The Digital Health Society Declaration

Introduction and purpose of the Declaration

The Estonian Government will hold the EU council Presidency of Europe from July to December 2017. Its main focus is related to the free flow of data in the European Union, fifth fundamental right of European Citizens, after the free flow of persons, products, services and capital.

Healthcare systems are today transformed by digital technologies, and most of the European policy-makers have defined strategies to implement digital health solutions, even if some barriers are still to be overcome.

The Ministry of Social Affairs of Estonia is thus launching the present **Declaration**, as a **call for actions** about "*Health in the Digital society and the Digital society for health*". This document will integrate inputs from all the stakeholders interested in the development of Digital health, **sharing a vision, between policy-makers, citizens, health professionals, scientists, companies and payers, about the strategies and actions to achieve the digital transformation of healthcare systems**.

A consultation will be engaged widely in Europe from April to September 2017. The final Declaration will be signed by its authors and promoters during the **high-level eHealth conference of the Estonian EU Presidency**, 16-18 October 2017.

The signatory organisations will then form a **permanent multi-stakeholders group** (continuously open to new members), which will, in collaboration with the European Commission, **monitor and measure the tangible progresses[1] related to the digitalisation of healthcare systems across Europe.**

The Declaration will constitute an input for the **EU Council of Ministers** debates and conclusions about Digital health between July and December 2017.

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[1] A list of indicators will be defined by the multi-stakeholders group and will be measured periodically besides case studies and concrete implementation results and examples.

Health empowered by Digital: opportunities

Improving the circulation and the sharing of health data could be beneficial for all stakeholders: citizens and patients, health and social care providers, professionals, policy-makers and institutions, innovative companies, public/private payers and insurers, universities and other research institutions.

In a context of trust, privacy, confidentiality and security, the latest technologies related to data treatment, such as Big data or Artificial intelligence, could benefit existing practices and healthcare services, but could also drive a real transformation of our European systems, supporting a shift from a curative-oriented approach to more prevention (potentially prediction) and better wellbeing for the EU population.

The European Commission has recognised the importance of eHealth and digital innovation in addressing the common challenges that the European health systems face in terms of increasing cost of healthcare and population ageing associated with a rise of chronic diseases and multi-morbidity[2].

Through its *eGovernment Action Plan*, the Commission has declared its support to Member States in the development of eHealth services that also enable cross-border exchanges of e-prescriptions, telemedicine and tele-monitoring solutions. In addition, the Commission will support the development of citizens' digital access to their health data.

Opportunities for citizens and patients

The benefits for citizens and patients from digital technologies cover several dimensions:

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[2] Communication from the Commission On effective, accessible and resilient health systems COM(2014) 215 final (4.4.2014)

- Empowerment and health education: better understanding of the health status (thanks to data) and a continuous monitoring of it, better understanding of the treatments. Access to personal health data and information allows patients to take an active role and it enables them to become managers of their own health throughout their life cycle.

- Inclusiveness and equality: better communication and access to healthcare services and professionals (using several channels physical or digital)

- Personalised health:
    - Innovative treatments and "*patient-centric*" interventions, based on personal data (health, lifestyle, environment…);
    - advices, motivations and incentives in order to improve their health status or change their health trajectory;

Opportunities for health and social care providers and professionals

Digital technologies facilitate the integration of services and an holistic approach of health, combining health and social care services.

Health challenges and stakes have changed since the design of the European healthcare systems. When acute care was a major objective for hospital-centred system, the current health conditions representing the major burden and the main challenges are preventable chronic diseases and ageing-related pathologies. So, when our current system is treating very well an exacerbation of a chronic heart failure, it is unable to anticipate it and deploy the intervention that would avoid it. The use of health data allows our systems to operate a switch from a pure curative model to a preventive one.

Information technology while applied to health and healthcare services can increase the efficiency of service provision such as the optimisation of patient flows, but also the management medical personnel's workload and workflows and the coordination of care.

