

E-HEALTH ACTION PLAN 2012-2020

BEUC response to the public consultation

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Summary

Large scale deployment of eHealth solutions:

The potential benefits for consumers

- Higher quality of healthcare
- Easier access to care
- Increased patient safety
- Consumer empowerment
- More patient-centred healthcare
- Continuity of care
- More efficient and sustainable healthcare systems
- Availability of data to conduct medical research

The main barriers

- Lack of evidence on the benefits of eHealth solutions
- Lack of security
- Lack of acceptance and awareness by both consumers and healthcare professionals
- Lack of equal access to the internet, ICT literacy and net neutrality

How to overcome the barriers and achieve the objectives of the action plan

- Guarantee privacy, data protection and truly informed consent
- Ensure the highest level of quality and safety
- Provide consumers more information on the implications of eHealth solutions, including benefits and possible shortcomings
- Improve interoperability
- Organise adequate training for healthcare professionals and education programmes for consumers
- Conduct research to identify the benefits, the risks and the costs of eHealth solutions

This is a consolidated version of the answers to the main questions of the public consultation on the EU e-health Action Plan 2012-2020 provided by BEUC via the on-line questionnaire¹.

1. What are the main benefits you expect from the large scale deployment of eHealth solutions²?

eHealth is an important instrument to improve safety, quality and access to healthcare. As the baby-boom generation retires, the European population of over-60s is increasing twice as fast as pre-2007, meaning some two million people a year. By 2050, the number of people over 50 will rise by 35% and the population of over 85 will triple. The ageing of the population, the consequent higher number of people affected by chronic diseases, increased citizens' expectations for high quality health services, the shortage of healthcare providers and rising costs are challenging the sustainability of healthcare systems. In this context, the potential benefits of ICT applications can be substantial and the large scale deployment of eHealth solutions could provide much needed help in addressing these problems. eHealth can contribute to the modernisation of healthcare systems, making them more efficient and effective. In addition, the application of eHealth tools can bring a paradigm shift, from symptom based to preventive healthcare and from hospital centred to patient centred care.

Provided that there is still lack of evidence on the overall implications of eHealth (see section 2.1), one of the main potential benefits for consumers we expect in relation to the large scale deployment of ICT solutions in health care is the introduction of the Electronic Health Record (hereafter EHR). EHRs can include information on patient demographics, treatment progress, problems, medications, vital signs, past medical history, laboratory data, results of screening initiatives and radiology reports.

EHRs can help empower patients by providing them with easier access to their health information, allowing them to exert more control over their health records, thereby becoming more responsible and more active in their own care while facilitating communication with their healthcare professionals.

Furthermore, storing and transferring patient information electronically has the potential to significantly reduce clinical errors and improve patient safety, as well as allowing clinicians to communicate more quickly and accurately by identifying relevant information more easily. It can contribute to the avoidance of cases where the same exam is performed twice, a better understanding of the patient's medical history and also ensure continuity of care. From a patient's perspective this translates to a higher quality of care and more sustainable healthcare systems.

Finally, EHRs could be useful for health research purposes and for policy decisions: if managed appropriately and if it is guaranteed that data can be fully anonymised (condition that at the moment we do not think can be fulfilled³), a huge amount of medical data could be easily collected and used in various scientific studies, including epidemiological analysis, evaluation of healthcare procedures, pharmacovigilance etc.

¹ <http://ec.europa.eu/yourvoice/ipm/forms/dispatch?form=ehap2012&lang=en>

² It is important to read this part in combination with the caveats expressed in section 2.1.

³ No Place to Hide — Reverse Identification of Patients from Published Maps, *New England Journal of Medicines*, 2006; 355: 1741-174. <http://www.nejm.org/doi/full/10.1056/NEJMc061891#t=article>

Another concrete benefit that can arise from the deployment of eHealth solutions is telemonitoring. The use of telemonitoring for conditions such as heart diseases can improve the patient's quality of life, avoiding unnecessary visits to the hospital and allowing him/her to remain in a familiar and friendly environment. Telemonitoring should be done using reliable technologies and under the supervision of medically qualified staff.

Telemedicine, for example teleradiology, could help address the problem of shortage of healthcare professionals and optimise the use of scarce resources.

Another eHealth solution already used in a relatively large scale is e-prescribing. This application is widely used in only a few Member States (e.g. Denmark, Estonia), but there are many pilot projects ongoing in different countries. It can reduce medication errors due for example to illegible doctor handwriting, but also help prevent side effects such as those due to interaction with other medicines, because the doctor can have access to the medication history of the patient. E-prescribing implies only the electronic transmission of the prescription from the prescriber's computer to a pharmacy computer and does not affect the fact that the doctor has to visit the patient before prescribing any medications. However, in some cases - for example refill of repetitive prescriptions for chronic patients - it could also be used to save time and avoid unnecessary visits to the doctor cabinet.

