

## CoR INTERREGIONAL GROUP ON HEALTH & WELL-BEING

Topic – Big data and the health sector: the way forward

Thursday 5 July 8h00 – 9h00

Room JDE 60, European Committee of the Regions

### Minutes

#### **Welcome and introduction by the Chair, Birgitta Sacrédeus**

The Chair, Birgitta Sacrédeus welcomed the participants and introduced the topic of the meeting: “Big data and the health sector: the way forward”. Ms Sacrédeus highlighted that the healthcare industry generates large amounts of data and it is now time to learn how to make best use of them in order to protect and promote health for every patient in the EU.

Ms Sacrédeus then gave the floor to Mr Arnaud Senn, Policy Officer, Unit E-Health, Well-Being and Ageing, DG CNECT, European Commission.

- **Management of Big Data: the Future of Health in Europe**

*Arnaud Senn, Policy Officer, Unit E-Health, Well-Being and Ageing, DG CNECT, European Commission*

Mr Senn started by stating that the digitisation of economies and daily life of citizens is one of the main trends of the last decade and a major challenge for the years to come. In the EU, digitalisation raises specific problems, such as the fragmentation of the market (which is more fragmented than in the United States or in China) and issues regarding privacy and data protection. It is now time to address these challenges in order to use digitisation as a springboard for growth, job creation, and improvement of citizens' life. Mr Senn underlined that it is important to keep in mind the demographic trends that lie ahead of us. According to the [2018 Ageing Report](#), the EU population is expected to increase over the next decades, while the working age population is already shrinking, especially in certain parts of the EU. As a consequence, many countries will face workforce shortages in the near future. At the same time, the dependency ratio (i.e. the ratio of the population over 65 compared to the population between 15 and 64) is rising, which brings additional challenges in the field of health and long-term care. All these

problems call for a shift in our healthcare delivery patterns: we will need to shift from acute care to long-term care; from a single-disease approach to the treatment of multiple chronic conditions, to more personalised care and more home-based care.

The European Commission has recently conducted a [Mid-Term Review of the Digital Single Market](#) which also included an EU-wide survey aimed at taking into account citizens' expectations and feelings about health data. The results showed that few citizens have easy access to their own data. In addition, very few hospitals allow citizens to access their own medical records (only 10% actually do grant easy access). As a consequence, exchange of information between health professionals and healthcare organisations is low. All this is due to a lack of secure infrastructures which would make it possible to organise and exchange data across borders so as to advance research and personalised medicine. In order to address all these issues, it is necessary to create a Common European Data Space, which includes the implementation of the [General Data Protection Regulation](#) (GDPR), the new legal framework for data protection in the EU, and increases the commitment of Member States (like in the recently-signed [Genomics Declaration](#)).

To this end, the [Communication on Enabling the Digital Transformation of Health and Care in the Digital Single Market](#) identifies three main priorities around which activities must be developed at local, regional, national, and European level:

- Securing data access and sharing, especially in cross-border cooperation
- Pooling health data for research, faster diagnosis and improved health
- Digital tools and data for citizen empowerment and person-centered health care

Mr Senn also underlined that, in order to advance in digital health, it is important to build on the already-existing regional experiences and mentioned the [European Innovation Partnership](#) (EIP) initiative as a very valuable tool. The EIP focuses on different action groups, each of them focusing on topics of common interest. The initiative has been successfully mobilizing people from the academic community, the civil society, the industry, and regional authorities and got them to work together on different issues with the support of technology. It has mainly focused on how to make best use of health data and technology to the benefit of citizens. Mr Senn pointed out that the EIP is also a very interesting framework to increase regions' visibility.

In addition to the EIP, the European Commission has supported a wide range of innovative projects in the field of digital health. One of the them is the [CareWell project](#) on integrated care. The project has pursued the delivery of integrated healthcare to frail elderly patients through comprehensive multidisciplinary programmes with the support of ICTs in 6 European regions. It has successfully

improved continuity of care, streamlined patients' discharge in transition periods, and improved the way in which applications and software are designed. Another good example is the [Consensus Conference of the Catholic University of Milan on Patient Engagement](#) in chronic diseases tackling the issue of poor observance of treatments with the support of eHealth technologies. Mr Senn highlighted that good and efficient observance is key to effectively monitoring patients in the long run and the project aims to address the following main issues:

- How to define patient engagement
- How to measure patient engagement
- How to promote patient engagement
- What role e-health technologies can play

Mr Senn concluded by saying that citizens have now strong expectations and requests when it comes to digital health which need to be taken into account. He added that, despite the current fragmentation of knowledge, there are already strong regional experiences on which we must build in order to work together in an effective way.

The Chair gave then the floor to regional experiences in the field.

## **2. Regional Best Practices: Health Data Analytics for Research and Innovation of Catalonia**

*Toni Dedeu, Director, Agency for Health Quality and Assessment of Catalonia*

*Ministry of Health, Government of Catalonia*

Mr Dedeu presented the [Programme for Health Data Analytics of Catalonia](#) (PADRIS) for research and innovation. He started by outlining the process which was carried out in order to get a consensus agreement between the different parties: political parties, the public, the citizens, researchers, and many other stakeholders. Since 1980, in order to be able to provide public services in Catalonia, providers have the duty to share their information with the Public Health Insurance (i.e. the Catalan Health Service) and the other providers. They also need to be able to work in interoperability. The Catalan government took the decision in order to centralise all the information in one agency. The HTA agency is the only one able to have access to all the data sets of the Catalan Health System and cross it with data that come from other sources (from the social sector, etc.).

