with the patient, and for this purpose, information brochures were mailed to all patients with diabetes in the selected pilot testing areas, an internet support was provided as well and more importantly,

specialist nurses made outbound phone calls to medium & high risk patients while putting a place allowing inbound calls for all patients. The information brochures were mailed to patients based on their specific needs.

The programme has been evaluated by an external contractor and it resulted that:

- Positive and statistically significant improvements were observed in the eligible population and in the enrolled population as compared to the controlled population, and
- Patients and their GPs see “sophia” as a professional and efficient support, 90% patients would recommend “sophia” to other patients.

As a result, the programme will be generalised in 2012-2013 for diabetes (all over the national territory) and it will be used for new chronic diseases (asthma, cardiovascular comorbidities) starting this year.

All presentations are available upon request: [info \(at\) copdcoalition.eu](mailto:info@copdcoalition.eu)

