

eHealth Task Force Report

Redesigning health in Europe for 2020



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Foreword



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***.

Toomas Hendrik Ilves
President, Estonia

A handwritten signature in black ink that reads "Toomas Hendrik Ilves".

Chairman of the EU Task Force on eHealth



Introduction

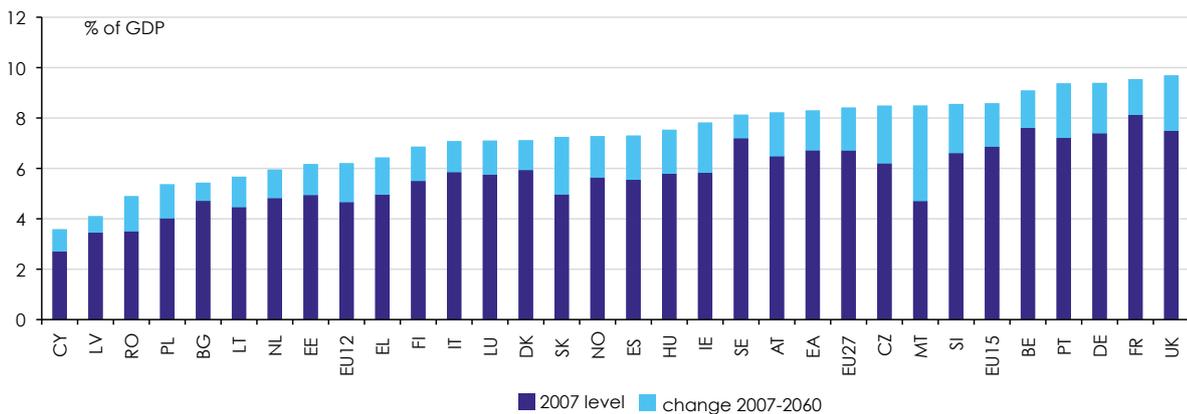
In 2020 the health and health care of our citizens could look quite different. We find ourselves today on the threshold of a new era with many opportunities for radical improvements in the way we manage and receive health care. In order to ensure the sustainability of our health care systems, there is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



Graph 1: Impact of the demographic change on public expenditure on health care (% of GDP, 2007-2060⁽¹⁾)

(1) 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.

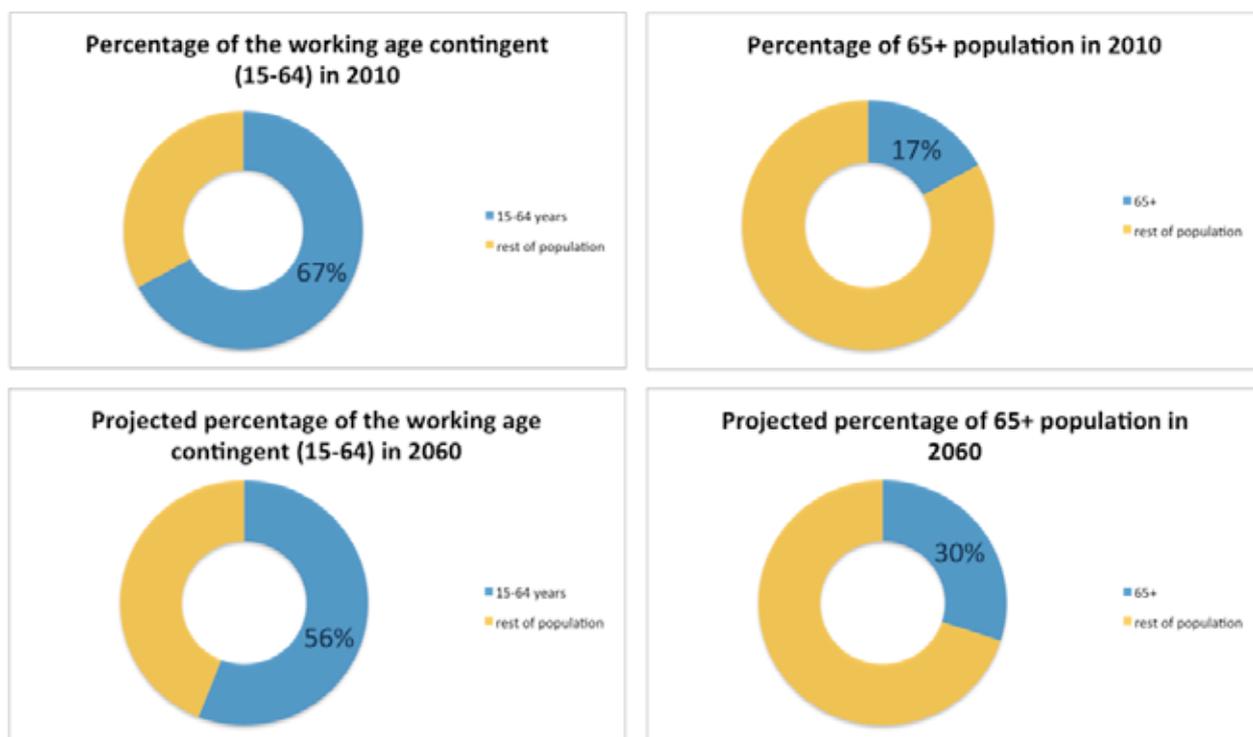
In terms of data production, the landscape is changing dramatically – from the amount of data produced, who produces it to the way it is stored and used. According to CSC, “experts point to a 4300% increase in annual data generation by 2020”⁽⁶⁾.

