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European Commission
ICT for Health Unit (Unit H1)
Directorate General Information Society and Media
Avenue de Beaulieu 31, 1st floor
B-1049 Brussels
Belgium

Brussels, 25 May 2011

Concerning: Public Consultation on the eHealth Action Plan (eHAP) 2012-2020

Dear Commissioner,

The European Federation of Nurses' Associations (EFN) welcomes the opportunity to participate in the public consultation on the eHealth Action Plan (eHAP) 2012-2020. The EFN consists of 34 National Nurses Associations from the 27 EU Member States + Croatia, Norway, Iceland, Switzerland, Former Yugoslav Republic of Macedonia, Montenegro, and Serbia, and aims to ensure a high quality and equitable health service in the EU by a strategic contribution to the development of an effective, competent and motivated workforce of nurses. As such, policy outcomes have an effect on the daily work of 6 million nurses throughout the European Union and Europe. The EFN is therefore well placed to contribute to this important EU policy document and we look forward to continue to play an active role in this process.

EFN Position

The EFN emphasises that the objective of the eHealth Action Plan is to provide integrated eHealth solutions to provide continuity of care, contributing to patient safety and quality of healthcare. Therefore, the following actions are essential for further developments:

1. **Access** of nurses to **information** to **ensure the continuity of care** and facilitating active links between community and hospital care. **Nursing Data** must therefore be included in patient records in a systematic way.
2. EHealth solutions must be developed with patients and healthcare professionals to enhance trust. **Patients and healthcare professionals will fully use the eHealth services when the tools make a positive difference for them.**
3. **Upgrading the knowledge and skills in eHealth.** This will lead to achieve a competent, well-motivated and sustainable professional workforce to encourage capacity building when taking innovative solutions.
4. **Innovative financing** through the use of **Social Cohesion Funds to make sure** that the innovative efforts are benefiting citizens in their work and everyday life.

Taking these actions to implementation will enable addressing the key healthcare challenges in the EU and Europe.

Yours Sincerely,

Unni Hembre
EFN President

**EFN INPUT TO THE
PUBLIC CONSULTATION ON THE EHEALTH ACTION PLAN (EHAP) 2012-2020**

BENEFITS OF EHEALTH SOLUTIONS

Question 3: In your view, what are the main benefits that you expect from the large scale deployment of eHealth solutions?

The EFN believes that through the eHealth developments already in play, several positive outcomes arise with a widespread use of eHealth services such as the Ambient Assisted Living, Smart House Tech/architecture, e-learning applications, electronic patient records and interoperability solutions. The main positive outcome is the **increase of patient independence**, improvements in the delivery of care, reduction of repeated hospitalisations rates and the use of emergency department. The major aim and objective of e-Health is first and foremost providing patients with quality healthcare, treating patients as long as possible at home.

Regarding the large deployment, the EFN expects as main benefits and goals that the European Commission should look for:

- Focus on patient safety, prevention and health promotion, available for all citizens.
- Focus towards patient empowerment.
- Access of healthcare professionals and patients to correct information about the patients' healthcare, when needed – ensuring continuity and facilitating active links between community care and hospital care.
- Integrated eHealth solutions and applications to providing an increase in quality and reuse of data, that contributes to patient safety and quality care
- Promote integrated care (from education and prevention to palliative care).
- Reduce health inequalities (remote and underserved areas)
- Provide high quality healthcare for EU citizens exercising their right of free movement.
- Facilitate cross border healthcare cooperation.

The EFN welcomes the rationale of the EC to deliver a new eHealth Action Plan, as it is time to realise that Europe has made significant investments and efforts in eHealth solutions but fragmented and not as a whole, leading to the current lack of interoperability. EFN stays committed to contribute proactively to an effective and efficient deployment of eHealth within the healthcare systems, addressing key challenges, such as the elderly, the need for an integrated care and promotion of community care and the skill matching of the EU health workforce. Therefore, EFN recommends extending eHealth services from monitoring focus to self-care focus by integrating care amongst all health service providers. To achieve this, nurses must be involved in development and integration of e-Health solutions. Nurses' knowledge is vital.

THE FOUR OBJECTIVES OF THE ACTION PLAN

Question 4: Taking into consideration the background described in the introduction and existing policy developments made since 2004, do you agree with the four objectives of the Action Plan?

