



eHealth – Care in the Home

A Position Paper

Prepared by the Patients' and Citizens Task Force, EHTEL

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

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Preface

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 forum to canvass patient opinion and to communicate these views to the stakeholders described above.

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:

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.

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.

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.

To some degree the issues raised in this paper can be viewed as a “wish list”. However, we view them as an important starting point in the identification of matters that require further investigation and development. They now need to be moved forward either as formal programmes of work or through political lobbying. It is important to note that the views in this paper are not “set in stone” and will be revisited over time to ensure that they accurately reflect changes in the delivery of healthcare and the management of related information.

It is in this context that the following position paper has been prepared.

A Summary of Our Position

The following points summarise our position in relation to EHomecare as an eHealth application:

- EHomecare has enormous potential to improve the quality of life, reinforce the care and treatment of patients, reduce costs and reduce inconvenience
- EHomecare can bring specialist consultations and monitoring to the patient that would not have been possible without the appropriate communications technology
- The technology has the potential to increase patient confidence and well-being
- EHomecare can be utilised to support the patient by increasing the effectiveness of their own condition management
- The equipment used for EHomecare has the potential to be utilised for wider purposes in order to enhance the quality of patients lives
- The potential exists for carers to have the ability to access limited areas of the patient record to record details of the care provided, concerns they may have and requests for additional treatment
- Patients need support in managing EHomecare technology preferably through a single point of contact for all elements
- Controlling authorities need to be clear about ownership and legal responsibilities relating to the technology and to make this clear to the patient
- The benefits and risks associated with the use of EHomecare need to be made transparent to the patient
- The views and needs of the patient need to be taken seriously. Others cannot assume this responsibility.
- Education and training for the patient, the professional and the carer are essential in order to gain acceptance by the user
- Training needs to encompass not just the use of the technology but also the interactions between professional and patient and, indeed, the support staff who maintain the equipment. Respect and sensitivity are key components in the acceptance of EHomecare
- The patient must have the right to refuse to use the technology with no repercussions regarding the quality of treatment they receive.

PATIENTS AND CITIZENS TASK FORCE

- Socio-economic considerations including ICT literacy, relationships within the family household and the potential for others to assume responsibility for any monitoring and consultation need to be taken into account
- The need for direct human contact needs to be considered very carefully
- The patient needs to be in control of the technology. This is particularly important when considering the area of privacy
- Telecommunication networks carrying personal medical information need to be properly secured and appropriate audit trails showing who has accessed such information should be maintained.
- Access controls need to be implemented in items of equipment that could be used by other members of the household
- All equipment installed in the home should be suitable accredited to recognised safety standards and installed to a professional level and in accordance with health and safety directives

Introduction

The potential for eHealth developments to improve the quality of life for older people disabled people and patients affected by 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 older 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. More time at home increasing the quality of life, 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. To some degree, however, the development, design and thinking behind electronic eHomecare systems has not been particularly radical. We believe that the potential exists for services that go beyond simple monitoring and might aid the individual in interacting with care services. Such facilities might include ordering meals, obtaining assistance for shopping and housework and providing advice and guidance in relation their particular needs. In addition, The potential exists for carers to have the ability to access limited areas of the patient record to record details of the care provided, concerns they may have and requests for additional treatment.

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, but not only, 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 direct 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

The Management of EHomecare

There are two factors that will have a major influence over the way in which EHomecare is managed. Firstly, the technology is relatively new and still developing. As such it will be an unfamiliar technology to most of its users. Secondly, the largest group of users (certainly in the early days) is likely to be older people who are not as comfortable with such technology as their younger counterparts. Accordingly, it will be very important that users are provided with a simple and straightforward method of obtaining help and assistance and that this is organised in such a way that there is a single point of contact for all aspects of the EHomecare service.

For this to happen, the responsible authorities need to be very clear about the ownership of the technology and who accepts legal responsibility for its installation, maintenance and, above all, safety.

Finally, given that EHomecare (from an eHealth perspective) is relatively new, we believe that it is important for the benefits, difficulties, pitfalls and problems to all stakeholders to be identified and measured over time. This is important to ensure that there are recognisable and evidence based benefits for the patient as a major stakeholder in this initiative.

Education and Training

EHomecare has the potential to provide many benefits for different groups of stakeholders. However, it has to be recognised that it will only be used if patients and professionals alike are comfortable with its operation. As we have discussed in our Patients Charter for Information Systems and in our position paper on the Electronic Health Record, there is a tendency for the views and needs of the patient to be overlooked on the basis that others can take decisions on their behalf.

The key to the acceptance and effective operation of EHomecare lies in the provision of comprehensive education and training. Such education and training needs to cover a range of subjects including an explanation of the benefits and problems associated with using the technology as well as instructions regarding the use of the equipment. From the patients perspective, having the advantages of using EHomecare explained can be a major enabler for

its acceptance and use. Conversely, if the patient can see no benefit to the introduction of EHomecare into their lives, then the reason for installing it must be both revisited and re-presented or, ultimately, the project abandoned. Our position is that the patient has to be in control and has the right to choose as to whether they accept the technology or not. An opportunity for education and training exists at the time that a patient is recovering in hospital and may be returning home to use eHomecare technology. The recovery time presents an ideal opportunity for the patient not only to consider whether they wish to use the technology but also to be trained in its operation.

This latter point is very important. The whole reasoning for the use of EHomecare for any individual needs to be transparent. The patient, in order to make sensible decisions, needs to understand why it is considered that the technology will benefit her, the obligations she is expected to accept, the nature of the technology, the potential risks and, ultimately the benefits to herself. Transparency is a key element in the debate and the patient's decision must be final.

