EUREGHA High Level Conference 2015
"Linking Chronic Diseases and Frailty – Creating Synergies and Collaboration between Efficient Policies for Disease Prevention and Management at European and Subnational Level"

Welcome by Toni Dedeu, Chair of EUREGHA and Director of Knowledge Exchange and Research, Digital Health Institute, Scotland

Toni Dedeu welcomed participants to the EUREGHA Annual Conference, "Linking Chronic Diseases and Frailty". Mr Dedeu proceeded to present EUREGHA, the European Network for Regional and Local Health Authorities. EUREGHA aims at promoting collaboration in the field of health and is a key network for the establishment of successful partnerships between its members and relevant stakeholders. The priority is not only to engage in European projects, but also to help shaping and give input to European health policy. The network plays an influential role at the EU level, giving regional and local authorities a more powerful voice.

Every year, EUREGHA organises a thematic conference on a topic of big importance for the member regions. The topic of today's conference, chronic diseases and frailty, is under the umbrella of regional decision-makers. EUREGHA represents the main bodies responsible for the development and implementation of policies related to chronic diseases and frailty. EUREGHA is also a direct channel to access the daily impact of these policies.

At European level, EUREGHA participates in several European initiatives related to chronic diseases and frailty, such as the Joint Action on Chronic Diseases and Healthy Ageing across the Life Cycle (CHRODIS), the European Innovation Partnership on Active and Healthy Ageing (EIP-AHA), and the SUNFRAIL Project. With representatives from all these initiatives present at the conference, it will also provide a good platform for discussion and dissemination of the work undertaken.

The European Commission's Priorities in the Field of Chronic Diseases and Frailty
Xavier Prats Monné, Director-General, European Commission's Directorate General for Health and Food Safety (DG SANTE)

Xavier Prats Monné, Director General of DG SANTE since September 2015, gave the first key note speech. He started by paying tribute to EUREGHA's work, especially highlighting the network's importance in bringing the regional and local perspectives into EU health policy making. It is important to have a strong organisation bringing together these actors that also engage in policy as this policy will have an impact on local needs.

Specifically on the topic of chronic diseases and frailty, he spoke about the importance of scaling up best practices developed at local and regional levels to reach a systemic impact of what is being accomplished. However, it is important to look at the local specificities and context of the best practice, taking into account the extraordinary difference of welfare states and regulatory frameworks in regions and countries.

Mr Prats Monné pointed to a policy lesson from the French economist Duflo developed in the book "Poor Economics" (2011), holding that most strategies for education and health, healthy ageing and primary healthcare are ambitious and multidisciplinary to the point where that may lead to

discouragement for the practitioner and used as an excuse for policy makers not to feel responsible. The lesson learned is that policy makers need to be attentive to what is being experienced on the ground. EUREGHA thus plays an important role in the EU health policy context and the systemic implications of the work being done by the network should be exploited.

While the Juncker Commission focuses on a limited number of priorities, where health may not be explicit, it is extremely difficult to look at almost any priority, such as sustainable growth, without thinking also about health systems, chronic diseases and frailty. Life expectancy has increased enormously during the past 100 years and a crucial task is to couple this increase with an increase in healthy life years. Currently, one in five Europeans live a life of frailty and disease. We are facing a paradigm change, and the technological developments need to be exploited to the fullest to face this challenge.

Prats Monné concluded with a few messages: there is no doubt of the importance of what EUREGHA does for the strategic importance of EU health policy, EU projects and Joint Actions bring inspiration and guidance and it is important to bring stakeholders together to gain legitimacy to these projects.

We have to look at what we can achieve as a better partnership between policy makers, industry and academia and to build better business models for innovation since return for innovation in decreasing.

There should be a focus on shaping policy to a strong contribution to the determinants on health as well as trying to finding a better balance between what needs to be done by whom, whether academia, regulators etc. Prats Monné concluded by thanking EUREGHA for the undertaken work over the last 10 years and hoped the network can contribute to future Commission strategies.

Investing in Health to Tackle Chronic Diseases and Frailty
Prof Jan de Maeseneer, Chair of the European Commission's Expert Panel on Effective Ways of Investing in Health

The second speech was given by Prof Jan de Maeseneer, Chair of the European Commission's Expert Panel on Effective Ways of Investing in Health.