✎ **Objective 1: increase awareness of the benefits and opportunities of eHealth, and empower citizens, patients and healthcare professionals.**

In the sense of increasing **awareness**, the necessity to continue the communication of the benefits of eHealth for healthcare systems with patient and society at large is clearly expressed by the commission. The fast growth of technology has promoted a quick deployment of solutions and services, even faster than the necessary changes in people's mind. Fortunately and despite of that, the examples we have already in the literature reveal that health professionals and citizens are taking the new services to support the management of their work and their conditions with a minimum training and practice. Even though some experiences show that some continuous training is necessary for both, patients and health professionals to take a better use of the services offered, they are already using the technology when it meets their needs. There are clear positive examples on how society has taken the developments and they have made them part of their daily life. **This is the reason why EFN partially agrees with this first objective as citizens, patients and healthcare professionals will fully use the eHealth services when they make a positive difference for them.**

eHealth solutions and applications must involve nurses and nursing, from direct care on through regulation and policy development and application. Technology alone cannot define the development and implementation of eHealth. The challenge is to ensure a development that addresses the needs for our future healthcare. If this is going to be successful nurses must contribute in the development of eHealth, there are few nurses involved in large scale EU projects.

There are many ethical issues to be considered when implementing e-Health technology and strategies. Nurses have an important role in addressing these issues so that our patients are not compromised. The use of restraint and unnecessary monitoring are examples of challenges that will need to be debated. This is our responsibility. In an EU report about European e-Health Strategies published January 2011, it is stated that one of the major barriers is that healthcare professionals lack knowledge about e-Health. It is therefore essential for health professionals to develop skills and competency in e-Health. Nurses all over Europe must make a special effort in gaining these skills and competencies.

As far as nurses are concerned, EFN collected good practices developed on the ground that already shows the awareness and positive attitude of nurses towards new technologies. Nurses appreciate innovations, but only if they increase quality and safety. Furthermore, their experiences relate to empowering patients and citizens in the process of care and putting the active interaction between nurses and patients central in the process of continuity of care. As such nurses are part of the paradigm shift of healthcare systems.

✎ **Objective 2: Address issues currently impeding eHealth interoperability**

The EFN agrees with this objective as it is a reality that eHealth interoperability is extremely difficult, within a country, let alone regionally. Experiences and the current difficulties have

shown that **cooperation and coordination at EU level** are necessary to make progress. There is a need for an official eHealth strategy with common goals agreed among the different institutions involved in order to also allow citizens to exercise their **rights of free movement having access to healthcare** in different locations with high quality and more reliable solutions. Interoperability Issues concerning interoperability are important for future cooperation and coordination at the EU level.

✎ **Objective 3: Improve legal certainty for eHealth**

The EFN agrees with the objective as legal and regulatory issues are among the most challenging aspects of eHealth (privacy, confidentiality, liability and data protection, but also reimbursement schemes). These aspects are of concern of users and are often described as barriers for implementation and further use of eHealth services. Nevertheless, some examples of good practices in that sense – e.g. the Norwegian law is very restrictive concerning privacy, confidentiality and data protection - Norwegian practice could serve as an example for further implementation in other countries.

✎ **Objective 4: Support research and innovation in eHealth and development of a competitive European market.**

The EFN partially agrees with this objective as it seems that the focus will be put where already have been since 2004. Currently there have been huge investments and research in eHealth solutions and there is already data that has not been used. EFN is against the promotion of new cutting edge tools that finally are going to be used by a minority of EU citizens and that ultimately lead to an increase of inequalities in healthcare accessibility.

The EFN believes that is time to address areas of concerns in everyday life for European citizens actively contributing to bring the technology to the daily care. Therefore, the new eHealth Action Plan needs to stress that the efforts on innovation will be done from social perspectives to address and fulfil in areas as community care, promotion of health, integrated care, self-management of chronic conditions and disease prevention and promotion of independent living. Areas that have not been yet enough tackled but that will represent a great boost towards the paradigm shift and the sustainability of healthcare systems. It is essential for the success of eHealth that research and innovation are promoted and funded. It is also important that eHealth solutions are evaluated.