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/11/80&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

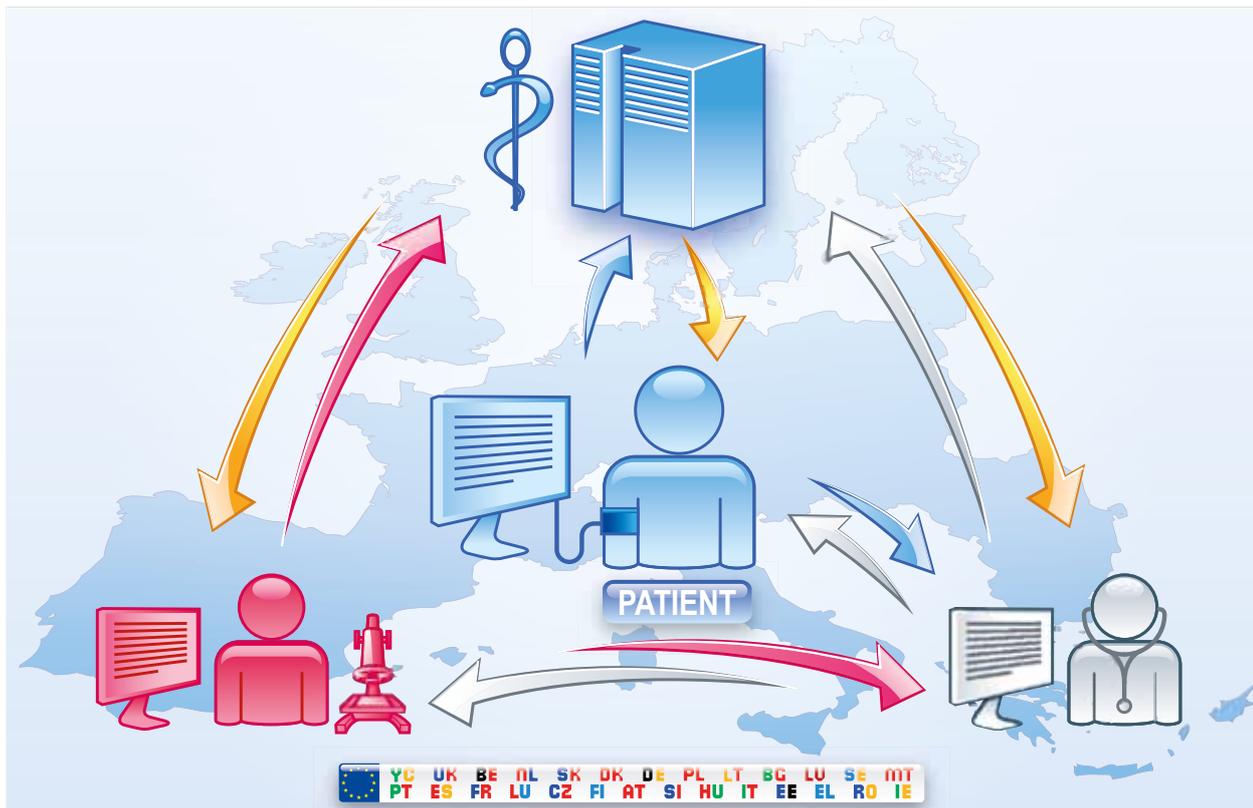
This section presents 5 levers for change – each of these levers are interconnected and build on each other. The starting point is enacting individual ownership of personal health data. Releasing the data from different silos throughout the health and care system and connecting to the vibrant digital 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.

