

## **eHealth Task Force Report**

# **Redesigning health in Europe for 2020**

**- Annexes -**

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## Annex I: The main preconditions and benefits for the levers of change

### 1) 'My data, my decisions'

Stakeholder group	Preconditions	Benefits
Citizens and patients	Individuals understand the benefits to themselves and the value to the entire health care system, feel trust in the data collection and management system.	Collaborative partnership with patients who take on a greater responsibility and more active role in managing their own wellbeing, more personalised medicines, better care, empowered citizens and informed patients.
Regulators and policy makers	Clear leadership, clarity on data categorisation, collection and ownership of data safeguards and standards, interoperability of systems and larger, more sophisticated data registers.	Increased efficiency (able to make more effective decisions with relevant, first hand data)
Clinicians and care professionals	Trusted and accepted system of data collection and management, accuracy and consistency in data input, positive communication on the benefits of data sharing, and how shared data will be used.	Development of new tools, new information sources, patient's better adherence to treatment, enhanced health literacy
Payers and insurers	No penalty for sharing data (e.g discrimination on genetic grounds or for pre-existing conditions)	Increased efficiency (better knowledge of what to reimburse)
Service providers and managers	Interoperability of the data collection and management systems used, positive communication on the benefits of data sharing, and how shared data will be used	Better information flows for decisions, breakdown of administration and professional barriers, greater trust and cooperation between health professionals, care givers and patients.
Researchers	Provision of information about how the data will be used, positive communication on the benefits of data sharing, and how shared data will be used, results of research are shared with other stakeholders.	Use of depersonalised data for epidemiological purposes

## 2) 'Liberate the data'

Stakeholder group	Preconditions	Benefits
Citizens and patients	Ability to give informed consent for data collection and update their consent as and when desired.	Improved health, new products and services to match their needs and interests, health becomes more 'user' focused rather than technology focused, faster development of new drugs and treatments.
Regulators and policy makers	Require institutions within the health and care systems to publish their data, require data management tools to be integrated with provision of care services	Business opportunities (act as consultant for less eHealth thinking countries), greater trust in the healthcare system (reputation of health services based on quality not name), greater flexibility and options for decisions based on accurate data, transparency leading to better strategic planning and resource allocation.
Clinicians and care professionals	Health data collected needs to be robust, gathered in a standard way.	Standardised protocol to follow, access to better tools, better and more complete information from patients, simplification and standardisation of medical record systems, lower administrative burden on busy healthcare workers.
Payers and insurers	Have an interest in benchmarking, commitment to better value for money for their clients and measuring return on investment.	Cost savings for healthcare, cost savings for employment, greater integration of health and care services, larger range of service providers.
Service providers and managers	Ensure health data is robust, gathered in a standard way, ensure data management tools are integrated with provision of care services.	More innovation, less monopoly, market and opportunity for increasing profits e.g. innovative apps and IT solutions, cost savings for employment, managers can focus on where improvements are needed and opportunities to deliver more efficiently
Researchers	Opportunities to access large databases, tools to analyse large data sets, ability to disseminate their research results with stakeholders.	Rich data flows – with proper protection – for research, analysis and policy making, increased availability of relevant data, innovation, faster development of new drugs and treatments through greater access to target data sets from across Europe.

