

Redesigning health in Europe for 2020



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Luxembourg: Publications Office of the European Union, 2012

ISBN 978-92-79-23542-9 doi:10.2759/82687

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Printed in Belgium

PRINTED ON RECYCLED PAPER

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Demography is one of the few areas of social science where we can predict the future. We know how many old and retired people Europe will have in 8, 28 or 48 years, as well as how many people of working age we will have to support them. In this regard, the future in Europe, barring any extreme developments, does not look good.

Europe is aging, the proportion of the elderly in our countries is increasing, due both to fewer children as well as increased life spans. How can we ensure that European healthcare in the future will be affordable, will not burden our economies and at the same time keep up with the latest advances in medicine? Moreover, in a Europe of increasing mobility, how do ensure that patients can be assured the highest quality of healthcare everywhere in the Union?

We know that in healthcare we lag at least 10 years behind virtually every other area in the implementation of IT solutions. We know from a wide range of other services that information technology applications can radically revolutionise and improve the way we do things. We know as well, from innovative approaches already used around the EU, that many solutions to the impending crisis in healthcare already exist. In other words, by implementing IT solutions to preventative and ongoing healthcare we can make life better for patients, indeed for all who require our healthcare services.

The following report outlines the Task Force's conclusions regarding the key issues faced by a fundamental re-organisation of healthcare to make use of already existing information technologies. These solutions are often not medical at all, but rather deal with how in the future we will need to treat data, privacy, research as well as the physician/patient relationship.

Since not only EU citizens but also their data move across borders, we require an EU approach, where we harmonise our legislation so everyone can operate using the same rules. If we fail to do this, we can rest assured that other solutions will be found, either mutually incompatible national rules or private sector initiatives, where our fundamental rights may not be guaranteed.

The task we face is to ensure that in the future all EU citizens have access to a high level of healthcare, anywhere in the Union, and at a reasonable cost to our healthcare systems. To do so, we must make use of solutions offered by information technology already today. This, ultimately, is the fundamental conclusion of the Task Force's report, **Redesigning health in Europe for 2020**.

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In 2020 the health and health care of our citizens could look quite different. We find ourselves today on the threshold of a new era with many opportunities for radical improvements in the way we manage and receive health care. In order to ensure the sustainability of our health care systems, there is a need to tackle considerable challenges.

This report focuses on how to achieve a vision of affordable, less intrusive and more personalised care. Ultimately, increasing the quality of life as well as lowering mortality. Such a vision depends on the application of ICT and the use of data. The Task Force behind this report was convened to explore the potential of ICT in health innovation in the EU and make recommendations on what could be done now to ensure that Europe reaps the full benefits of eHealth in 2020.

Today, healthcare costs in Europe are climbing. Healthcare is a constantly growing component of public finances, rising to 9 % of GDP and representing between 6% and 15% of government spending in most EU countries. These costs are driven by demographic changes, a dramatic increase in chronic conditions linked to unhealthy lifestyles, expensive new technologies and products, the need for more specialised skills and the demand for high level care (Graph 1).

As Europe ages, the older population will be living with several health conditions which need ongoing monitoring and management. Chronic disease, already 80 % of the disease burden, continues to rise – driven by the explosion in unhealthy lifestyles in recent decades. Not only is the need for health and social care increasing exponentially, but patients are more demanding about the care that they receive. Over 100 million citizens, or 40% of the population in Europe above the age of 15, are reported to have a chronic disease; and two out of three people, who have reached retirement age, have had at least two chronic conditions⁽²⁾. Moreover, it is widely acknowledged that 70% or more of healthcare costs are spent on chronic diseases⁽³⁾. This corresponds to 700 billion EUR or more in the European Union and this figure is expected to rise in the coming years.





 Source: Commission Services, EPC http://ec.europa.eu/economy_ finance/publications/publication14992_en.pdf

(2) European Chronic Disease Alliance; WHO Europe

(3) See http://www.oecd.org/dataoecd/43/9/48245231.pdf and "The future of healthcare in Europe", The Economist Intelligence Unit Limited 2011 (http://www.eufutureofhealthcare.com/sites/default/ files/EIU-Janssen%20Healthcare_Web%20version.pdf) Adding to this, are the fertility and mortality projections made by Eurostat stating that by 2060 the EU population will be both slightly bigger and considerably older than today. Most critically, the working age contingent – main contributor to the social protection systems – is projected to fall dramatically, whilst the share of elderly (65+) and very old (80+) population is projected to grow (see Graph 2). Furthermore, the ongoing economic uncertainty brings into sharp focus the fact that current healthcare models are financially unsustainable.