MAIN BARRIERS

Question 5: What do you consider to be the main barriers preventing the large scale deployment of eHealth solutions? (Choose maximum 5)

The EFN selected answers are in bold.

- a. **Lack of large scale evidence for potential improvements to healthcare processes**
- b. **Budgetary constrains**
- c. Lack of leadership (policy makers, local manager)
- d. Lack of user´s (patients and healthcare professionals) awareness.
- e. Limited users´ skills in using ICT (patients and/or healthcare professionals)
- f. Health professionals´ acceptance
- g. **Inappropriate legal frameworks and lack of reimbursement schemes**
- h. **Lack of interoperability**

- i. Inappropriate organisation of the healthcare process
- j. Access to standards
- k. **Lack of cross-sectoral coordination/Integrated healthcare schemes**

Question 6: In your view, how should the European Commission contribute to addressing the barriers you selected above, and provide incentives to promote eHealth solutions? (Choose maximum 5).

The EFN selected options are **in bold**.

- a. Propose legislation
- b. Facilitate cooperation between Member States and/or regions to address common challenges
- c. **Support systematic evaluation of the benefits and costs, effectiveness/usefulness of eHealth solutions**
- d. **Provide guidance on planning, implementation, and change management processes.**
- e. Support deployment of eHealth services/solutions based on evidence
- f. **Explore innovative financing, reimbursement and incentive schemes to promote innovation in eHealth**
- g. **Provide guidance for achieving EU wide interoperability, for example use of common standards, profiles, terminologies, etc.**
- h. Enhance awareness of benefits and opportunities of eHealth.
- i. **Improve ICT skills of users (citizens, patients, health professionals).**

Comments

The EFN emphasises that it is necessary to promote links between the industry developments and market needs, and to fit in the market needs it is needed to involve the users during the design and implementation of technologies. When the technology is made to help users' needs, the adoption is complete. This is revealed in examples where a correlative relation exists between the positive attitudes to technologies and the geographical position: professionals and patients of rural areas are more positive using eHealth than those working or living closer to a city. The better incentive for patients and health professionals is to give them something useful. In some studies, nurses have reported an additional administrative work when using eHealth solutions; for any reason health professionals will take for granted technologies that make their work more complicated^{1,2}. The EFN asks the Commission to acknowledge that poor consultation with nursing staff often results in ineffective IT systems, which fail to deliver the promised improvements, so it is vital that users' voices are heard and their opinions taken on board. Effective consultation during the development phases of clinical IT systems will not only lead to a greater sense of ownership but also will ensure that the right questions are asked to the right people at the right time.

Regarding the necessary cooperation between MS and regions, EFN recommends that as some countries have already implemented various eHealth tools, the European Commission should promote and make possible the exchange of experiences and transferability of practices. EFN welcomes the Commission approach in exploring innovative financing also for improving ICT skills for users through the use of Social Cohesion Funds, for example. The society needs

¹ Pols J. The heart of the matter. About Good Nursing and Telecare. Health Care Anal. 2010 Dec;18(4):374-88. PMID: 20063198

² Ernesäter A, Holmström I, Engström M. Telenurses' experiences of working with computerised decision support: supporting, inhibiting and quality improving. J Adv Nurs 2009 May;65(5):1074-83

organisational and some educational support that will lead to a major confidence in the use of technology. An expanded capability is essential to achieve more success and so help to boost eHealth investment. **Upgrading the knowledge of healthcare professionals** and the provision of the necessary **skills** in eHealth are essential to the introduction of eHealth care.

For EFN, the development of an eHealth infrastructure implies more than technology. As an example, Slovak republic³ is a Member State which recently has developed a very detailed strategy and implementation plan, based on a comprehensive needs analysis for eHealth implementation. A **catalogue of stakeholders' eHealth needs and requirements was prepared** which served as a basis for the procurement of eHealth solutions and input to the iterative software development processes. In the meantime, as part of the eHealth governance structures, many countries have also advisory bodies involving professional associations, patient representatives, third party payers or care providers.

Question 6.1: OBJECTIVE 1: Increase awareness of the benefits and opportunities of eHealth, and empower citizens, patients and healthcare professionals.

In your view, what actions should the EC consider to improve awareness and empowerment of citizens and patients?