This represents a shift in the power relationships within health-care; 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.

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.

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 de-personalised 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.

Lever for change #2: Liberate the data

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)

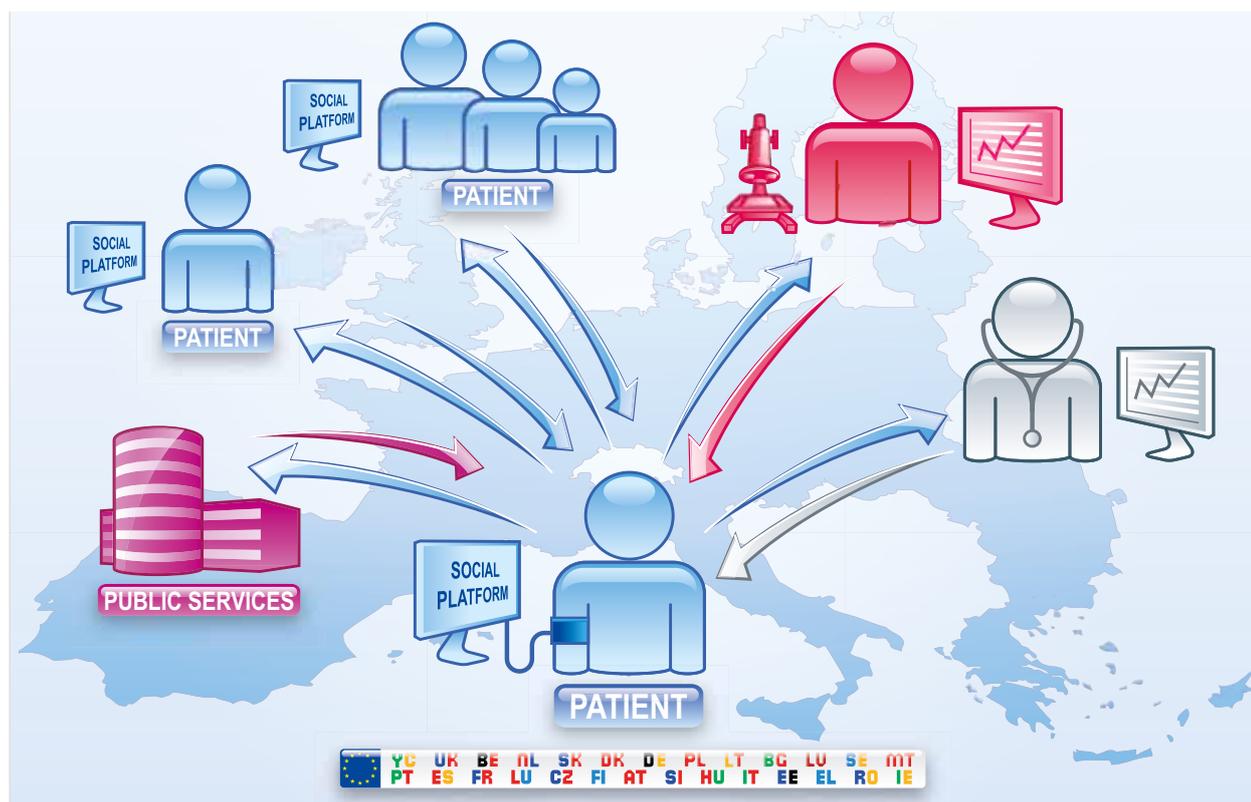
but there are gaps, inconsistencies and quality issues. In a new culture of transparency, quality levels will need to be higher and flaws in data will be more visible.

