Patient Empowerment Framework for Cardiac Patients

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Abstract. The iCARDEA Patient Empowerment Framework (PEF) provides a core architecture supporting services for patient empowerment, data exchange, and a Personal Health Record (PHR) system. The iCARDEA PEF supports key issues of patient empowerment and the architecture supports interoperability (IHE PCC profile) and provides integration features to support personal health applications.

Keywords. Patient Empowerment, PHR, Interoperability, iCARDEA, CIED

Patient empowerment should lead patients to making good decisions regarding their health. The crucial issue is how to incorporate patient empowerment into the daily life of patients and, in particular, into the healthcare process. The iCARDEA project [1] addresses patient empowerment in a comprehensive way. The overall goal of iCARDEA is to develop an intelligent platform to semi-automate the follow-up of CIED (Cardiovascular Implantable Electronic Device) patients using adaptable computer interpretable clinical guideline models for healthcare professionals and a Patient Empowerment Framework (PEF) for CIED patients. iCARDEA will assist medical professionals performing remote monitoring with decision support tools that semi-automatically execute computerized clinical guidelines that include relevant patient data from Electronic Health Record (EHR) and Personal Health Record (PHR) systems. Patients would use the PEF features to help them take a more active role in their own healthcare management.

There are several key issues that support patient empowerment (Table 1)

Table 1. Key issues for patient empowerment

Key issues	Description
Managing the patients own health data	PHR systems facilitate the process of accessing and managing the patient's own health data and allow individuals to manage their health information. [2]
Access to relevant health information	Information empowers patients and hence, facilitates patients to become a more qualified partner in their health care process. Informed patients will take better care of their health. [2]
Fostering self-management	Self-management strengthens patients to cope better with their daily life by taking in account their chronic disease. [3]
Trustful patient-physician relationship	This can lead to more self-confidence and comfort of patients. [4]

The iCARDEA Patient Empowerment Framework (PEF) supports key issues for patient empowerment by offering patients multiple services for self-management and for managing their own health information. The PEF is an open source framework, including PHR system components and web portal, that supports two primary objectives: facilitate patients in their disease-related self-management, and depending on the consent manager, facilitate the sharing of authorized data from the PHR system with medical professionals using iCARDEA decision support and patient monitoring tools. The PEF includes patient empowerment services supporting patients to:

- Manage their PHR data collected in the PHR system or from EHR systems through interoperability services between PHR and EHR systems or health applications.
- Facilitate their behaviour changes by managing their daily tasks through a personal Action Plan, Calendar, and observation collection tools.
- Monitor and report their Observations of Daily Living associated with their Action plan or to support trend analysis and evaluation of goals.
- Manage privacy of their health information using a Consent Editor.
- Utilize educational and support services using integrated social software tools that facilitate patient support and the exchange of knowledge with peers or experts. Writing is encouraged using blogs, forums, and wikis. Participating in online communities (e.g. self-help groups) also supports offline activities using community calendar, wiki, forum, blog and other social components.
- Exchange data with other clinical systems, PHR systems or health apps. Interoperability is supported by IHE Patient Care Coordination profile (PCC 9,10). Data exchange and authorization services support health applications.

Although the focus in iCARDEA is on cardiac patients, an important objective of the open source PEF is to grow an infrastructure of services supporting patient empowerment. Consequently, PEF should enable and support other health applications e.g. involving chronic diseases or even personal fitness related activities found in mobile applications.

Acknowledgements

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