In your view, what actions should the EC consider to improve healthcare professionals' awareness and acceptance?

eHealth could have the potential, when thinking out of the traditional medical box, for a sound 'resource' addressing some of the main healthcare challenges in the EU and Europe. It is necessary to move away from the traditional doctor-patient relationship (paternalism approach) towards the empowerment of patients within the reallocation of the provision of high quality services within the Single European Market. To empower citizens, patients and healthcare professionals within this re-engineering process, EFN asks the European Commission to consider the following actions:

- Address and focus on major health challenges in Europe.
- All eHealth solutions must have the goal of being patient centred and empowerment.
- Promotion of eHealth unique capacity and role in moving patients towards the self-management of long term conditions increasing **patient independence**, improvements in the delivery of care, reduce of repeated hospitalisations rates and the use of emergency department.
- eHealth solutions should be developed together with users and stakeholders, patients, healthcare professionals.
- Invest in healthcare professional eHealth skills and competency, ensuring that all levels of education include eHealth, the optimal skill matching of the EU healthcare workforce is also needed. Advanced roles have emerged and evidence exists that nurses in advanced roles can run the health system and can design and implement eHealth technologies and approaches more effectively and efficiently. Empowerment of the patients implies giving up traditional ownerships of healthcare services in a European single market.

³ European countries and their journey towards national eHealth infrastructure. Final European progress report. KA Stroetmann et al. January 2011.

- Up scaling the examples of positive users' perceptions using eHealth, as they are a source of valuable experience that should be transferred to create awareness in other parts of Europe. With the key message of 'technology fit to meet user's needs' builds on an effective and efficient consultation during the development phases of clinical IT systems leading to a greater sense of broader ownership ensuring that the right questions are asked to the right users at the right time.
- Incentivise other professionals (in our case nurses) that have taken the leadership in making a paradigm shift using eHealth services. The Commission should include all users needed in the uptake of eHealth services in their communications and activities to promote the inclusiveness and the sense of ownership among all.
- **eHealth services** need to be recognised **value but as a support** for both, patients and professionals, not all the solutions are ready for every individual and country. It is therefore important to explore how each individual needs can be addressed in terms of healthcare and health management. The technologies need to complement the traditional healthcare making sound human links with innovative healthcare. Identifying users' needs will help ensure that eHealth applications will assist health professionals who are focused on providing patient care. Besides it is crucial to emphasise that they will never replace the human contact.
- Furthermore, considering that the 92% of the nursing workforce are women, a **gender approach** should orient the activities and developments when designing eHealth tools for a success implementation. If we want that eHealth leads to new jobs, new skills and economic growth, e-Health needs to be more gender sensitive in which mainly the industry, policy-makers, and professional associations should advocate more for gender sensitivity. If the design is not made by women, women will not use it and consequently, the health system will not use it.
- Taking into account the ongoing **EU enlargement** and the possible **inequalities** that can arise with the promotion of eHealth services, eastern EU countries should use more their social cohesion funds to implement E-health solutions.

In your view, in which of the areas listed below European cooperation is most important? (choose 3 maximum).

The EFN selection is **in bold**.

- a. **ICT system for clinical use (decision support systems, EHR, ePrescription, Radiology Information Systems, etc.)**
- b. ICT system for non-clinical use (administrative software, booking, statistic applications, professional education, etc.)
- c. **Information systems for Public Health (patient registries, other data bases for public health, research, etc.)**
- d. **ICT systems for patients, individuals (lifestyle, prevention, monitoring)**
- e. Other.

Comment

The EFN considers extremely important the development of ICT systems for patients and individuals in areas as lifestyle, education, prevention and monitoring, as it is essential in the cross border attention and the continuity of care, as if a person has received healthcare attention in one country he/she should be able to receive the cares needed in the home country, without compromising the quality of care.

Question 6.2: OBJECTIVE 2: Address issues to achieve eHealth interoperability

In your view, in which of the areas listed below European cooperation is most important? (choose maximum 3 options)

The EFN selection is in **bold**.