Thus, health systems may have been the pride of European democracies but they have not evolved to respond to the modern environment and are no longer fit for purpose. Indeed, European health systems are large, unwieldy and highly fragmented. Change is hard to achieve because stakeholders with vested interests protect their own turf. Health services are largely still configured to respond to the health threats of the mid twentieth century by providing acute care in expensive institutions. The power in healthcare rests with service providers rather than users and there is a lack of transparency in the way that the system operates.

A **radical redesign of health** is needed to meet these challenges, integrating health and social care services configured around the needs of the patient. Technology can help health systems to respond to these challenges, by delivering greater efficiency, lower costs and better health outcomes. However, healthcare is a decade behind most other sectors in adopting

and using information technology tools and much of the innovation is being developed outside the healthcare system.

In terms of data production, the landscape is changing dramatically – from the amount of data produced, who produces it to the way it is stored and used. According to CSC, "experts point to a 4300% increase in annual data generation by 2020"⁽⁶⁾.

Finally, recognising that change is driven by public demand for something new and better, a supportive legal framework and the market opportunities to cut costs and make money, this Report sets out what needs to happen for these three elements to converge. Using the common thread of health data, we highlight 5 levers for change and 5 recommendations for action which address the broader environment for eHealth.

The **first section** of this report describes the five levers that could create the momentum for change in health, setting out the preconditions and benefits for different groups of stakeholders.

The **second section** highlights five recommendations for action in order to achieve the vision of eHealth in 2020. The recommendations for action are addressed primarily to policymakers at the European and national levels. All stakeholders gain through the use of eHealth although the impact differs for each category of stakeholder and the benefits may be direct or indirect (see Annex II).

The **Annexes** to this report provide explanatory tables for preconditions and benefits, some examples of good practice and innovation, and a list of terms relevant for eHealth and key EU actions on eHealth⁽⁷⁾.



Graph 2: Impact of the demographic change -15-64 years⁽⁴⁾ and 65+ population⁽⁵⁾ (2010-2060)

(4) http://epp.eurostat.ec.europa.eu/NavTree_prod/NodeInfoServices ?lang=en&nodeId=102863 and http://epp.eurostat.ec.europa.eu/ NavTree_prod/NodeInfoServices?lang=en&nodeId=93332

(5) http://europa.eu/rapid/pressReleasesAction.do?reference=STAT/11/8 0&type=HTML (6) Data from CSC, Website accessed 13/04/2012: http://www.csc.com/ insights/flxwd/78931-big_data_just_beginning_to_explode

 (7) the annexes are available at: http://ec.europa.eu/information_society/activities/health/policy/ ehtask force/index en.htm

Section 1

eHealth in 2020 – 5 levers for change

This section presents 5 levers for change – each of these levers are interconnected and build on each other. The starting point is enacting individual ownership of personal health data. Releasing the data from different silos throughout the health and care system and connecting to the vibrant digital environment for health information will transform the landscape of health. The principle of ensuring that all citizens can use and benefit from eHealth will create opportunities for innovation.

Lever for change #1: My data, my decisions

Individuals are the owners and controllers of their own health data, with the right to make decisions over access to the data and to be informed about how it will be used. This principle is outlined in EU law and European jurisprudence but is rarely fully implemented in health systems. This represents a shift in the power relationships within healthcare; away from the unrestrained authority of the medical professional and towards a more collaborative partnership with patients taking on a greater responsibility and more active role in managing their own wellbeing. To manage their new responsibilities, users need not only to understand the possibilities of such eHealth tools but they also need to feel that they have control over how they interact with them.

There are different ways of dealing with these new scenarios of individuals owning their own data. One possibility is the shared ownership between the patient and the health system depending on the use; i.e. patients as owners of personal health information but allowing the health system to use depersonalised or 'pseudonymised' data for epidemiological purpose with or without requiring additional consent. Existing models of positive and negative consent from the fields of bioethics and organ transplantation could be a template for consent for processing personal data.



