



**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 and Care in the Home**

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 Care in the Home. This can be summarised as:

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- ▼ 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.
- ▼ 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”

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