Opportunities for the research

Health data should also be widely used for research and development in the health sector. Data analysis methods available today allow research to tackle complex issues that were not solvable in the past. Several centres can now share and compare data coming from several centres and countries around a same disease / case, then the scientists and physicians can create stronger models and thanks to correlations, can identify faster innovative treatments. Also, an obvious benefit is related to rare diseases, as sharing data allows the development of new research projects, which were impossible by the past, because of the tiny samples available in one single centre.

Opportunities for business

The potential market for Digital health solution has been highly evaluated recently but it is still not always tangible for all European companies.

European IT sector is highly skilled, employs millions of Europeans and generates growth across the EU. It could benefit from the massive integration of IT technologies in healthcare sector. Number of companies involved in other industries could find here a way of diversification and business growth. It is also the opportunity to create number of innovative and disruptive start-ups.

Moreover, Digital health require innovation across industry sectors and disciplines such as IT (big data, artificial intelligence, data analytics, algorithms...), digital (web techs, virtual reality, games, ...), design, social sciences (behaviour change, psychology) ...

European industry should invest in the Digital health sector, taking into account that the potential market is not limited to the EU, but also the rest of the world, from the Americas (north and south) to the Middle East and Asia.

Opportunities for governments and policy-makers

Governments and policy-makers have the opportunity, thanks to data-driven systems and solutions, to adapt their health and social care systems to the modern challenges (demography, chronic diseases), by switching the model from mainly curative to preventive.

Digital technologies offer also the tools to re-organise the system, improve its efficiency and continuously monitor and pilot public policies for health in a more precise and meaningful way.

Digital health require innovation. By the implementation of innovative solutions, Governments and policy-makers are not considering anymore the health expenditures as a pure cost, but as an investment, fostering the growth of companies by innovation, and supporting the creation of jobs and new businesses.

Barriers to overcome

Preconditions

To enjoy the full potential of innovation in health the free flow of health data within the EU is a fundamental precondition. These data should also be readable and understandable both by humans and by machines. Currently, this is not the case and practices, such as the citizens themselves travelling with their health information and data on paper, USB stick or through e-mail, introduce a number of issues related to privacy, security, confidentiality and safety.

Barriers

The present Declaration and its promoters aims to overcome a number of barriers and progress with the implementation of Digital health in Europe. The main barriers' factors could be described as follows:

Lack of awareness and meaning

Citizens are not well enough informed about the benefits of the use of data for healthcare services or research. A lack of understanding (meaning) often leads to the non-acceptance for sharing data.

Lack of confidence and trust

Citizens should be assured that their data are protected and that all precaution have been taken to guarantee issues around privacy, confidentiality and security.

Lack of interoperability

In order to achieve the free flow of data, health data producers of the European countries and regions should embrace a common strategy regarding the interoperability of data, at the technical and at the semantic level.

Lack of clear legal framework

Related to the confidence and trust, European countries and regions should define clearly the conditions for health data use, based in the citizens informed consent, (indicating which are the characteristic of data that could be used, for which purpose, by what type of stakeholders).

Lack of training for institutions, healthcare providers and professionals

Data will be collected correctly and used in day-to-day practices of health professionals, if specific training are provided (to students in medical/nurses school and to current workforce).

Lack of change management strategy in healthcare systems

As in all sectors, the implementation of digital technologies is not only equipping the on-going work process and organisation. It requires a re-think and re-organisation of the whole system, the role of the stakeholders and the approach for the healthcare service delivery. Digital brings a complete transformation.

Lack of meaningful and integrated solutions

Simple rough and general data information is not impacting behaviours. The citizens need to understand the meaning of each set of data, to have a view on the impact of their actions and choices on their health status and so on. The basic *quantified self*, thanks to all personal devices and wearables currently on the

market, are not triggering the expected behaviour changes, because of the lack of meaningful information and the lack of integration within the healthcare systems.