There is a rapidly growing market of online applications and social media tools for health, with little focus on the issue of ownership and protection of data. Currently most online activity takes place on commercially developed platforms that are free for users. They set weak privacy settings by default to facilitate posting and sharing information. These generate revenue using the information posted to sell goods and services. Companies pay a premium for access to consumers through such sites because they are able to target them so specifically thanks to the detailed information provided. This question of who owns the information put on social media sites is critical as there are growing concerns about privacy.

The main preconditions for this lever for change are trusted, accepted and interoperable data collection and management, established by policy makers, professionals, and service providers; clarity on data safeguards by regulators and on data use by service providers and researchers; no penalties for sharing by payers and insurers while ensuring non-discrimination and privacy for citizens; understanding of the benefits by all stakeholders.

The main benefits from this lever for change are above all for patients who are empowered to manage their own health – if they wish – and get personalised treatment. Policy makers and insurers can increase efficiency. Health professionals, service providers and researchers should improve the quality of their decision making with more and better data.

Important issues to consider:

Safeguards – How can privacy be maintained and patients' rights protected as health data is processed? What data confidentiality and security measures should be used? What rules should apply for data management and ownership if a company is sold or becomes bankrupt?

Transparency – How will health data be collected, monitored, aggregated, shared or sold? How to ensure quality standards in the use of data? What is meant by informed consent for different uses of health data? Health data has financial value, how to balance personal benefit and public good?

This lever for change is supported by Recommendations I, III and IV.



Data can be compared to oil: In the ground it is unusable and worthless. Extracted and refined, it has huge value. Large amounts of data currently sit in different silos within health and social care systems. If this data is released in an appropriate manner and used effectively it could transform the way that care is provided.

Governments should ensure that health data is robust (accurate and reliable), gathered in a standard way, anonymised and then made freely available to anyone that can add value to it. This 'open data' approach encourages many entrepreneurs to innovate rather than creating a monopoly or market domination by a few service providers. There is good evidence that liberated data can generate cost savings for healthcare as well as employment and skills. Our view is that governments should require all institutions within health and care systems to publish their data.

One of the major expenses that dominates health budgets is hospital care which is expensive and not well suited to ongoing managing of chronic disease. Healthcare reforms seek to shift patient care back into homes and the community, redefining



pathways for general care and urgent care. eHealth tools such as telemonitoring, remote health services and self monitoring will be important in reducing the burden on hospitals. Fully integrating data management tools with provision of care services is essential Transparent reporting of the data leads to greater trust in the health system and allows the managers to focus on where improvements are needed and opportunities to deliver more efficiently. An improvement of just a few percentage points in the management of chronic conditions would fully cover the cost of collecting, aggregating and releasing anonymised data.

The main precondition for this lever for change is that regulators and policymakers to require institutions to publish their data; for professionals and service providers to ensure robust data, gathered in a standardised way, integrated with care services, and made available to researchers with the informed consent of citizens and patients – the owners of the data.

The main benefits from this lever for change are from accelerated innovation and increased scale (from standardisation) and spread across all actors in the form of lower costs, integrated services, rich data flows for research and policy making, new services, more choice through more competition, better and more evidence. Citizens and patients will benefit from health being more 'user' focused and availability of new drugs and treatments.

Important issues to consider:

Quality of data – Data needs to be collected in a standardised way so that it can be comparable and usable, e.g infection statistics in hospitals, outcomes per surgeon or intervention. Much health information is already produced in a standardised way for submission to public bodies (surveillance authorities etc)

but there are gaps, inconsistencies and quality issues. In a new culture of transparency, quality levels will need to be higher and flaws in data will be more visible.

This lever for change is supported by Recommendations I, II and III.



The digital environment is growing and evolving rapidly with an increasing trend of interaction and sharing. The popularity of online networking and social spaces has created a parallel digital existence for millions of people. Each person is the publisher of their digital life stream, adding their own content and curating information submitted by others individuals, institutions and applications The plethora of available data can be used by individuals to monitor their physical and emotional wellbeing and share it with others. Much of this data will be geo-tagged, making it extremely valuable for public health surveillance and epidemiology.

The question is how will official institutions engage with these digital life-streams? The multiple public services would need to access, and be accessible via, the life-stream. For example, population services (birth, marriage, death, ID cards), education, policing and justice services, health and welfare services. Interfaces would need to be designed to allow citizens to interrogate central databases, submit information and request services. The health sector has been slow to adopt new communication tools for a variety of institutional, economic and personal reasons. However, patients will increasingly demand that their health professionals and institutions use the