### 3) 'Connect up everything'

Stakeholder group	Preconditions	Benefits
Citizens and patients	Interest in generating own health data, using tools and sharing the information with health system.	Greater integration between their digital life-stream and health services, more accurate and personalised care based on the rich information accessible to health and care professionals and improved quality of research evidence, improved patient safety through fewer medical errors, reduction in inappropriate or untimely treatment.
Regulators and policy makers	Multiple public services are publicly accessible with user friendly interfaces allowing citizens to interrogate central databases, submit information, request services. Minimum standards and safeguards for health apps and tools to build trust among users (citizens and clinicians), defined technical standards for external IT tools to be interoperable with the health system	Stronger evidence base for policy-making, rationale for decisions about resources, more accurate forecasting of trends allowing better forward planning.
Clinicians and care professionals	Appreciate the value of user generated information, incorporate it into health decision-making and treatment plans.	Enhanced, greater opportunity for learning from each other, improved patient safety through fewer medical errors, reduction in inappropriate or untimely treatment, greater clarity on patient's wishes for pre-empted care e.g. organ donation.
Payers and insurers	Supportive of the creation of apps and tools for users to monitor, track and record their information.	Better return on investment for care provision because greater certainty that it is tailored, timely and effective, better health outcomes, less duplication and gaps in the system.
Service providers and managers	Compliance with good practice in data management and meet standards for interoperability with their own IT systems. Monitoring of clinicians use of data and provision of data into the system. Use of new IT tools that are user friendly, multi-platform and meet the standards for interoperability with health systems.	More efficient management of services, greater emphasis on prevention and user monitoring which lessens demand for services, early warning about problems in services from user experiences, closer integration between health and care services, improved efficiency in service delivery: less duplication in procedures and record keeping.
Researchers	Input to standards for classifying	Access to large data sets from different online

and indexing health data that is generated by users so that it is medically useful and robust.

tools, much of which might be geotagged (surveillance and epidemiology) school and work environments, friendship networks, photos, timeline of major life events.

#### 4) 'Revolutionise health'

Stakeholder group	Preconditions	Benefits
Citizens and patients	Empowered and knowledgeable patients that demand greater input in decision-making about health and want to take responsibility for their health, opportunities and tools to provide feedback on their experience of care.	Empowered citizens and informed patients with opportunities to manage their own health. Full transparency about health outcomes and opportunities for feedback on quality of care received. Patients engage with managing their health conditions, gaining insight from other patients and increasingly demanding a more equal partnership with clinicians.
Regulators and policy makers	Commitment to radical reconfiguration of the health system, based on evidence and need. Communicate the benefits of change.	New paradigms for quality, greater citizens interest in wellbeing and participation, stronger evidence base for decision-making and resource allocation in health
Clinicians and care professionals	Accept an erosion of the primary leadership of healthcare, appreciate the role of other professions (engineers, statisticians, communications experts, social scientists, designers, experts in ergonomics and user interface).	Breaking down of silos and encouraging multidisciplinary approaches to care, feedback from patients on their experience, good practice is recognised, greater use of telehealth and other tools to support community based care.
Payers and insurers	An interest in improved return on investment, use of financial incentives to re-configure services, support for greater individual responsibility for health and tools for empowerment.	Funding allocated on empirical basis to institutions that deliver good care and where patients want to be treated (money follows the patient)
Service providers and managers	Mechanisms for feedback from patients and users about their experience. Interest in generating new tools.	Streamlined information management, allowing greater insight into the process of care, identifying gaps, areas of excellence and weakness, reform of urgent care (hospital based), shift towards community based care, development and use of patient pathways for care, improved monitoring of health outcomes.
Researchers	Change in approach to research, data analysis and design of trials to give users more input, pro-actively, recruit patients and users.	Wide range of new data sources and indicators, easier and simpler to create trials and involve users more actively.

## 5) 'Include everyone'

Stakeholder group	Preconditions	Benefits
Citizens and patients	Basic literacy about IT and general awareness about health.	Fewer barriers to access care, greater involvement and participation in self care, improved health awareness and support, improved equity in health with lower barriers to access to quality care.
Regulators and policy makers	Commitment to tackle health inequalities and differences in health outcomes.	Greater social cohesion and improved health status.
Clinicians and care professionals	Non discrimination in provision of care, commitment to ensuring equity of access.	Greater range of treatment options for people with complex health and social problems Better evidence base on what works in tackling complex health problems. More integrated health and social care, greater self care and disease management tools will reduce the heavy use of healthcare services, freeing up capacity and human resources.
Payers and insurers	Equity built into the system, avoid barriers (cost) to the use of eHealth tools.	More accurate prioritisation and resource allocation in order to address greatest need.
Service providers and managers	Benefits of personalised monitoring and care available to all, not just wealthy elite, use technology to reduce linguistic or administrative barriers.	Lower demand for services from heavy-users, improved equity in health with lower barriers to access to quality care.
Researchers	Analysis and monitoring of health inequalities.	Better understanding of barriers to good health, identify effective outreach methods for disadvantaged or excluded groups, generate new insights into ergonomics of use for eHealth tools, new findings on individual motivation for change on lifestyle and identify success factors for behaviour modification programmes.