To ensure that consumers truly benefit from eHealth solutions, the technologies should respond to the needs and the expectations of the patients and their carers. Consumers will not reward innovation for the sake of innovation but only innovation that has an added value and improve their health and wellbeing.

2. What are the main barriers?

We consider the main barriers so far to the large scale deployment of eHealth solutions are:

2.1 Lack of evidence of the benefits of eHealth solutions

The impact of using information and communication technology tools and services in health can have enormous potential, however it has been difficult to measure its benefits. For instance, reviews⁴ made by Cochrane in 2002 and 2008 regarding telemedicine versus face-to-face patient care respectively, conclude that there is little evidence of its clinical benefits and more research is needed. In 2010, the European Commission published a report⁵ on the socio-economic impact of interoperable EHR and ePrescribing systems in Europe. For all cases analysed, the socio-economic gains to society from interoperable EHR and ePrescribing systems eventually exceed the respective costs. But one of the key findings of the study is also that the benefits from EHR and ePrescribing investments come under some broad, diverse categories, that their occurrence is very specific to the context and the benefits can be measured only after a considerable period of time.

⁴ a) Martin S, Kelly G, Kernohan WG, McCreight B, Nugent C. Smart home technologies for health and social care support. Cochrane Database of Systematic Reviews, 2008, Issue 4.

b) Currell R, Urquhart C, Wainwright P, Lewis R. Telemedicine versus face to face patient care: effects on professional practice and health care outcomes. Cochrane Database of Systematic Reviews, 2000, Issue 2.

⁵ Study Report 2010 EC. Interoperable eHealth is worth it. <http://www.ifap.ru/library/book476.pdf>

Many studies⁶ highlight the benefits of using ICT, both in the quality of care - for example in disease management - and in economic terms - for example reducing hospital admissions. At the same time, a systematic literature review⁷ of studies on the impact of eHealth on the quality and safety of care concludes that *"There is a large gap between the postulated and empirically demonstrated benefits of eHealth technologies. In addition, there is a lack of robust research on the risks of implementing these technologies and their cost-effectiveness has yet to be demonstrated, despite being frequently promoted by policymakers and "techno-enthusiasts" as if this was a given. In the light of the paucity of evidence in relation to improvements in patient outcomes, as well as the lack of evidence on their cost-effectiveness, it is vital that future eHealth technologies are evaluated against a comprehensive set of measures, ideally throughout all stages of the technology's life cycle. Such evaluation should be characterized by careful attention to socio-technical factors to maximize the likelihood of successful implementation and adoption"* (Black et al., 2011).

2.2 Lack of security

One of the biggest challenges to the uptake of eHealth solutions is the security of the system with regard to privacy and data protection. The unauthorised disclosure of a medical condition or diagnosis could negatively impact an individual's personal and professional life. The storage, transfer and processing of health information using ICT tools (including electronic health records and e-prescriptions) open a new risk scenario⁸ in the processing of personal health data, exposing consumers to the risk that their health information could accidentally end up in the hands of unauthorised parties. Many eHealth solutions, thus pose significant challenges in ensuring that only appropriate health professionals gain access to information for legitimate purposes related to the treatment of the patient. The possibility of abuse is significant and the risk increases when systems become more interconnected. This means that consumers, healthcare professionals and decision-makers still have major concerns regarding the security of the system and are reluctant to use these new technologies. A recent decision of the Dutch Parliament clearly shows the problem. After investing almost a decade and several hundred million euro in developing the EHR in The Netherlands, the implementation plan presented by the Ministry of health was rejected by the Parliament due to privacy concerns⁹.

2.3 Lack of users' acceptance and awareness

eHealth solutions are going to change the way consumers deal with their own health and also health care professionals practice. Thus in order for them to uptake these new technologies, they have to be more informed and more involved. At the moment, many consumers and health care professionals lack knowledge as to the clear benefits of eHealth and its implications. They are unaware of how the technologies work and