The Expert Panel on Effective Ways of Investing in Health (EXPH) has the mission of providing the Commission with advice. It works towards the following objectives: fostering good health in an ageing Europe; protecting citizens from health threats and supporting dynamic health systems and new technologies. It is composed by 12 members, including scientists from academia, research or other scientific bodies and national administrations, who were adopted by the Director General in personal capacity following an open call in autumn 2012. To date, the EXPH has adopted five opinions, and the most relevant one in relation to chronic diseases and frailty is "Definition of a frame of reference in relation to primary care with a special emphasis on financing systems and referral system".

According to Prof de Maeseneer, society is changing in many aspects, including demographics, epidemiological developments, scientific and technological progress and globalisation. Societies and health systems are currently not necessarily addressing the needs of the population and responding to these changes accurately. We need to rethink how to organise care, through a paradigm shift from a problem-oriented understanding of care (health as absence of disease) to a goal-oriented one (health as maximum desirable and achievable quality and/or quantity of life as defined by each individual).

Prof de Maeseneer emphasised that the patient needs to be put in the centre as the evaluator of success, and that measures of success should be shifted from "Accuracy of diagnosis, appropriateness of treatment and eradication of disease" to achievement of individual goals. Multimorbidity is particularly challenging and a patient-centred perspective is especially important to avoid

fragmentation of care and contradictions in therapy, and to look at what really matters for the patient (often functional status and social participation).

Another important issue to address is “inequity by disease”, meaning receiving different care for same symptom depending on what is the diagnosed disease, which is a growing problem both in developed and developing countries. These inequities are especially important to tackle as they are created by the healthcare systems themselves.

The Links Between Frailty and Chronic Diseases
Prof Josep Redón, Scientific Director of INCLIVA Health Research Institute, Valencia

Prof Josep Redón gave a speech from a medical/research perspective about the links between chronic diseases and frailty. He started by giving some initial definitions of the concepts: *Chronic diseases* (CDs) are those conditions requiring continuous management over a period of years and decades. *Multimorbidity* is the concurrent presence of two or more CDs. *Frailty* is a syndrome of vulnerability to one stressor identified by a characterised phenotype. Though there is no commonly agreed upon definition of frailty, various scales have been developed to assess the clinical presence of frailty in a person, including the Frail scale (combine **F**atigue, **R**esistance, **A**mbulation, **I**llness, **L**oss), the Fried scale (measuring weight loss, physical activity, gait speed, grip strength, exhaustion), the multidomain scale and the allostatic load-based scale.

Prof Redón then painted the familiar picture of the changing age structure of the EU population. Around 25% of the EU population are older than 60, a number which is projected to increase to 30% by 2050. The process of ageing in itself implies losing physical capacity and basic skills. There are however also external and addressable factors that influences this process, for instance socioeconomic factors.

The links between frailty, chronic diseases and multimorbidity are tangible and Prof Redón stressed that multimorbidity is the key challenge that our healthcare systems need to tackle. Regardless of which chronic disease one has, there will be co-morbidities. As an example, he mentioned that 73% of the patients with frailty that are treated at the INCLIVA institute have at least one chronic disease.

Through the existence of frailty in a person, risks may be calculated for different follow-up syndromes. People with frailty have poorer outcomes from other diseases. These facts show that there are common mechanisms at play in chronic diseases and frailty, and in order to tailor future interventions, these should be further looked into and studied in more detail.

Pro Redón also emphasised that there is a correlation between the number of chronic diseases in one patient and the risk of developing depression. Even though depression is not often mentioned in relation to chronic diseases, it is indeed one of the most important co-morbidities and chronic diseases according to Prof Redón.

Prof Redón further listed a few of the unmet needs identified in related to frailty:

- The use of biomarkers for early detection of disease should be more developed, for instance through Nano photonics technology
- Identification of symptoms and characteristics of pre-frailty
- A universal operational definition of frailty needs to be developed to produce common understandings and avoid uncertainties
- Frailty needs to be possible to control and tailored clinical decisions should be taken in frailty subjects
- Facilitating for the use of big data to tailor clinical decisions on frailty

- More focus should be put on creating “health-friendly environments”, for instance tackling urban air quality, which is a risk factor not only for COPD, but also for CVD.