When the process started, in 2013, there was a very serious political reaction: people were frightened about the use of very sensitive data, as they did not know the concept of big data at all. They did not

want to develop a programme which could share their own sensitive information. They were concerned about the possible use of the data. So, the agency started a public debate which lasted for more than three years and brought all the parties together (politicians, researchers, the public in general, the industry, medical societies, patients groups, etc.) in order to address this communication problem and eventually reached a consensus. Mr Dedeu highlighted that one of the key commitments included in the consensus agreement was transparency on what happens with the information provided and how it is used.

Before the programme, researchers needed to collect the data by consulting different sources. Now the idea is to have one single agency which is able to access all the existing data sets. Today researchers, planners, and innovators can go to the agency, present a study research proposal and ask to be granted access to the data they need.

The legal framework of the programme has always been the [General Data Protection Regulation](#) (GDPR), as the regulation was already written when the programme was designed. In addition to the GDPR, if someone has any doubt about the use of health data, they can consult the Data Protection Authority in Catalonia. Mr Dedeu also explained that the programme has an opt-out approach, which means that, unless you state that you don't want to share the information for research purposes, your data will automatically become available. So far only 30 people out of 7.5 million citizens have opted out. Moreover, every study proposal must go through the assessment of an Ethical Committee before being able to access the programme.

Mr Dedeu also underlined that the programme is based on key ethical principles, such as:

- respect for people;
- patient-to-patient solidarity (everyone understands that their own data is a common good for the society as a whole);
- justice (when granting access to anonymised data for research purposes, priority is given to minorities such as research studies on rare diseases);
- efficiency (the programme does not affect the normal budget allocated for healthcare provision)

The programme also has a well-defined governance structure consisting of the Operational Committee of the agency (chaired by Mr Dedeu), an external Monitoring Committee which is accountable to the society for what the programme does, an Advisory Board, an Executive Board.

Mr Dedeu concluded by saying that the programme has demonstrated that, through the use of big data, there is an improvement of the research capacity and care processes which leads to a significant improvement of the health of the population.

### **3. Big Data in a World of Non-Communicable Chronic Diseases**

*Prof Josep Redón, Head of the Internal Medicine Institute, University Clinic Hospital of Valencia*

Mr Redón's presentation focused on the use of big data in non-communicable chronic diseases (NCCDs). Chronic diseases are those diseases requiring continuous management over a period of years and decades and are related to the concepts of multi-morbidity and co-morbidity. The former refers to the concurrent presence of two or more non-communicable chronic diseases with no apparent links between each other. The latter implies that there are well-established links between the different NCCDs. Mr Redón highlighted that age is an important factor in order to establish multimorbidity, as the oldest the people are, the highest the percentage of multimorbidity is. Moreover, NCCDs account for 80% of the total healthcare budget of the EU. Therefore, we are already investing a lot in NCCDs and we risk losing a lot of resources in the future. This is the main threat facing the management of healthcare in the future and the use of big data can help address the issue.

Mr Redón then talked about the potential for big data in the health sector. Big data can help in healthcare management, risk assessment, clinical issues and therapeutics. Moreover, they can be particularly useful for a better understanding, planning and delivering of prevention and care in NCCDs, as they can support many activities, such as surveillance, the creation of a prevention-driven approach, proactive prevention, research and comparative studies (such as the propensity matched score), preventing waste, increasing effectiveness, boosting the use of electronic health records (EHRs) across the EU.

Mr Redón also gave some practical examples of how big data can be used in the health sector to see what is happening in a given population. Big data allow doing multi-layer levels of research by crossing data from clinical data, -omics, and the social sector. In other words, it is possible to get a lot of useful information on the social habits and characteristics of the patient which is not included in the clinical records.

However, the management of big data also faces a number of obstacles, such as:

- Clinical and cultural obstacles:  
with big data we have data-driven, and not hypothesis-driven, research. The best approach in order to make significant progress in research is to combine evidence-based medicine with big

data analytics. In order to do so, however, it is essential to improve the existing infrastructure and architecture of health data, so that healthcare systems can speak to each other. Moreover, physicians also need specific trainings in order to be able to fully harness the potential of big data;

- Legal framework:

the [General Data Protection Regulation](#) (GDPR) has enhanced the individual rights of patients and has underlined the importance of the accountability of the organisation using the data;

- Technical challenges:

The current electronic health records store relevant information but have limited capabilities to perform data analytics or prediction. Moreover, the issue of unstructured data is very important.

Finally, Mr Redón talked about the [Bigmedilytics project](#), an EU-funded project aiming to transform the EU healthcare sector by using state-of-the-art Big Data technologies to achieve breakthrough productivity by:

- reducing costs
- improving patient outcomes
- delivering better access to healthcare facilities

Mr Redón concluded by outlining four main take-away messages:

- NCCDs account for 80% of the health care cost in Europe and the percentage is rapidly increasing;
- Big-data (real-world data) is a valuable tool for improving health care quality, for better planning, and to reduce costs;
- Despite some challenges, a rapid development of the use of big data can bring about important changes;
- The European Parliament should provide a new framework to facilitate cooperation across the EU so as to speed up advances in the health sector.

### **Close of meeting**

The Chair thanked the Committee of the Regions for hosting the meeting and the speakers, as well as the participants.

The next meeting of the CoR Interregional Group on Health and Well-being will take place on 9 October on the topic “Global Challenges, Territorial Answers: the Future of Health in Europe”. The



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meeting will be part of the [European Week of Regions and Cities 2018](#) and will involve high-level speakers and participants. Further information about the event will be circulated soon.