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

Lever for change #3: Connect up everything

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



same ubiquitous technology they use in everyday life, such as multi-platform apps.

In general, new consumer products and services are developed to match the needs and interests of consumers, and framed by their understanding of what is valuable and useful. In contrast, in the health sector, decisions are made around the needs of the system itself and the interests of health professionals.

On the one hand, the difference between medical information and lifestyle information is getting increasingly blurry. On the other hand, monitoring done at home is an increasing source of data – measuring blood pressure, tracking food intake, physical activity or other behavioural choices. This is relevant for health, but there are questions about how medically, legally and ethically to integrate this user-generated data into the body of health information collected by medical professionals.

This user generated data can also be used for epidemiology and behavioural studies as well as improved care for individuals.

The main preconditions for this lever for change are that policymakers and regulators provide for open access to public services and require minimum standardisation and safety of health apps that serve interest in citizens' and patients' generating information; for clinicians, care professionals and service providers to appreciate and incorporate such information into health decision-making and treatment plans.

The main benefits from this lever for change will accrue to citizens who will receive support for continuous health treatment and healthy living rather than only interventions. Throughout the health 'chain' all other actors can benefit from more accurate and personalised care, reduced waiting times

and waste, sharing best practice and greater emphasis on prevention.

Important issues to consider:

Lifestyle vs health – where is the boundary between lifestyle information and health information?

Quality – Who sets the quality and technical standards for user generated health information? How do health professionals and institutions trust and use health data collected by users?

