



eHealth Information Systems

A High Level Position Paper

Prepared by EHTEL's Patients and Citizens Task Force

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Prepared by the Patients' and Citizens' Task Force
of the
European Health Telematics Association (EHTEL)

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Introduction

The emerging world of eHealth can be defined as the application of information, communication and video technologies to the delivery of timely, professional and safe healthcare. Systems now exist that hold increasingly detailed levels of clinical information, remotely monitor vital signs, enable remote diagnosis and treatment and more recently have facilitated surgery by professionals located thousands of miles away from the patient. While supporting professionals in the delivery of healthcare, eHealth information systems also have the potential to empower the patient.

Information systems now pervade the healthcare system and these are being developed at a local, national and international (European) levels. Regardless of where these systems are developed, three key issues remain unaffected: patients have the same problems, the demands on the healthcare system continue to increase and the principles against which information is managed increase in complexity.

The delivery of healthcare is focused on the patient. This may seem obvious but it is an important statement recognising that there are significant differences between the patient and the citizen, particularly in terms of their views and expectations regarding healthcare. Citizens may become patients for a short period of time, but generally they are not engaged with the healthcare system. Thus, their expectations and requirements will differ from the patient who is currently receiving treatment either on a short or a long term basis.

In ideal world, the patient would be in total control of the healthcare that he or she receives and take decisions regarding the way in which they are treated. In reality they can only do this with the support of professionals and with the provision of accurate and timely information. Given that we do not live in a perfect world and that professional time is both expensive and limited, patients increasingly rely on peer support groups to advise them.

It is against this background that EHTEL's Patient and Citizens Task Force was established. It is a unique group within the European eHealth community consisting of individuals who are patients in their own right or who represent patient groups but who are also highly qualified from a strategic, technical and managerial perspective within health and medical informatics. At the highest level, it has two main aims: to influence other stakeholders in the ICT and healthcare areas and to empower other patient groups.

Currently, most discussion about the development of eHealth systems happens between the developers and national institutions while there is very little interaction between those organisations and the patient. A key role for the Group is therefore to provide a bypass between the developers of systems and the patient.

Roles for the Group

The Task Force has two audiences for its work: the key stakeholders in the eHealth/ICT community such as developers and national institutions and, separately, patient organisations. In broad terms, the Task Force has a number of roles to perform in relation to each of these audiences as described below:

National Stakeholders

A vital activity for the Task Force is in ensuring that stakeholders such as politicians, national health authorities, professional medical and nursing groups and also system developers are made aware of the patient position in relation to eHealth. There is a common feeling that, “we’re all patients anyway so we understand the patient view”. This is a typical reaction from most national stakeholders and the fact that it is promoted demonstrates a clear misunderstanding of what a patient is and what his/or her view on a particular issue is likely to be. It is commonly used to circumvent the patient view.

Firstly, we are **not** all patients. The vast majority of people are fit and well and go through life as healthy **citizens** who occasionally fall ill and, temporarily, become patients. Others may suffer from chronic diseases or conditions that do place them in the position of being both citizens and patients throughout their lives.

Views and opinions offered on the delivery of healthcare by healthy citizens will be very different from those offered by the same individuals when they are undergoing treatment. Comments in the first category will tend to focus on issues such as cost, waiting times, cleanliness of healthcare facilities, friendliness of staff and quality of food. Once undergoing treatment, however, the emphasis will shift rapidly to much more personal issues such as dignity, self-respect, privacy and the need for information. These key concerns often rapidly fade as the patient recovers to assume the role of the healthy citizen.

It is important therefore that constant and ongoing patient orientated issues are available to policy makers and others in order to ensure that important decisions encompass the needs and requirements of the patient. For eHealth to succeed, acceptance by patients – both short and long term – is vitally important. Decisions taken around the committee table by healthy citizens are unlikely to reflect the views of the patient unless a conscious effort is made to listen to them.

Thus the Task force seeks to interact with the national stakeholders across the European Union either directly or by encouraging the involvement of patient organisations in the decision making process. It can do this in two ways: by providing consultancy services to stakeholder groups and by producing position papers that address the many different aspects of eHealth development.

In this regard the Task Force has already produced two key documents¹ and in the paragraphs below sets out its high level view on a number of other areas where it feels that a patient perspective is essential.

One final role for the group lies in its relationship with the designers and suppliers of future eHealth systems. Its Patients Charter establishes a number of principles regarding the facilities that future system might and should offer patients, although these are couched in high level terms. However, the Group would wish to develop a series of checklists for the advice and guidance of system developers that would meet the specific patient requirements set out in the Charter.