Lack of innovation in funding models

Lack of money is also often indicated as one of the main barrier factors but it is debatable. If we observe the allocation of resources in the area of digital health, and particularly related to electronic health data deployment at the EU or at the Member States level, we realise that large sums have been or are being invested. The issue seems to identify creative and innovative funding models. Because EU systems are widely based on fee-for-services models, the added-value of data-based systems and solutions focused on integrated care, services quality, prevention and outcomes of the interventions don't find their place in current purchase processes and contracts model. The challenge is then to break down the budget silos between health and social care or between secondary and primary care, to incentivise the stakeholders, to deploy more widely, innovative public procurement models, and new types of contracts, outcomes-based and involving risk sharing between the parties (suppliers-buyers-care providers).

Finding the solutions

The barriers listed above demonstrate that moving forward for the implementation and deployment of Digital health in Europe means to adopt a systemic approach where all part of the system, policy-makers, citizens, health and social care providers and professionals, companies and start-ups, researchers, payers, have to take a role and agree together around the orientations to follow.

The Digital Health Society Declaration aims to bring together all stakeholders in Europe, interested in moving this agenda forward with acting each of them at their level, with a set of actions defined by themselves, but converging all in a common and share vision of the Digital health in the EU.

What should be done at the EU level?

At the EU level, even if the health competence remains the responsibility of each Member State, this common understanding should be formed into an agreement that fixes common components and common infrastructure, that enables the free flow of health data. While common components lay in the grey areas, each Member State has launched projects around the redesign of their systems. An agreement has to be achieved between Member States around interoperability.

While at the EU level the necessary legal framework already exist, such as the 2016 General Data Protection Regulation (GDPR[3]), legal uncertainty still remains. It is due to the large amount of relevant legal provisions in a variety of regulations and directives. It is paradoxical that the legal frameworks content is not the barrier but the format and amount of it has become a barrier. The clarity of these rules and their transparency for EU citizens should also be an objective. While working on reduction, short and simple guidelines for public could be created and made available.

What should be done at Member States level?

Number of European Member States (MS) have already designed their healthcare system in order to digitalise the data. The remaining MS should implement strategies and policies for the creation of electronic health records across their country, in order to stimulate the innovation for health and exchanges capacities with other EU countries.

All Member States should actively seek for a fixed common agreement at EU level in order to develop the common components of the digitalisation of health and social care systems in a coordinated and interoperable way.

As trust is fundamentally an important factor, Member States should review their regulations and legal framework, in order to assure citizens, patients and health professionals that even in a digital format, the patient-doctor confidentiality is still guaranteed. If there is lack of trust the quality of health data is questionable and therefore the use of this dada is problematic as it can result in faulty outcomes.

Member States should also raise awareness of the society through communication campaigns, targeted to citizens but also to health and social care professionals, about successful existing eHealth solutions and their results.

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[3] http://ec.europa.eu/justice/data-protection/reform/files/regulation_oj_en.pdf

What could be done by patients' organizations?

Promote that patients are and should always be the centre of healthcare. New systems created, decisions made should all be from the patients' perspective.

Make it clear that patients are aware of the possible value that can be created for them by using electronic health data. The value added can be better quality or new technical solutions or entirely new health, healthcare, social or integrated services.

Demonstrate that patients are already using technology such as various apps for monitoring and/or improving their health; a number of patients are progressive, responsible and volunteers in their use of technology, and are ready to become "Data donors". EU governments should be at least on the same level.

Demonstrate that patients are familiar with the need of using their health data not only for their own but for public interest (research) and willing to accept it as far as in the process the privacy and integrity of the patients is guaranteed.

What could be done by health and social care professionals organisations?

Promote the belief that, thanks to big data and artificial intelligence technologies, having access to more relevant and pre-analysed information about patients' condition helps health and social care professionals to make better decisions. The free flow of health data within and across Member States borders breaks down barriers, for instance if the treatment of a patient needs to take place in more than one health institution. Therefore, treatment can be faster, less tests and analyses need to be taken as the ones taken can be reused

However, care must be taken to protect professionals time, more and more information can actually be a problem unless data management tools convert information overload to meaningful data to support professional decisions.