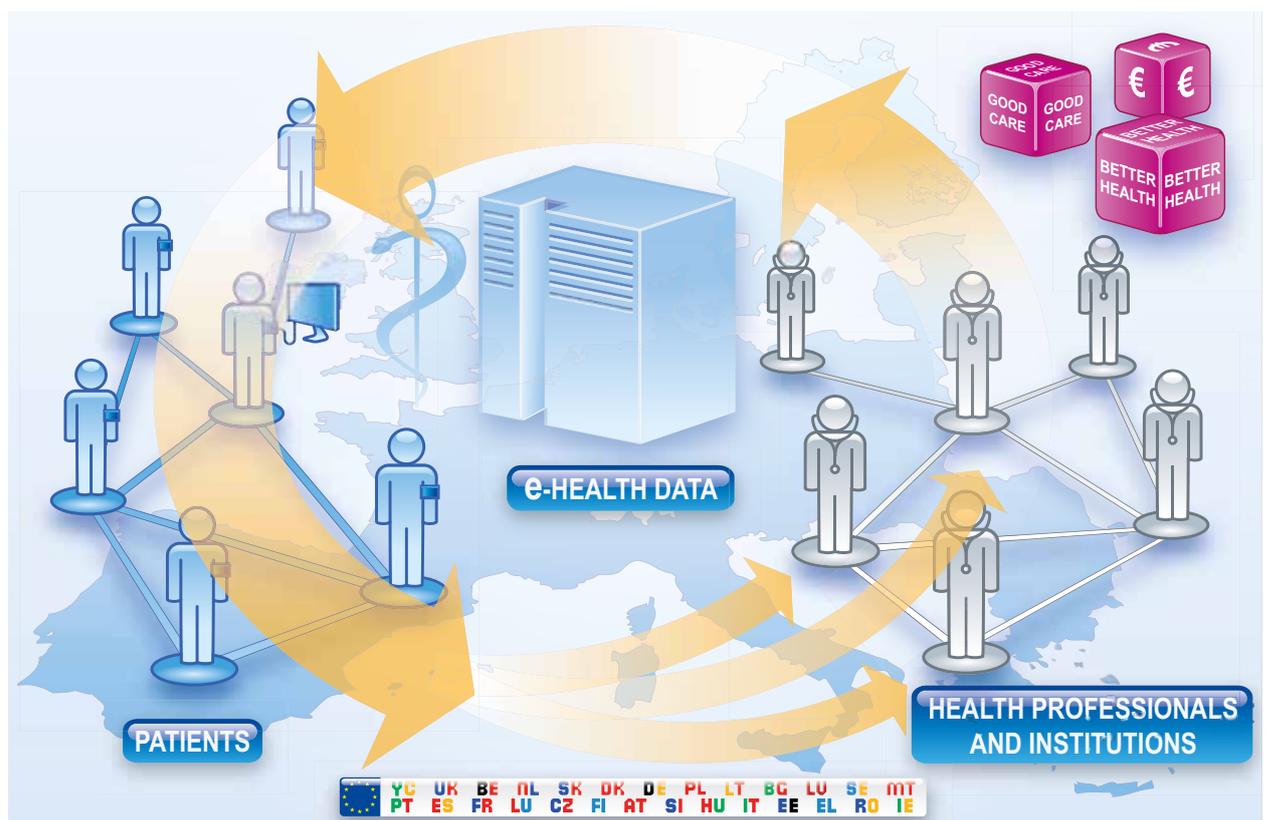
Ownership – Who owns the information put into health apps and how is it used?

External interoperability – how open can eHealth systems be to other applications and programmes, while ensuring security of transactions within the health sphere?

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

Lever for change #4: Revolutionise health

Full transparency will unleash disruptive innovation across the health sector. Armed with data about the performance of health professionals and institutions – and how these differ from one another – patients will be able to make more informed choices about where and how they want to be treated. This will have real impact on resource allocation in health, as funding follows the patients. This bottom-up process contributes towards an enabling environment for eHealth and will be the momentum driving the pace of change.



Resistance from existing providers and health professionals can be overcome if there is consistent public pressure for transparency and accountability. Service providers used to operate within the existing health systems need to understand the new culture of transparency and appreciate the benefits of adopting eHealth technologies so that they are motivated to invest in change.

As pointed out previously, demarcation lines between the health sector and other sectors will become increasingly blurred. The social care and welfare sectors will need to be integrated with health, providing seamless services for patients. This is part of the paradigm shift in power relationships that has already begun: patients are researching their health conditions, gaining insight from other patients and are increasingly demanding a more equal partnership with clinicians. Experience shows that once people get access to information and experience transparency, it is very hard to withdraw it. Transparency is also conducive for good administration of the health system (See *Charter of Fundamental Rights: right to good administration*).

The main preconditions for this lever for change are the commitment of regulators and policy makers to radical reconfiguration of the health system as well as clinicians and care professionals accepting an erosion of their primary leadership of healthcare, the willingness of payers and insurers to provide financial incentives; and empowered and knowledgeable patients taking greater responsibility for their own health.

The main benefit from this lever for change is that good, multidisciplinary care will be well recognised and delivered. Citizens and patients will be empowered to actively participate in managing their own health; clinicians and care professionals

will provide integrated, community based care; funding will be allocated to institutions that provide good care with better return on investment; health outcomes will be better monitored; decision-making and resource allocation in health will be based on stronger evidence.

Important issues to consider:

Transparency – What are the minimum transparency requirements for stakeholders in the health system?

Awareness and understanding – How to create momentum for change by ensuring that patients understand and receive the benefits of transparency?