We feel very strongly about the need for professionals to be trained in the use of the technology, not just from the perspective of its operation but also in the way in which they conduct remote consultations bearing mind that the technology removes some of the non-verbal communication from the session. They must also bear in mind that at times when uncomfortable diagnoses have to be relayed or where an older patient has to take a difficult decision, they may have no-one with them for support. Thus, recognition of the need for sensitivity and respect will be required in any professional training.

Similarly, we believe that technicians entering a patient's home for the purposes of installation, maintenance or repair should also be trained in the need for respect and reassurance.

Another community that should be not overlooked in terms of education and training are the carers as these individuals may need to help to operate the equipment on behalf of the patient.

Socio-Economic Considerations

Regardless of the actual technology, there are a number of "softer" issues that need to be borne in mind when considering the use of EHomecare. Firstly, it needs to be recognised that there is still a significant gap in the levels of understanding of the type of technology used for eHealth across different socio-economic groups. Put quite simply, it is wrong to assume that everybody has encountered a personal computer or the Internet due to issues such as age or economic status. These factors need to be considered as they have the potential to impact on the acceptability of the technology within certain social groups. That is not to say that such groups should be excluded from the benefits that EHomecare offers but that the controllers of EHomecare need to be aware of the issues and take appropriate action.

Secondly, there is an issue regarding the balance of power within the home whereby younger, more technology aware members of the family, may take control of the equipment. This could lead to the patient being kept away from direct contact with the healthcare institution with an

intermediary acting on their behalf. Again, this is a factor that needs to be recognised when considering the implementation of an automated EHomecare service.

Thirdly, and very significantly, the introduction of EHomecare has the potential to radically alter the way in which patients are treated and the degree of human contact involved. While recognising the benefits that EHomecare can bring, there is a danger that the amount of human contact for the patient will be drastically reduced. For many people, particularly older people the regular visits by care staff may be their only human contact for some time. Indeed, for some, it may be their only such contact. Accordingly, our position in this regard is to emphasise the need for controlling authorities not to neglect this important aspect of patient treatment and care.

Conversely, some patients will resent the intrusion into their homes of technicians and other EHomecare technology support staff. Our message therefore is that those responsible for the management of EHomecare need to take time to understand the requirements of individual patients and to respect them.

Privacy and the Use of EHomecare

As with the Electronic Health Record (EHR), a significant issue for the patient in relation to EHomecare is the issue of privacy. During the course of our deliberations we have become aware of proposals for the use of closed circuit television (CCTV) cameras in the home in order to monitor patients in case they fall, become unconscious or suffer some other problem.

In itself, we can see the benefits of this approach and the increased safety that it could bring. However, there are times in our daily lives when it would not be appropriate for such monitoring to be undertaken. Our position on this matter is that where such monitoring takes place, it should be under the control of the patient who should have the facility to turn off the cameras or we would seek the development of more subtle and privacy friendly technology such as motion detectors.

Over and above direct monitoring of the individual, personal clinical information will need to be transmitted across telecommunication networks. Accordingly, those responsible for providing the technical infrastructure and those contracting for the service must ensure that these comply to appropriate security standards to ensure that sensitive data cannot be intercepted or misrouted. We also believe it important that audit trails are maintained to ensure that individuals accessing personal medical data are authorised to do so.

Finally, there is the issue of breaches of confidentiality occurring in the home involving other members of the family. As a private individual anyone has the right to withhold information about themselves, for whatever reason, even from close family members. Thus when designing EHomecare equipment, adequate facilities will need to be provided in order to ensure that the patient can restrict access to his or her personal medical information. This is an issue connected with the balance of power in the family group discussed in socio-economic considerations above.

EHomecare Safety

The introduction of EHomecare into the domestic environment increases the potential for system malfunction leading to possible fire hazards and additional cabling also has the potential to cause problems for patients with limited mobility. All such factors are recognised by health and safety standards implemented across the European Union.

With the introduction of such technology into patients homes, our position is that all such equipment should be tested and accredited to the highest standards and the installation carried out to agreed, legally binding and monitored specifications.

Wider Benefits

While the focus of EHomecare will be primarily on the use of technology for remote consultation and monitoring of various clinical indicators, there is scope for these developments to be exploited even further. We believe, for example, that the provision of networked equipment in the home could be used to promote increased understanding of the patients medical condition and to educate them in its management. In addition, patients could be directed to approved information sites and, indeed, encouraged to search the Internet for information. In the latter case, however, we believe that patients should be educated about the variable quality of information within that medium and in this regard we have endorsed the EC Guidelines for Quality Criteria for Health Related Websites in our Patients Charter.

There are clear possibilities for eHomecare technology to be exploited to assist with reminding people about drug and other treatment regimes through simple alerts and screen displays.

Where the installed equipment is compatible, the potential to exploit email also becomes a possibility. From the patient's perspective, the ability to seek information, guidance or reassurance through electronic messaging would be a significant development for those who are currently without this facility. It could also be used to encourage patients to enter into dialogues with peers in the form of self-help groups. Ultimately, it could simply be a method of reducing some of the loneliness experienced by certain sectors of society.

- **Conclusion**

eHealth in the form of EHomecare has the potential to bring significant benefits to large groups of patients in any number of locations. However, it is important to recognise that the introduction of technology into people's homes has to be done with sensitivity and respect. It must also be managed with the patient very much at the forefront of the process. Under no circumstances should it be viewed as a way of saving money regardless of the patient's wishes.

By default, eHealth EHomecare implies remoteness in terms of contact with the individual. It must be recognised that for some groups, contact with the healthcare professional or their support staff provides much needed human interaction and thus any implementation of the EHomecare technologies must recognise this fact.



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