



**A Position Paper
prepared by
the Patients' and Citizens Task Force
of EHETEL
in the context of the participation in the
User & Citizens Open Group of Healthware**

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Summary

eHealth: The Electronic Health Record

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

The Task Force has considered its position in relation to eHealth and the Electronic Health Record. This can be summarised as:

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- ▼ The patient has the right to expect that his or her privacy is respected and protected and that the EHR is handled with due regard to professional duties of confidentiality
- ▼ Controls for the reinforcement of privacy should not be weakened for the purposes of reducing costs
- ▼ The patient should be considered to be the master of the Electronic Health Record



- ▼ Patients should give their consent to the sharing of their personal information although this should be a simple and straightforward process supplemented by regular reviews. This process should also contain a facility for patients to be informed about the uses to which their information is to be put.
- ▼ The patient should retain the right (with recognised authority) to intervene if they are concerned abuses of privilege by others when sharing information.
- ▼ The right to opt out from having information shared should be available although individuals doing so should recognise that it could have a detrimental effect on their healthcare.
- ▼ Such an opt out should not be used as a method for denying individuals the right to treatment or care
- ▼ Technical innovations should be explored to handle specific situations where the patient may wish to have information withheld from certain organisations or individuals.
- ▼ The EHR should include electronic communications (eg emails where permitted) as part of the record
- ▼ The use of innovative methods of recording consultations should be investigated.
- ▼ The EHR should only be accessible by healthcare professionals who are under a duty of confidentiality.
- ▼ Managers and administrative staff should only have access to personal medical information on an exception basis and only after they have signed an appropriate confidentiality agreement.
- ▼ The systems processing and transmitting the EHR should be the subject of formal testing and accreditation in order to ensure their integrity.
- ▼ Patients should have unfettered access to their records and provided with assistance to understand them. The provision of a summary record should be considered.
- ▼ In certain cases (albeit with regard to strict limitations) the clinician should have the right to veto access where access to the information might have a harmful effect on the patient.
 - All electronic communications and records about a patient's health, medical care or personal information should be prepared and handled in a confidential and discreet manner.
 - The provision of a log-book showing who has accessed the EHR and what actions they have taken is considered to be an essential safeguard.



- Every eHealth system should have an associated security policy that clearly describes how the confidentiality, integrity and availability of records will be preserved. This should be freely available for patients to access. System administrators should not have the right to access personal medical data.
 - As part of the development process, system specifications should be produced which explain (in an easily understood form) how the system works and what measures have been taken to protect the patient.
- ▼ National healthcare authorities across the European Union should work to formalise and harmonise guidelines relating the use and processing of the EHR.
- ▼ These fundamental rights should apply to legal representatives of patients when the patients are unable to act for themselves.”

The entire position paper is available at
<http://healthware.alcasat.net/publications/publications.html>