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

Lever for change #5: Include everyone

People in unequal societies have poorer health, as the WHO Commission on the Social Determinants of Health revealed. Within and between EU countries there are entrenched health inequalities that result in differences in life expectancies of up to 15 years between the wealthy and the poor. Those without the skills, capacity and opportunity to use eHealth risk being further excluded. New ICT tools have the potential to reduce these inequalities but they need to be designed to actively promote and enhance equity. This means ensuring that rural communities have access to services and that products are usable for patients with a diverse range of literacy and technical abilities.



Service providers need to be aware that there may be sub-groups of the population that are outside the reach of eHealth tools – those without access to the internet / computers and individuals that choose not to interact intensively with technology. These ‘vulnerable communities’ and their needs need to be accommodated, because if not carefully planned, eHealth could disenfranchise rather than empower. Ensuring such accommodation will be the role of the safeguards built into the system.

The main preconditions for this lever for change are political and regulatory commitment to reduction of health inequalities; with professional, providers, and payers ensuring no discrimination in provision of care, equity of access and in using eHealth tools; and citizens and patients having understanding health and having basic IT literacy.

The main benefit from this lever for change is improved health status. This includes availability of a greater range of treatment options for complex health problems, better resource allocation, better understanding of barriers to good health, improved involvement of patients and citizens in self care and improved health awareness.

Important issues to consider:

As data management becomes more central to the eHealth vision, ethical concerns need to be addressed:

How to balance individual rights? – Due to rapidly evolving areas of research such as genetics, a societal debate on how to balance individual rights (e.g. such as the right to know about genetic profiles and the right not to know) will have to be further considered.

How to prevent discrimination on the grounds of genetics? – The new legal frameworks will need to ensure that health information does not become a new way of excluding population groups.

How to ensure health inequalities are not exacerbated through technology? – Consumerisation of health, with the emphasis on lifestyle choices, excludes those with chronic or genetic conditions whose opportunities for choice are more limited.

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

Summary Table of the levers for change

Stakeholder group	My data, my decisions	Liberate the data	Revolutionise health	Connect up everything	Include everyone
	<i>Patients and institutions share their data, flexible consent mechanisms</i>	<i>Health outcomes and performance data freely published with full transparency</i>	<i>Technology and information management drives the pace of change</i>	<i>Link lifestyle data with health data, lots of new apps and tools from entrepreneurs</i>	<i>Contribution to and benefit from eHealth for all</i>
Citizens and patients	High	High	High	High	High
Regulators and policy makers	Medium	High	Medium	Medium	Medium
Clinicians and care professionals	Medium	High	High	High	High
Payers and insurers	Medium	High	High	Medium	Low
Service providers and managers	Low	High	High	High	High
Researchers	High	High	Medium	High	High

High:

if the preconditions were met and this lever utilised, there would be a high-level impact on the stakeholder group.

Medium:

if the preconditions were met and this lever utilised, there would be a medium-level impact on the stakeholder group.

Low:

if the preconditions were met and this lever utilised, there would be a low-level impact on the stakeholder group.

Section 2

Recommendations for action

These recommendations for action are designed to support the five levers of change in order to realise the vision of health in 2020.

Recommendation I: A new legal basis for health data in Europe

Most urgently, the Task Force calls upon policy makers to act quickly (while they still can) to create a **legal framework and space** to manage the explosion of health data. This needs to put in place the **safeguards** that will allow citizens to use health apps with confidence that their data is handled appropriately and subsequently it will **create the conditions for the integration of user-generated data** with official medical data so that care can be more integrated, personalised and useful for patients.

The terms and conditions of the new applications and tools collecting data are being set by the providers and there are inadequate safeguards and protections for such sensitive data. Legislative frameworks are not yet ready for the explosion of data as new applications allow individuals to monitor physical and mental wellbeing. Most current approaches to health data involve using it for a single care process and then storing it.