## Annex II: Potential direct and indirect benefit from eHealth for different stakeholders

	Benefits	Citizens and patients	Regulators and policy makers	Clinicians and care professionals	Payers and insurers	Service Providers and Managers	Researchers
<b>Patient experience</b>	Empowered and informed patients with opportunities to manage their own health						
	Improved patient safety through fewer medical errors, reduction in inappropriate or untimely treatment.						
	Improved equity in health with lower barriers to access good quality care.						
	Better adherence to treatment, greater engagement with lifestyle changes to improve health.						
	Enhanced health literacy and awareness about personal health						
	Peer support and patient communities which reduce social isolation						
	Greater clarity on patient wishes for pre-empted care, e.g; organ donation, end of life and palliative care						
<b>Economic benefit</b>	Transparency leading to better strategic planning and resource allocation						
	Improved efficiency in service delivery: less duplication in procedures and record-keeping						
	Lower transaction costs to manage and treat patients						
	Faster uptake and implementation of innovations in health and care systems						
	Shift in power within health system encouraging an attitude of co-generation for good health						
	Integrated health and social care that is personalised for the patient						
	Less fragmentation of services, improved continuity of care, fewer bureaucratic barriers						
	New market opportunities for innovative apps and IT solutions						
<b>Effectiveness of care</b>	Transparency about operation of health system and outcomes. Better strategic planning and resource allocations.						
	Development and use of patient pathways for care						
	Improved monitoring of health outcomes, greater emphasis on prevention						
	Greater trust and cooperation between health professionals, care givers and patients						
	Rich data flows - with proper protection - for research, analysis and policy-making						
	Reform of urgent care (hospital based), shift towards community based care						
<b>Quality</b>	Faster development of new treatments and drugs through access to large datasets from across Europe						
	Greater consistency in care, based on updated protocols and guidelines developed using large datasets from across Europe						
	Simplification and standardisation of medical record systems, lower administrative burden on busy healthcare workers						
	Greater use of telehealth and other tools to support community based care						

Legend - Benefits :

Direct  
Indirect

## Annex III: Examples of good practice

### Examples of user driven innovation

In August 2011, the UK Department of Health issued an open call for ideas for apps that could add value to patients by promoting better management of chronic conditions or supporting healthy living. In the 6 week duration of the call, almost 500 entries were submitted and more than 12,600 votes cast. Popular apps were Patient Know Best, a patient controlled medical record system, Moodscope which allows users to manage their mental wellbeing by measuring their mood and sharing it with up to 5 friends, a free smartphone app to track management of diabetes and Rally Round which helps carers to seek and coordinate practical help from family and friends.

There is an increasing interest in the use of online tools to support behaviour change and improved lifestyle. For example, the MealTracker application and service is a visual food journal that allows you to connect with and get guidance from nutrition professionals. You can create your meal journal from pictures taken with a digital camera or cell phone. This is an example of a scalable solution for improving health through changing habits. ([www.wellnessfoundry.com](http://www.wellnessfoundry.com)).

### Taltioni - a Finnish personal health records and platform

Taltioni is a platform with a wide range of services that individuals can use on the site or access many other services that are Taltioni compatible. This platform allows individuals to control, use and produce information on their own health and well-being. Apps may use the information stored on the platform or any other Taltioni service. The citizen is in charge of their data stored into the database. They can decide who or which service provider can access the data. Special services allow health professionals to access the data in order to provide care for the patient.