Prof Redón ended his speech with three take home messages:

- There is a close relationship and interaction between chronic diseases and frailty in the framework of ageing
- Clustering of chronic diseases enlarge the risk of frailty
- Unmet needs should be addressed in the future to improve quality of life of elderly subjects and reduce the mounting burden of disease

Panel Discussion: European Tools on Chronic Diseases and Frailty

This session was an interactive panel discussion with representative from European initiatives on chronic diseases and frailty; the Joint Action on Chronic Diseases (JA CHRODIS), Mr Carlos Segovia; the upcoming Joint Action on Prevention of Frailty, Ms Inés García-Sánchez and the Action Groups on frailty and integrated care of the European Innovation Partnership on Active and Healthy Ageing (EIP-AHA), Ms Maddalena Illario and Ms Stella Tsartsara respectively. The session was moderated by Prof Jan de Maeseneer.

Prevention is a main theme in all these European initiatives. Mr Segovia informed that one of the work packages in Joint Action CHRODIS is on prevention. So far this Work Package has discussed the quality criteria to select best practices and asked different stakeholders to present their experiences. In total, 41 best practices on chronic diseases management from national, regional and local level have been collected. These include many different initiatives in different sectors including for instance cities organising physical activity programmes and activities in schools.

Ms García-Sánchez said that the Commission works to support Member States and different organisations in creating awareness of specific issues and support the ways in which this can happen, including prevention of frailty. This is done mainly through conferences and meetings creating awareness in a specific topic, but also through working with the Committee of the Regions (CoR), the Council and through funding opportunities in Horizon2020 and the Health Programme. The purpose of the Joint Action on Frailty which will be launched in 2016 has as its main focus to create awareness of frailty.

On the experiences of the EIP-AHA Action Group on frailty, Ms Illario informed that much work has been done regarding defining frailty, including the psychosocial dimensions of frailty, and that there are examples of projects supported by the Commission that are delivering results in the field of assessment of frailty. At least six initiatives have been scaled up at regional level and are ready to be scaled up also in other countries. Nine Reference Sites take part in the Action Group, providing a huge added value in how to scale up the deliverables.

On creating *synergies* between initiatives, Ms Tsartsara informed that there is a new scheme favouring synergies within the EIP-AHA. So far, vertical integration is working, but efforts are still needed to ensure horizontal integration. Ms Illario said that the work of bringing together multidisciplinary experts has been one of the major efforts. To increase the capacity for the active involvement of healthcare professionals has been crucial. That many universities participate in the Action Group, creates a momentum of starting to think in a more horizontal and multidisciplinary way.

Discussing *challenges*, Prof De Maeseneer called for a paradigm shift across disciplines and to frame challenges in a new context, especially training, education and continuous professional development are crucial to achieve this. Ms Tsartsara emphasised that the challenge with frailty is that it is not a

disease, but a condition. It is not reimbursed, neither taken care of in primary care or in models for integrated care, and that there needs to be a model developed to produce “spin-offs”.

Ms Segovia on the other hand emphasised that European health systems were created to deal with acute problems, we now need a new vision for the construction of health systems facing the new challenges. Advantages with EU projects dealing with exchange of good practices is to speak with someone from a different country not bound by the national definition of what is right/wrong and free to learn from others.

Regarding *synergies*, a Sicilian representative from the audience pointed to the distance between programmes and policies from different DGs and different groups of experts, as well as the tools to implement them. She said that the structural funds could be better used to align the funds in a connected way to the results of the work being done in the EIP-AHA and the Joint Actions. An Italian survey showed worrying results about a lack of knowledge about the potential to use the structural funds to invest in health and the results of the EIP-AHA. Following this, Ms Garcia-Sánchez informed that the Commission has produced a guide for the health investments through the European Structural and Investment Funds.

It was also pointed out that taking on a broader view on health, involving all actors in a common framework, creating synergies between providers and avoiding goal conflicts are crucial elements. Mr Segovia pointed at increasing the “systems thinking”, adopting a holistic view, appreciating that touching one factor may touch upon many others. He further mentioned that CHRODIS has a Work Package which is focused on multimorbidity, and that it strives to coordinate primary health care with social care.

Ms Illario suggested to think of health service providers as a chain, which would represent a new framework to develop together. This would include developing common tools, a common operability and change management.

Ms Garcia Sánchez informed that DG SANTE are already working on many of the issues raised relating to chronic diseases and frailty, since they have been listening to Member States and other partners for a long time. There is funding available through Horizon2020 for research in these areas that will hopefully provide answers to some of the issues that have been raised.