¹ “eHealth Information Systems – A Patients Charter”, December 2002. “Electronic Prescribing: A Position Paper”, April 2003.

Patient Organisations

There are thousands of patient support groups in existence across the European Union ranging from well-supported national groups to small focused groups often run by individuals from their own homes. Funding for these groups is, in the main, limited and the vast majority have little or no understanding or experience of the emerging eHealth technologies.

The task force aims to support these groups by ensuring that they receive briefings in the form of position papers and by establishing electronic communication channels with them. The aim is to empower these groups by ensuring that they have an understanding of the patient related issues associated with eHealth developments and to ensure that they are equipped to recognise both the positive and negative elements of these developments. By so doing, the Task Force believes it can enable wider and meaningful discussion between patients, their representatives and the national stakeholders.

The Patient Position on Emerging eHealth Developments

Introduction

As already noted, the Task Force has produced its Patient Charter that acts as an umbrella document setting out the guiding principles for eHealth development from a patient perspective. The Task Force seeks to produce a number of position papers, each of which will translate those guiding principles into more specific requirements for each topic area. Proposals for how those papers might be produced are contained in a separate document². As noted above, the Task Force has already produced a position paper on electronic prescribing although it would seek to refine this should sufficient funding be available.

The following paragraphs describe the Task Force's position in relation to a number of eHealth developments. Each of these is presented as a statement of high level views based on personal and professional experience but all requiring further research.

Patient Monitoring in the Home (eHome)

The potential for eHealth developments to improve the quality of life for elderly and disabled patients and those suffering from chronic diseases and other conditions is enormous. Monitoring of vital signs that was once only possible by having the patient moved to a specialist centre can now be undertaken remotely. Equally, the straightforward process of simply watching over elderly and infirm patients can now be undertaken from a distance and without the need for routine but expensive visits by a health professional or carer to the patient's home.

The advantages are easy to identify. Less expensive professional time is used in undertaking monitoring that can now (with the help of emerging technology) be placed in the hands of the patient. Patients in remote areas can be provided with access to fast remote support and the potential exists to help the patient remain at home for longer thus vastly increasing the quality of life.

² “ “

However, such support raises issues that need to be addressed at a serious and professional level. These include privacy where the patient must be provided with the right to have control over surveillance devices such as cameras particularly in private areas such as the bathroom and the bedroom. The dependency on technology must also be borne in mind. What is the effect on the patient if some or all of the technology fails? What safeguards will be in place to address this situation? What is the potential for harm? What training should be provided to technicians and newly qualified professionals entering peoples' homes? Finally, work needs to be undertaken to understand the potential for problems arising from less personal contact with the patient.

The Task Force considers this to be an important area that needs to be developed further but seeks to ensure that control over potentially invasive technology is placed firmly in the hands of the patient.

The Use of Technology for Remote Consultation (eConsultation)

This is an exciting area of eHealth which brings the potential for many benefits for the patient. It provides the opportunity to use communication technologies and other media to open up access to specialised consultation that would have been denied the patient previously due to issues of distance and national borders. It appears also to have the potential to assist in breaking down communication barriers and encourage openness as patients are, in some circumstances, more relaxed about discussing personal issues at a distance than when involved in a more traditional face-to-face consultation. This is particularly true in the case of written communication such as email.

However, issues of privacy and the security of the consultation need to be actively considered. How secure are the communication links? Who else is involved in the consultation that the patient may not be aware of?

Another key issue that needs careful consideration and more research is the training of professional staff in the way in which questions are phrased in order not to embarrass or mislead and to elucidate the best information in this artificial environment.

The Task Force believes that this area of eHealth has enormous potential to enhance the provision of healthcare by providing patients with greater access to a wider range of specialist skills

Opportunities to Counter Adverse Drug Reactions

Recent research has revealed disturbing figures relating to adverse reactions occurring during the prescribing/medication process resulting in potential harm to patients. Recent developments in the area of Order Entry appear to have demonstrated major improvements in this area and the Task Force would wish to see further investigation into the potential for improving patient safety in this area.

The Development of the Electronic Patient and Health Record (eRecord)

Accurate record keeping and the controlled dissemination of that information are crucial to the provision of effective healthcare. Furthermore, the development of electronic patient records for treatment of current conditions supported by the birth-to-death electronic health record provides a potent tool for effective treatment of patients and one that would be/is

welcomed by them. Potential benefits includes timeliness of information (there when it is needed), increased accuracy, fuller histories for new professional staff treating the patients and the potential to support cross-border flows.