- a. Taking steps to achieve secure, unambiguous and portable electronic identification of EU citizens.
- b. Taking steps to advance technical interoperability to facilitate de-fragmentation of the eHealth market.**
- c. Taking steps to advance semantic interoperability to lay the foundation for a European level info-structure, to facilitate the access to and the reuse of common semantic interoperability resources.**
- d. Taking steps to address legal barriers to interoperability
- e. Taking steps to address lack of financial resources-through coordination, support actions, pilots, knowledge sharing, etc.**
- f. Other.

A European Interoperability Framework could be developed to provide support to Member States and stakeholders to solve interoperability issues. In your view, in which areas listed below is European cooperation most important? (Choose 3 maximum).

The EFN selection is in **bold**.

- a. The harmonised standards, profiles and technical specifications to be used to ensure cross border eHealth interoperability.**
- b. The harmonised interoperability testing and conformance systems to be put in place.
- c. The harmonised medical terminologies, ontology, classifications and codification systems that need to be used at EU level.**
- d. Defining common interoperability use cases for cross-border healthcare.
- e. Defining measures to achieve convergence of national eHealth interoperability frameworks.**

The EFN calls the European Commission to include the necessary terminology of all the professionals that are part of the patient health records. Nursing terminology and classification of cares are the utmost importance when aiming to provide continuity of healthcare. Health information systems must include reference terminology for nursing. The integration of international terminology (such as International Classification for Nursing Practice) in the electronic health record will achieve continuity, increase communication and secure relevant and reliable data about nursing practice and outcomes. The benefits of integrating eHealth and nursing terminologies are enormous. Combining the forces of research with International Classification for Nursing Practice will provide important benefits, supporting patient safety and quality of care.

The EFN believes that the development of EU Quality and Safety Standards regarding eHealth services should be undertaken.

Question 6.3: OBJECTIVE 3: Improve legal certainty for eHealth

In your view, how should the European Commission address legal issues related to eHealth? (Choose 3 maximum).

The EFN selection is in **bold**.

- a. **Encourage and support Member States in addressing relevant legal and organisational issues in a coordinated manner.**
- b. Propose a European legal framework to cover the rights of users of eHealth services in cross border cooperation.
- c. **Encourage professional associations, scientific societies and civil society representatives to promote best practices through the development of guidelines and or codes of conduct for eHealth services.**
- d. Other

Comments

The European Commission should safeguard citizens' privacy with mandatory standards for managing confidential information. Also, it should clarify issues as data protection and identification while exchanging health information.

In your views, which areas should the European Commission focus on?

The EFN selection is in **bold**.

- a. **Liability**
- b. Reimbursement
- c. **Data protection**
- d. **Licensing and accreditation of professionals and healthcare providers.**
- e. Other.

Question 6.4: OBJECTIVE 4: Support research and innovation in eHealth and development of a competitive European and global market.

In your view, how should the European Commission support innovation? (maximum 3)

The EFN selection is in **bold**.

- a. Provide strategic recommendations to Member States and stakeholders
- b. **Provide funding for the scaling up of innovative eHealth solutions, for example by facilitation deployment of research results.**
- c. Provide more flexible financing mechanism to support research and innovation.
- d. **Support collection, dissemination and analysis of information on innovative healthcare services.**
- e. **Support user-driven research through use of appropriate financial instruments**
- f. Other.

Comments

The EFN believes that the involvement of nurses and users in the whole process is crucial to ensure that the developments are health driven.



In your views, in which of the areas listed below should the European commission cooperate with international partners?

The EFN selection is **in bold**.

- a. Stimulate the international policy dialogue to facilitate the deployment of eHealth solutions
- b. Taking steps to advance interoperability
- c. Support R&D to advance new innovative solutions (Virtual Physiological Human, Personal Health systems, ICT for Public Health).
- d. Promote benchmarking and evaluation projects in order to provide evidence to support deployment of eHealth solutions.**
- e. Promote the use of EHR**
- f. Promote deployment of telemedicine services**
- g. Other

The Commission should look for other ways of collaboration with the social partners, next to the ones who represent the field where health professionals and citizens are living and working, and where eHealth services have to be used.

Taking into account the ongoing **EU enlargement** and the possible **inequalities** that can arise with the promotion of eHealth services, eastern EU countries should use more their social cohesion funds to implement eHealth solutions and the European Commission should find more ways of collaboration with them.