### Demonstrating the benefits of telehealth

In December 2011, the UK Department of Health released preliminary findings of their large scale demonstration project:<sup>1</sup>

*"The early indications show that if used correctly, telehealth can deliver a 15 % reduction in Accident and Emergency visits, a 20% reduction in emergency admissions, a 14 % reduction in elective admissions, a 14 % reduction in bed days and an 8 % reduction in tariff costs. More strikingly they also demonstrate a 45 % reduction in mortality rates."*

This highlights the win-win-win from a well implemented ICT system for healthcare; greater efficiency, lower costs and better health outcomes. It is important to note that these benefits only accrue with close integration of health and social care services regarding individual level data and at organisational and financial level.

### Transparency on the outcomes by healthcare professionals

Individual ratings of doctors began in 1997 in the UK with the publication of mortality and outcome

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1 The '[Whole System Demonstrator Programme](#)' is one of the most comprehensive and complex trials undertaken by the UK Department of Health, involving 6,191 patients and 238 GP practices across 3 sites. 3,030 people with one of three conditions (diabetes, heart failure and COPD) were involved and data was collected for at least 12 months.

data of cardio-thoracic surgeons. Initially controversial, the data became more widely used and the variance between the best and worst performers has narrowed. Those surgeons that continue to operate have achieved better outcomes because they have actively sought to learn from each other. A 2007 review found that overall mortality rates had dropped from the European average of 2.4 % to 1.8 %, average length of stay in hospital is at least a day less than the European average of 10 days<sup>2</sup>. These improvements in health outcomes also resulted in cost savings of £6.4 million and fears that data publication would lead to fewer high risk patients undergoing surgery have proved unfounded. Cardiothoracic surgeons are now leading advocates for data transparency, David Taggart, President of the Society for Cardiothoracic Surgery in Great Britain and Ireland stated in the media<sup>3</sup>

*"UK cardiac surgeons are very proud of the fact that they publish the most comprehensive cardiac surgery data in Europe. This not only demonstrates a strong commitment to quality and transparency but also provides enormous reassurance for patients. The results confirm that cardiac surgery in the UK is amongst the very best in Europe and that mortality rates have fallen by half over the past five years [through] collection, analysis and publication of outcome data. Our European partners should be encouraged that this approach is likely to lead to a similar improvement."*

### **Network analysis to improve quality of care**

Data mining can reveal inefficiencies or inconsistencies in practice. For example, data analysis in Hungary revealed that 70 % of newly diagnosed HER 2 +ve breast cancer patients were not prescribed Herceptin medication but 17 % the patients with HER 2 -ve cancer did receive the drug. If the standardised protocol was followed it would have improved health and used scarce resources more effectively.

The UK has released a data stream of 260 quality indicators for GPs, is free to access and is continually updated. Software developers are being invited to use this data to create apps that patients and healthcare managers can use.

### **eHealth as a bridge for eHealth**

The growing area of personalised medicine is another opportunity for eHealth applications: bringing together researchers, health professionals and patients to explore real life health challenges. Delivering individual treatment requires access to specialised databases with information drawn from multiple sources and clinical research centres. As patients become the owners and controllers of their information, new agreements will need to be created in order to create the shared repository of data that is so valuable for researchers.

Another valuable use for data is to change the paradigm of patient care. Leading research organisations such as the Champalimaud Foundation in Portugal contribute to and draw upon national databases for example of bone marrow donors. However, this data needs to be integrated into more sophisticated and larger data registers that would allow doctors to find better matches for treatment. Individual care is improved if treatment is no longer left to the intuition of doctors

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2\_ <http://heart.bmj.com/content/93/6/744.abstract>,

3\_ <http://www.guardian.co.uk/uk/2010/nov/25/nhs-heart-surgeons-low-mortality>

but is based on research results from large population groups. The evidence is emerging on how different patients are from each other in terms of phenotypes, highlighting the importance of accessing and processing large data sets for personalised medical treatment. Such warehouses of anonymised data need to be as large as possible, meaning that should be created at the highest possible governance level - the EU. Health professionals can have better tools for clinical treatment if data has been anonymised and classified in a standard way.