Ms Tsartsara pointed to the time constraints in adopting effective solutions, since already in five years’ time, the “baby boomers” will retire and the ageing of patients is continuing. Solutions will have to be found by communities as the states might be delayed in adopting efficient policies.

De Maeseneer concluded the session by pointing to the importance of always addressing health inequalities and the social gradient in health. He also praised the approach for a comprehensive and integrated view of health as a beautiful European product.

Panel Discussion: Regional and Local Good Practices on Tackling Chronic Diseases and/or Frailty

The final panel discussion, moderated by Nick Batey, Health Department, Social Services, Wales gathered good practices from the local and regional level in the domain of chronic diseases and frailty.

1. The first presentation was given by **Mirca Barbolini, Governance of Research Unit, Regional Agency for Health and Social Affairs, Emilia Romagna (IT).**
She presented Emilia Romagna’s experience in developing and implementing a population-based model, to predict, identify and manage the risk of multimorbidity and frailty. The model uses a

longitudinal administrative database that was developed as a regional predictive model and was applied to the whole adult population of the region. Risk is calculated on a scale (1-10) and has shown a high statistical accuracy. The information collected include chronic diseases/multimorbidity, pharmaceuticals, specialist visits, hospitalisation, emergency care and adherence to guidelines.

In 2014, 84% of the population were estimated to be at low risk, while 10% at moderate risk, 3.3% at high risk and 2.7% at very high risk.

The results of the model, along with profiles of patients identified as high risk, are provided to the healthcare professionals associated with the Patient Centred Medical Homes, which are local primary healthcare centres. The aim is for the model to help the Patient Centred Medical Homes in planning care management and interventions to reduce the likelihood of preventable high-cost hospitalisations. Privacy of the patients' data is secured through general practitioners only accessing the evaluated risk (whether high/moderate/low) to activate the response.

Ms Barbolini further presented the SUNFRAIL project, where Emilia-Romagna is the lead partner, and where EUREGHA leads the dissemination work package. The project receives funding from the EU Health Programme 2014-2020 and aims to reach an operational definition of frailty and pre-frailty. Here, importantly, not only the biomedical, but also the psychosocial dimension should be considered. The project also aims at sharing experiences, practices and tools to identify and manage frailty and multimorbidity. In concrete terms, the project aims at developing a shared model of good practices on frailty and multimorbidity and a tool kit for the prediction of the same.

2. The second presentation was given by **Anne Hendry, National and Clinical Lead for Integrated Care, Scotland (UK).**
Future care and support from older people in Scotland is defined in the vision "Reshaping Care for Older People (RCOP): A Programme for Change 2011-2021. Between 2011 and 2015, a national improvement programme and a £300 million Change Fund supported the development of health and social care partnerships to enable older people to live at home or in the community through preventative, anticipatory and coordinated care and support, intermediate care to improve outcomes at times of transition and technology to empower greater choice and control.

Ms Hendry emphasised that instead of starting with a national policy, the work in Scotland started from the bottom-up and includes a strong profile of the voluntary sector. Furthermore, 39% of the Change Fund support carers.

The national improvement programme aims at reshaping care pathways through four pillars: Preventative and anticipatory care; Proactive care and support at home; Effective care at times of transition and Hospitals and care homes. There are 32 partnerships composed of the NHS (primary, acute and mental health), local authorities (social care and housing), Third and independent sectors and older people and carers.

Frailty is considered as a real challenge and, importantly, as a continuum ranging from robust, frail, functional limitation, disability to dependency. The potential of reversibility along this scale is central and there is potential to prevent and intervene early.

Within the Joint Improvement Team, the Improvement Network aims at cross-sectoral collaboration to support innovation and to test and spread actions which collectively improve outcomes through virtual meetings, a web platform, themed learning events etc. In these activities, the individual is always at the heart of the conversations.

Ms Hendry also presented Scotland's risk prediction model, the "SPARRA risk prediction tool", which aims at predicting the risk of emergency admissions to hospital. This tool enables developing anticipatory health plans including treatment ceilings and ideas of preferred place of care, which are electronically transferred from primary care to hospitals through a "GP contract".

Ms Hendry concluded by presenting the initial results of the Scottish programme, which include 1300 fewer older people in hospitals every day and two million more days spent at home, 17% fewer older people conveyed to hospital after a fall, and 4000 fewer people than expected in care homes per day.

3. Dave Horsfield, NHS Liverpool Clinical Commissioning Group, Liverpool (UK) presented their experience of developing a tailored telehealth services for the monitoring of patients with chronic conditions and to scale up its deployment within the city.