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- ⁶ a) RAND, 2006. <http://www.rand.org/news/press/2006/04/11.html>
 b) Stroetmann Karl, Jones Tom, Dobrev Alexander, Stroetmann Veli . E-health is worth it- the economic benefits of implemented e.health solutions at ten European sites, European Commission, 2006.
 c) Economic impact of telehealth. A systematic review. Journal of Telemedicine and Telecare, volume 9 number 6, 2003.
- ⁷ Black AD, Car J, Pagliari C, Anandan C, Cresswell K, et al (2011). The impact of eHealth on the quality and safety of health care: a systematic review. PLoS Med 8(1):e1000387. doi: 10.1371/journal.pmed.1000387.
- ⁸ Article 29 Working Party Working Document 131 on the processing of personal data relating to health in electronic health records (EHR), adopted on 15 February, 2007. http://ec.europa.eu/justice_home/fsj/privacy/docs/wpdocs/2007/wp131_en.pdf
- ⁹ News article retrieved from www.anp.nl on 5 April 2010.

how data can be handled. In some cases they do not even know that the technology is available even when they would be willing to use it¹⁰. The lack of adequate information hinders the acceptance of eHealth solutions by consumers. With regard to healthcare professionals we assume that their resistance is mainly due to security concerns, monetary issues, lack of technical training, lack of trust in the reliability of the system, lack of time, cultural barriers and the overall lack of incentives¹¹.

2.4 Lack of equal access to the internet, ICT literacy and net neutrality

When speaking about eHealth solutions it is worth noting that access to the internet is not universal. In some countries consumers do not have easy access to the internet and/or to a fast connection and often the cost of internet is an obstacle for its use.

A study¹² from the European Commission in 2007 shows that only 60% of all general practitioners use a computer during a consultation (EU27). The national percentages vary from 100% in Finland to only 8% in Italy. The communication and exchange of data between hospitals and general practitioners within Europe only happens in 20% of cases. This national data varies from 76% in Denmark to 0% in Romania, indicating that there are large differences between the European countries and that there is still a long way to go before the use of ICT becomes a reality in medical practice.

We are also concerned about the impact of the net neutrality debate on the development of e-Health. Any constraints in terms of degradation or blocking of Internet traffic would significantly affect the successful roll-out of eHealth services. The current lack of a strong regulatory framework that would guarantee net neutrality and would ensure a minimum quality of service needs to be addressed.

All these issues should be taken into consideration in order to make sure that new ICT tools provide equal access to all and do not create new inequities.

3. How to overcome the barriers and achieve the objectives identified in the Action Plan?

We fully support the objectives of the Action Plan so far identified by the European Commission¹³, but we would also like to stress that health is not an area where advances in technology can be simply imposed. The barriers to the large scale deployment of eHealth solutions relate also to the non-technical elements, in other words the underlying philosophy and ethics of healthcare and the complexities of the human relationships that make the technology work¹⁴.

More specifically, in order to overcome the barriers mentioned above and to achieve the objectives presented in the Action Plan we recommend to:

¹⁰ Test-Saude, n.84 April 2010.

¹¹ Boonstra, B. Broekhuis, M. (2010) Barriers to the acceptance of electronic medical records by physicians from systematic review to taxonomy and interventions. BMC Health services Research 10:231

¹² http://ec.europa.eu/information_society/eeurope/i2010/docs/benchmarking/gp_survey_final_report.pdf

¹³ <http://ec.europa.eu/yourvoice/ipm/forms/dispatch?form=ehap2012&lang=en>

¹⁴ Phelps, K. Enhancing Privacy and Confidentiality in the World of E-Health. Health On-Line Summit, Adelaide, Australia, 3 August 2000.

3.1 Guarantee privacy and data protection and a truly informed consent

According to the European Data Protection Legislation¹⁵ health data have to be considered as sensitive data and require a special level of protection. For eHealth solutions to be trusted and accepted it is essential to guarantee consumers' that their health information is treated as highly sensitive and is fully secured.

Maintaining the legal standard of confidentiality applicable to traditional paper form may be insufficient to protect the privacy interests of a patient once the information is online. Therefore the deployment of eHealth solutions should be preceded by the reinforcement of the legal framework on data protection. Consumers should be in charge of their own medical file, they should be able to 'log in' and inspect it. The option to access one's own information is a fundamental right that is embodied in the Data Protection legislation.

In 2010 Test-Achats¹⁶ asked consumers about their expectations of eHealth solutions: 95% of consumers expressed the desire to view their own medical files and 89% believe it is important to see who accessed their medical file.

Consumers should be able to decide if they want their data in electronic form and, if so, which data. Moreover, they should be provided with all the information to give truly informed consent, whether it is exchange, analysis, adaptation or removal of medical data. Certain categories of personal health data such as genetic information should be subject to especially strict access controls. A system of data modules or sealed envelopes could help establish a different level of confidentiality and restrict access to some information to some healthcare professionals only.

Moreover access to patients' health records should only be permitted to the health professionals directly involved with the patient's condition.