The fear is that, if this framework is not set by governments, within a few years public authorities will have to negotiate with commercial companies that have created the popular tools. Such scenarios are already taking place with personal data. Global companies like Facebook or Google are making their own rules. There is a brief window – probably the next 5 years – within which EU policymakers have the opportunity to set the rules. The legal basis could use the enhanced cooperation mechanism between Member States as set out in the Lisbon Treaty or it could be a new Treaty as the Schengen and Prüm agreements.

The legal framework needs to set out different types of health data and their uses. Principles are needed to ensure mutual compatibility of data (i.e. a set of rules how data is defined and

exchanged between applications) and safeguard measures for security and privacy.

The rapid success of social networking tools show that individuals are prepared to both provide large amounts of personal information and give away ownership of such data. Most individuals are largely unaware – or not fully aware – of the implications of their decisions. Sharing health information raises a different level of complexity: new tools provide unique opportunities to monitor health in real time in real life situations but increases the stakes for issues of data confidentiality and the need for robust security measures. There are already tens of thousands of health or medical applications for smart phones.

There are currently no quality criteria for these applications, no standards for data management and provision of information for consumers. In this area, users need to be better educated about the risks and informed about their rights. Companies that host the data need to operate within appropriately defined legal and financial frameworks. There needs to be transparency on how data is monitored, aggregated or shared and whether it is portable between devices and applications. Additionally, there is the question of what happens with the data if the company is sold or goes bankrupt and who owns it. If the data is stored outside the jurisdiction of the EU there may be an additional complication. These are all areas that will need attention in order to build trust and reliability into an eHealth system.

Recommendation II: Create a 'beacon group' of Member States and regions committed to open data and eHealth

Each country has a very different culture and way of organising their health system. There is no unique eHealth model that can be imposed across Europe, but the experience of others can be shared and the lessons learned. This means transferring knowledge rather than solutions. The EU facilitates this by creating the central space for national initiatives to flourish and be shared. Successful models developed in different regions or

countries can be disseminated. A leadership group from regions and countries that have invested in eHealth applications (such as Denmark, Sweden, Estonia, Spain) could be pioneers. The EU could facilitate such a group and finance experts who can evaluate eHealth projects from inception to delivery.

Public sector innovation can also be stimulated by the availability of relevant data. Data sharing can generate new business opportunities for public authorities that have invested in eHealth. Member States seeking to compare their health outcomes and the performance of their health sector with others across the EU could contract expertise from countries like Estonia that have established their advanced data management tools. If Europe finds ways of delivering health and social care more efficiently, then there could be a valuable market for European service providers in countries like Japan with similar demographic situations and emerging economies such as China, Russia, Brazil, India etc with growing health needs of their older populations.



Recommendation III: Support health literacy

As doctors are no longer the sole arbiters and interpreters of medical information for patients and as patients are playing a more active role, health data thus needs to be translatable into information that citizens understand. In eHealth, as in banking, education efforts have focussed on professionals but missed the opportunity to empower patients/citizens. Health literacy efforts should begin in school, in Portugal it is an element in the core curricula as part of citizenship education.

Indeed, citizens can only exercise control over their own data – and subsequently use the data – if it is both in an understandable language and format with user friendly interfaces.

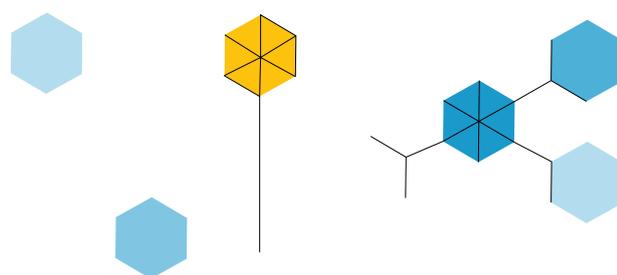
Furthermore, if people are aware of how their data, appropriately anonymised or pseudonymised, could contribute towards new knowledge in health and improved quality of health services, they will probably be more willing to allow their data to be integrated into a central system. Health literacy will help to develop this public awareness about the value of data and how it can be used as well as the broader issue of individual health rights and responsibilities. Greater access to their own data for patients should be combined with a request that patients allow such anonymous or pseudonymised secondary use. This is currently not permitted in some European countries.