**Example of a full integrated eHealth system in Estonia (source: TERVIS - Estonian eHealth Foundation)**

The Estonian government has chosen to be an innovator in the implementation of electronic public services. The population of 1.3 million is served by a range of healthcare providers: governmental, municipal and private. Healthcare costs represent 5 % of GDP, a relatively low proportion compared to the OECD average. Internet penetration is high: 75 % of the population regularly use the internet, 67 % of households have a PC almost all of which are connected to the internet. A wide range of e-services have already been implemented including e-elections, e-tax returns, e-schools and e-commerce registration.

By 2013, all public services will be available digitally through an 'X Road' infrastructure which is service oriented. The X Road integrates and aggregates 360 different databases, meaning that data is stored where it is collected but is available to other users across the system. Some 2,000 e-services are linked via the X Road and 500 different organisations have integrated their electronic systems into the X Road, which was used more than 420 million times in 2009.

To oversee the process, a national eHealth Foundation has been created, with membership from hospitals, universities, relevant Ministries and associations of doctors. The system of access is regulated by legislation. All healthcare providers must submit data for the electronic health record. Access is restricted to licensed medical professionals using the 'attending doctor' concept, meaning that only professionals with a direct treatment relationship with the patient have access. Patients have the right to 'opt out' of the system by locking their own information that is within the central database. Citizens can access their own data, monitor who has consulted their electronic health record and state their intentions or preferences in terms of healthcare. Access to the system requires an ID card for authentication and digital signature process.

When e-prescription services were added to the eHealth system in 2010 there was immediate uptake of the service. Within 9 months, 80 % of prescriptions (written and filled) were electronic.

## Annex IV: EU actions on eHealth

The European Commission has developed a number of policy initiatives to increase the uptake of eHealth technologies and works with national authorities and eHealth stakeholders to ensure that new issues arising from technological change or medical developments are addressed.

The economic growth potential of eHealth has also been recognised, the EU 2020 Strategy features the flagship initiatives [Digital Agenda for Europe](#) and [Innovation Union](#), both of which include a number of targeted eHealth actions and goals.

### Legislative framework for eHealth

As a legislative and regulatory body, the Commission has set legal and technical conditions for eHealth. These include legislative frameworks that cover accreditation, liability, transparency of reimbursement, data protection, privacy, ethical and security concerns. EU legislation with relevance for eHealth includes the Data Protection Directive<sup>4</sup>, Directive on Electronic Signatures<sup>5</sup>, E-Commerce Directive<sup>6</sup>, Medical Devices Directive<sup>7</sup> and implementing legislation.

A proposal for a Regulation on Trust and Confidence in Electronic Transactions in the Internal Market is planned to be adopted in the first half of 2012. The proposal will ensure the mutual recognition and acceptance of electronic identification and authentication mechanisms across the EU. Secondly, it fully revises the [eSignature Directive \(1999/93/EC\)](#) enhancing the interoperability and usability of electronic signatures across the EU. Thirdly, it will also cover additional trust services such as time stamping, electronic seals or electronic delivery. These are all essential preconditions for eHealth.

The proposed update and change of the [Data Protection law into a Regulation](#) will contribute towards improving trust of citizens to use eHealth. The objective is to ensure adequate level of protection of highly sensitive personal health data, but also to ensure the opportunity of using these data for health and research purposes that benefits patients and society.

The new Directive on Cross-Border Healthcare<sup>8</sup> is a landmark because it codifies the European Court of Justice (ECJ) jurisprudence on patients rights to be reimbursed form healthcare in other EU Member States creates. It also creates a voluntary network of National Authorities with responsibility for eHealth. This network will focus on three key issues: guidelines of a list of data to be included in the patient summary records that can be consulted across borders by health professionals, methodology for the use of medical information for public health and medical research and common identification and authentication measures for transfer of data in cross-border healthcare.