In cases of a breach of security, leading to the accidental loss, alteration or unauthorised disclosure of personal health data, the individuals concerned and the national data protection supervisory authorities should be promptly informed. In such cases consumers should have legal grounds to file a complaint and consumer friendly mechanisms to seek redress and compensation. Special measures should be put in place to prevent consumers from being illegally induced to disclose their personal health data. It is also important to encourage the deployment of security-enhancing technologies and services to prevent identity theft or other privacy-intrusive attacks.

3.2 Ensure the highest level of quality and safety

The quality and the safety of the technology used, as well as the service associated with them, should be carefully assessed by the competent authorities via a proper certification system and should not be driven exclusively by commercial interests. Consumers should be reassured that the technology is used only by authorised and specifically trained medical staff, subject to the obligation of professional secrecy.

The technology should also ensure a reliable identification of the patients and the healthcare professional. eHealth systems should be fully safe from a technical point of view against breaches and crashes (e.g. backup system).

The quality and the safety of eHealth applications also depend on good infrastructures, including broadband and high speed internet connections.

¹⁵ Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and Directive 2002/58/EC on privacy and electronic communications.

¹⁶ Test-Sante, n.99 November 2010.

eHealth technologies should be user-friendly and designed for, with and around the end user - who should be involved from the early development of the technology. Consumers should have the possibility to access data concerning their health in a range of formats - not only online – and the information should be provided in a language and with a layout which is easy to understand, also for people with special needs (e.g. the elderly).

3.3 Provide consumers with more information on the implications of eHealth solutions

Providing consumers with additional tools to be more actively involved in the decisions regarding their health and increasing awareness of the benefits and the opportunities of eHealth is of vital importance. In order to make informed choices consumers should receive complete information, including on the challenges and the threats associated with the increased use of ICT in healthcare.

Many consumers will only focus on a few, key criteria to make healthcare choices, so effective provision and communication of information via eHealth solutions will be key to supporting them and preventing them from being overwhelmed by too much information. Patients will need assurance that those who provide them with (and interpret) healthcare information can be trusted to do this in a credible, honest, authoritative, consumer-friendly and objective way.

Consumers are entitled to clear information on the use and processing of their personal data. However, at the moment most consumers are unaware of where their data is stored, how their data is accessed, and what they can do to keep their data safe. In addition, consumers should have clear information on their rights to seek redress and compensation in case things go wrong (e.g. accidental disclosure of their data). The positive aspects of eHealth solutions should also be made visible to the consumer. When the importance and the benefits are not perceived by end-users, it is more difficult for them to accept it. This means that the deployment of eHealth applications should be accompanied with information campaigns and training activities. Patients who are unable or unwilling to access and use eHealth technologies for whatever reason should not suffer any detriment and should be provided with suitable alternatives and adequate support.

3.4 Improve interoperability

With consumers becoming more and more mobile within their country and between EU Member States, interoperability is essential. We believe that at the moment it is hindered mainly by legal and technical issues but also by cultural barriers. It is therefore urgent to enable interoperability between health information shared among different healthcare professionals – including pharmacists – and among different healthcare settings and systems provided that they guarantee a sufficient level of data protection. An adequate legal framework – including the concept of multi-layered liability - and networked infrastructures should be built to cover the entire continuum of care.

A change of culture in the healthcare management system and among healthcare professionals' is also needed: the system should not be designed around the physician, the hospital or the insurance system, but rather for the patient. All measures should be put in place to allow the health information (e.g. EHR or the e-prescription) to move together with the patient.

3.5 Organise adequate training for healthcare professionals and education programmes for consumers

Consumers must be educated about the nature and purpose of the equipment, any potential breaches of confidentiality inherent in the technologies deployed and questioned regarding the level of satisfaction with the services. In this respect, knowledge needs to be gained on how to influence cognitive, physical or literacy barriers on workflow and outcomes of using health records.

With the growing introduction of ICT services in all phases of the care process, the physician's responsibilities also increase. Therefore, there is a need to educate healthcare professionals to make adequate use of these technological innovations, without affecting the health care professional/patient relationship.

3.6 Conduct research on the benefits, the risks and the costs of eHealth solutions

Research on eHealth should be 'patient driven' and should seek to identify consumers' key concerns. Research should not only be dedicated to find innovative solutions but also to assess the safety, effectiveness and the real benefits of existing eHealth applications. Moreover, before investing in any large deployment of eHealth solutions, a detailed cost/benefit and benefit/risk analysis is required. An evaluation system should be put in place to monitor and assess the implementation of the new technologies and make improvements.

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