Recommendation IV: Use the power of data

Data often sits in silos in primary, secondary and tertiary health institutions. This silo mentality mirrors the way that health professionals guard their own competence and areas of expertise. In the new era of eHealth, this has to end. Multidisciplinary teams of different actors, not all of whom are healthcare professionals, are part of future picture of health. Currently there is a sharp divide between 'official' medical data and the wealth of other health information generated by users that is not used for care. We need to find a way of making this data more trustworthy. The key question is what people do with this information and how they can use it. New rules are needed to define how to integrate official data and user data to create a more holistic picture of patient situation for health care as well provide early feedback for preventive care. Certification of applications is one way forward but it should be based on a set of principles for how health related data should be treated rather than regulation.

Health institutions must publish the data on their performance and health outcomes. This information should be regularly collected, comparable and publicly available. This will support a drive to the top as high performing organisations and individuals can be identified and used as an example to inspire change. In health, performance is not just how efficiently the system operates but also the patient experience of the care. Publication of such data in other sectors has led to strong public demand for better performance and a greater focus on accountability and results.





Recommendation V: Re-orient EU funding and policies

User driven innovation in health is happening in many categories of health whether this may be monitoring of symptoms, enhancing wellbeing and/or supporting behaviour change through gaming and other entertainment approaches. These new tools emerge as new market opportunities are spotted and filled. The majority of public funding at EU and national level allocated to eHealth has been invested in centralised, large-scale, top-down solutions. These have failed to address and integrate the user experience sufficiently. The next phase should see investment in tools that citizens can use to support their wellbeing and manage their lives.

Entrepreneurs and innovators need a level playing field and seed funding to test out new ideas. EU funding mechanisms with their multi-annual frameworks are too slow and bureaucratic. Specific budget lines are needed. These need to be agile, responsive and should foster the develop of good ideas into fast prototyping and testing.

For many EU countries, the main source of predictable finance for health investment in the coming years is the EU Structural Funds. Such financing should not only be used to create infrastructure and IT tools but also contribute towards the broader eHealth framework. Some issues need to be addressed at EU level such as catalogues and nomenclature, data standards, etc.

This would avoid duplication of effort at national or regional level and allows authorities to set the standards and then facilitate uptake by stakeholders.

If enacted the five recommendations will support the five levers for change and create the conditions for eHealth to transform healthcare.

The five recommendations for action are summarised in the table below.

Recommendations	Suggested Actions
I: A new legal basis for health data in Europe	Move quickly to create legal clarity on the pan-European use of health data, establishing strong safeguards and providing a stable market environment to encourage innovation. This should set out the different uses of data and an updated framework approach to informed consent.
II: Create a 'beacon group' of Member States and regions committed to open data and eHealth	Public authorities (national or regional) that have advanced eHealth activities to create a 'beacon group' for rapid progress. This group can provide leadership and inspiration for other EU countries and third countries. The EU can facilitate learning and exchange of experience, promoting the uptake of proven technologies and sharing the results of new initiatives.
III: Support health literacy	Increase public understanding about the opportunities of eHealth to monitor, measure and manage their wellbeing. Raise awareness of what data is collected, the different ways that it can be used and the benefits for the individual and the health system. Provide mediators and skill building for vulnerable groups.
IV: Use the power of data	Create a culture of transparency in health Benchmarking and monitoring performance of the health system. Encourage the integration of data into large European data sets and enhance access for researchers. Closer integration between research and health practice.
V: Re-orient EU funding and policies	Require transparency from institutions in health systems through procurement and funding criteria. Earmark EU funds for user driven innovation, support for fast proto-typing and low threshold to access.

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