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4 EU [‘Data Protection’ Directive](#) 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data

5 EU Directive on a [Community framework for electronic signatures](#) 1999/93

6 [EU Directive on electronic commerce](#), 2000/31/EC

7 [EU Directive on Medical Devices](#), 93/42

8 [EU Directive on Cross Border Healthcare](#)

## Policy initiatives

Other key initiatives from the European Commission include the [EU standardisation framework](#), the [EU Communication on Telemedicine](#), and the [European Innovation Partnership for Active and Healthy ageing](#). The most recent example is a consultation for an eHealth Action Plan (2012-2020). Among the outstanding issues that need legal clarification are the following: reimbursement of e-health activities and the issue of (no-fault) liability as well as new approaches to dealing with protection of data and the issue of consent in the formats that eHealth offers.

## EU funded eHealth projects

For more than two decades, the European Commission has invested 500 million Euros in research and large scale pilot projects in eHealth. These include:

- ✦ The [CALLIOPE thematic network](#) which developed a common interoperability roadmap for eHealth and facilitated pre-standardisation processes.
- ✦ [European Patients Smart Open Services \(epSOS\)](#) is a large scale project that develops, tests and validates patient summaries and ePrescriptions in 23 countries.
- ✦ [RENEWING HEALTH](#) - Nine EU regions in eHealth implementation will measure efficiency and the cost-effectiveness of telemedicine for remote monitoring and treatment of chronic patients suffering from diabetes or cardiovascular diseases.
- ✦ [STORK](#) (Secure Identity Across Borders Linked) – designed to implement an EU wide eID interoperability platform for cross- border eID identification and authentication.
- ✦ [HITCH](#) on a Roadmap for eHealth technical standards interoperability (2011) which aims to propose a European Interoperability Framework for technical standards on eHealth (in September 2012).
- ✦ [SEMANTIC HEALTH NET](#) - seeking to create a scalable and sustainable pan-European organisational and governance process for the semantic interoperability of clinical and biomedical knowledge.

## Annex V: Glossary of Terms

- eHealth** eHealth means ICT tools and services for health. eHealth covers the interaction between patients and health-service providers, institution-to-institution transmission of data, or peer-to-peer communication between patients and/or health professionals. Examples include health information networks, electronic health records, telemedicine services, wearable and portable systems which communicate, health portals, and many other ICT-based tools assisting disease prevention, diagnosis, treatment, health monitoring and lifestyle management. (Source: European Commission).
- Primary use** Use of health data for the main purpose for which they were originally collected directly from the individuals concerned (e.g. hospital patients or participants in research projects). A New ISO standard ISO/TS 14265:2011, *Health informatics – Classification of purposes for processing personal health information*, defines a set of high-level categories of purposes for which such personal health information can be processed.
- Secondary use** Use of existing data for purposes other than those for which they were originally obtained, this might include clinical research, clinical trials for which informed consent is required. Greater clarity is needed about consent processes for secondary use of data such as clinical audit, clinical governance, health service management, disease registries, epidemiological surveillance etc but also for research that was not in mind when the data were originally collected.
- Anonymisation** Three broad levels of anonymisation can be distinguished:
- (a) **fully identifiable data**, where the clinical/genetic record is linked to an identifiable individual;
  - (b) **de-identified (anonymised) data**, where individual identifying information is replaced by a code (which could be made very secure) allowing data and individual identifiers to be re-linked under certain circumstances; and
  - (c) **permanently de-linked data**, where any link between the data and the individuals from whom they were collected has been completely destroyed.

The report, the annexes and other material as audio/video can be found on:  
[http://ec.europa.eu/information\\_society/activities/health/policy/ehtask\\_force](http://ec.europa.eu/information_society/activities/health/policy/ehtask_force)