The cohort of the initiative included 1600 patients over 65 years of age. Some initial results from the patients enrolled in the cohort point to a 23% reduction in admissions, a 20% reduction in costs and an 18% reduction in visits, and there are continued efforts to strengthen the statistical power of these numbers.

Mr Horsfield focused his presentation on lessons learned from the implementation of the initiative, and especially on the initial mistakes made. Some key lessons learned from this experience included:

- Understanding the diverse target population through an insight research to be able to pinpoint the subjects who would benefit from a telehealth intervention. Some patients, especially the very ill, may for instance not be receptive due to other, more acute, issues that need to be resolved first, such as ensuring proper housing and adequate care for their conditions.
- The variety of attitudes among healthcare professionals to work with telehealth must also be taken into account. Importantly, the introduction of telehealth solutions should not be perceived as increasing the workload of General Practitioners and other healthcare professionals.
- Similarly, it was shown more efficient to launch the initiative through the patients, who would then indicate interest to their GPs, rather than starting with the health professionals. This also ensured that patients who took part in the programme were inclined to keep using the system, since they were on board from the very beginning. According to a survey, 91% of the patients indicated to "feel more in control, have gained confidence and/or feel better able to cope with their long-term conditions" and 54% of telehealth users reported a decrease in at least one form of healthcare utilisation (GP visits, community matron or hospital).

4. The final presentation was given by **Maddalena Illario** on **Progetto Mattone Internazionale**, the project supporting the Italian regions in cooperating and sharing resources and tools in the field of health.

The Mattone project started in 2010, and is led by Veneto Region and co-coordinated by Tuscany. The organisation of the project is divided into five pillars (National Training Plans, Database, Communication and Information, Local Training Plans and Internationalisation of Health Systems). The project works on informing and training the actors of the Italian health system on European policies, possibility of inclusion in policy processes and on seizing funding opportunities.

Since the launch of the European Innovation Partnership on Active and Healthy Ageing (EIP AHA), the Mattone project has worked on informing all relevant actors so as to promote the participation of regional and local health authorities. Four of the Italian regions have been nominated as Reference

Sites. Mattone works to promote synergies of objectives, intentions and actions of these regions and to ensure their connection with the other regions and other relevant stakeholders.

In the preparation of the Joint Action on Prevention of Frailty, the Italian regions, through the Mattone Project, joined forces to bring forward their points of view, taking advantage of local experiences and of the work carried out at the technical level of the Italian Ministry of Health. Campania Region, Piemonte, Emilia-Romagna and Liguria were involved in the Joint Action, through the Marche Region since the initial drawing of the project by the Ministry of Health. These regions contributed to the technical work packages, and showed a particular interest in dissemination activities in which they will ask support from Mattone Internazionale.

For the future, Mattone aims at strengthening the expert teams of the Italian regions and local health authorities, consolidate the coordination, support the transposition and application of the directive of patients' rights in cross-border health care and continue supporting the regional presence towards the initiatives of the European Commission.

Discussion

During the discussion that followed, panellists agreed that one of the most important issues to improve care is through training of healthcare professionals. This especially includes ICT training for management and decision makers as the technical level often works ahead of policy development. Interdisciplinary educational training should be put in place so that a goal-oriented approach is promoted across sectors.

On the exchange of good practices, it was noted that getting input from others is crucial and helps organisations evolving. However, the issue is not about just duplicating work, but to take home relevant aspects and lessons learned and contextualise it to the own framework.

On innovation, it was emphasised that our health systems need to be courageous enough to invest in innovation to increase the productivity. A comparison was made to the private sector, where companies are more inclined to invest even if the initial costs are high, since they know that other companies will make the investment if they do not.

To conclude the session, Nick Batey asked the panellists what single advice they would give to the European Commission to facilitate their work. The messages were:

- to invest in human capacity building
- to facilitate knowledge exchange and create opportunities for interregional study visits to see and learn in practice
- to talk honestly about outcomes
- to make sure that criteria for best practices with potential to scale up are clear and evidence-based.

Batey concluded by reiterating the importance to include patients in strategies and their implementation – "nothing about us without us!"

Conclusions

Toni Dedeu concluded the conference by thanking all participants, speakers and moderators. The richness of networks and of EUREGHA lies in the mutual learning and sharing of experiences, as exemplified from today's discussions.