From the patient perspective, however, privacy is paramount. The potential for information to flow into areas that the patient may not be aware of and may not approve of is always present, as is the desire of researchers to have access to such information. Thus safeguards need to be in place to reassure patients that professional duties of confidentiality are being met and that formal arrangements for obtaining consent are established. The patient position is not to obstruct appropriate and proper use of information but to ensure that basic human rights regarding privacy are respected and met.

The guiding principle that must be applied to this area in the future is that the patient is the master of his or her file and is at the steering wheel in deciding where and when information may be shared. With this point firmly established it is clear that the patient must have full and free access to their personal information to ensure accuracy and for personal understanding of their treatment. This is a right and not a privilege.

The Use of Technology to Support Self Management

The days of “doctor knows best and the patient concurs” are fast disappearing as much through necessity as through a basic desire on the part patients to better understand and contribute to their own treatment. The internet has brought a wealth of information to the patient’s own home and provides a welcome facility to research aspects of medication and alternative management strategies. Indeed, the patient can often have more time to spend on this issue than a pressured and time-limited professional.

Increased availability of information provides the patient with empowerment and more control. It is also leading to the increased sharing of information within patient support groups and the development of coping strategies supported by other patients.

Thus the concept of the “informed patient” is one that needs to infiltrate the existing consultation and treatment regime. The views of the patient need to be listened to and respected although it is recognised that this will have an effect on the time available for the consultation process.

It is also a fact that some patients seek to obtain their own medication from the growing number of “pharmacies” now appearing on the Internet. The Task Force does not endorse this practice recognising the serious dangers and potential harm that could arise from self-medication. Its position is, however, that if patients are seeking to follow this course of action, then research is required to understand why they choose to do so. If patients obtain supplies of Viagra – an obvious example – from the Internet rather than from their own doctors, something would seem to be going wrong with the existing consultation process.

Whilst increased involvement of the patient in the management of their condition is to be welcomed, it is recognised that they are not medically qualified practitioners. Thus the potential for misinterpretation and, in the case of self medication and some alternative therapies, personal harm is obviously present. However, self management and treatment is not going to stop, indeed it is likely to increase. Thus, in the future, work needs to be undertaken to provide advice and guidance to patients about options, sources of information and the potential dangers of self-managed regimes. In turn, further research and work is

required in developing quality control for information sources and, if necessary, in the supply of medicines. In this regard, the Task Force has endorsed the work of the European Commission in relation to improving and marking the quality of web sites providing health related information.

Smart Cards

The Task Force notes that this technology has been in existence for many years and yet still has to find a widespread use in the field of healthcare across the European Union. Its potential as a means of identification, authentication and as a medium for holding key health data appears to be enormous.

There are negative issues regarding how smartcards are to be used particularly by national authorities where the ability to establish links between health and non-health systems is an issue in some States. Also, there is a need to “add value” to health related smart cards if patients are to remember to carry them at all times.

The Task Force position in relation to smart cards at this point in time (and with a need to carry out more research) can be broken down into four parts, namely:

- No personal medical data, other than key, life supporting information such as blood type, allergies, chronic conditions etc, should be carried on the card
- The card should be used as a method of securely and privately linking to databases that hold personal information
- The use of the card should be under the personal control of the individual to which it relates
- The card should add value and bring benefits over and above healthcare to the individual

Cross Border Mobility

The Patient and Citizen Task Force recognises the enormous potential for cross-border that eHealth developments can bring. It seeks to ensure, however, that consistent standards apply in all areas of patient treatment, respect, dignity and privacy are enabled throughout the Member States of the European Union and in accordance with the specific principles embodied in the Patients Charter for eHealth Information Systems.

Conclusion

It is becoming clear that developments in eHealth are set to increase significantly in the near future. With the patient as their ultimate focus, it is critical that the views of this sector are taken into account when formulating policy and strategy and when designing and implementing new delivery mechanisms and systems. The Task Force believes that without such involvement the potential for eHealth developments to transform the delivery of healthcare (ultimately to the benefit of the patient) will not be achieved

PATIENTS AND CITIZENS TASK FORCE

However, in order for this to happen, it is clear that the major stakeholders such as national authorities have to recognise the importance of the patient voice and to support further work in this area. This includes involvement of patients in policy and planning groups, consultation with system designers and the undertaking of research in key areas such as those described above. There must also be recognition of the need for funding in these areas to enable such activities to move forward.

To date, the Task Force has sought to raise awareness of the patient perspective through presentations and discussion but this is not enough. The time has come to move forward and to begin to take real action in the area of empowering the patient.

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