

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 and a Personal Health Record (PHR) system. The iCARDEA PEF supports key issues of patient empowerment such as managing the patients own health data, offering access to relevant health information, enabling self-management and facilitating a trustful patient-physician relationship. Additionally, the iCARDEA PEF architecture should emphasize interoperability and integration features to support patient empowerment functionalities with other personal health applications.

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

Introduction

Up to the 20th century the primary cause of illness were acute diseases. Patients were inexperienced and passive recipients of immediate medical care. In post-war Europe, chronic diseases have become the dominant medical problem and consequently, patients have become partners in the health care process, contributing themselves to decision-making about their healthcare. With chronic conditions such as diabetes or cardiovascular diseases, the patient's life changes in a grave manner. This is the reason why the concept of patient empowerment has entered the discourse on medical care. Hence, patient empowerment solutions are gaining popularity and can be seen as "a philosophy of healthcare that proceeds from the perspective that optimal outcomes of healthcare interventions are achieved when patients become active participants in the healthcare process" [1]. Patient empowerment should lead patients to making good decisions regarding their health and their treatment [2] and the crucial issue is how to incorporate patient empowerment into the daily life of patients and in particular into the healthcare process. Ultimately this aims to re-establish a sense of identity, self-efficacy, knowledge, competence, action and control, which is particularly important for cardiac patients that must live with an electronic implant [3].

The iCARDEA project [4] 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 assists medical professionals in remote monitoring with decision support tools that will semi-automatically execute computerized clinical guidelines by integrating relevant patient data from Electronic Health Record (EHR) and Personal Health Record (PHR) systems [5]. Additionally, patients can use the PEF features to help them take a more active role in their own healthcare management. This paper focuses on concepts and services of the iCARDEA Patient Empowerment Framework.

1. Method

Currently, Patient Empowerment is an umbrella term covering a number of issues that can occur at different levels. Some patients simply want to be given information about their conditions whilst others want to have full control over all medical decision-making situations [1]. Hence, there are several key issues for supporting patient empowerment in a sustainable manner as described in 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. [1]
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. [1]
Fostering self-management	Self-management strengthens patients to cope better with their daily life by taking in account their chronic disease. [6]
Trustful patient-physician relationship	This can lead to more self-confidence and comfort of patients. [7]

On a conceptual level iCARDEA supports these key issues for patient empowerment in the following way:

Managing the patients own health data – increasingly, patient data are distributed over more and more data silos (EHRs, PHRs, Personal Health Applications) and without any comprehensive, common access or view of the patient's data. iCARDEA integrates patient data into the PEF from different sources such as CIED data and EHR data from a Hospital Information System (HIS). Compared to other PHR systems, the iCARDEA patient can edit, add, and annotate his own data or annotate EHR data imported from the HIS, and then allow data access via the Consent Manager to other medical professionals. Specifically for a PHR system, one important benefit for interoperability and accessibility is to expose a PHR system as a clinical data source based on relevant IHE Integration Profile requirements [8].

Access to relevant health information – the information material available in iCARDEA should be authored those with the appropriate expertise so that patients can educate themselves about their conditions or situation. Furthermore, we need to provide patients with materials on how they can actually empower themselves, even to help change behaviours – currently iCARDEA can provide unstructured decision aids and information material for helping patients to make decisions and to create their PEF action plan for supporting self-management or behavioural changes.

Fostering self-management – within the iCARDEA project, the PEF is adapted to address basic services for self-management. This includes amongst others the support of behavioural changes based on personalised Action Plans and the reporting of Observations of Daily Living (ODLs) [9], in particular cardiac-related symptoms such as chest pain, shortness of breath or weight gain. A special interest in iCARDEA is also for medication compliance such as dosage or medication changes, and patient general status e.g. indirectly reporting symptoms via a electronic diary or a calendar event log.

Trustful patient-physician relationship – when consulting with medical professionals, the patients share reports or data regarding their Action Plans, activities, Observations of Daily Living and trends, including how they feel during the day – indirectly providing input for symptoms relative to any treatments, medications, or conditions. The patient could become more active in their healthcare, fostering proactive behaviour, and leading to confidence and trust in a relationship of greater shared decision-making.

2. Results

The iCARDEA Patient Empowerment Framework (PEF) supports these key issues for patient empowerment by offering patients multiple services for self-management and for managing their own health information (see Figure 1). The PEF is an open source framework, including a PHR system and web portal front-end that supports two primary objectives: it facilitates patients in their disease-related self-management, and depending on the consent manager, it facilitates the sharing of patient data from the PHR system with medical professionals using an iCARDEA guideline-based decision support tool.

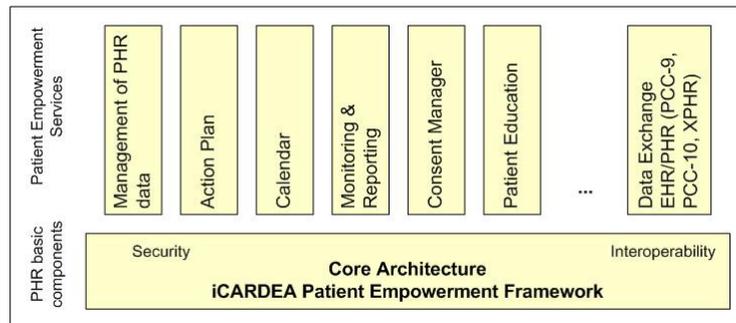


Figure 1. The architecture of the iCARDEA Patient Empowerment Framework

Figure 1 depicts an overview of the iCARDEA patient empowerment services. By engaging patients in these activities, one goal is to keep the patient mindful of their health and convince patients that they have control over their health. The process of monitoring their daily health or fitness observations is one step, together with their Action Plan [6], to keep the patient mindful of a situation they wish to control or monitor, and perhaps to facilitate a change in their behaviours for health reasons. Using the patient empowerment services, patients are therefore encouraged 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.

The main approach to interoperability between systems is guided by the appropriate IHE profiles. These IHE Patient Care Coordination (PCC) profiles support the exchange of patient information:

- PCC transactions: PCC-9 Care Management Data Query and PCC-10 Care Management Query Update enable a PHR system to act as a clinical data source [10].
- XPHR (Exchange of Personal Health Record profile) profile [10] and the appropriate IHE XD* (Cross Domain) transactions support the sharing of patient information between PHR and EHR, or other PHR systems.

Besides interoperability and security, the core architecture should maximize the integration potential to (Personal) Health Applications, including social web or portal applications. The core architecture provides basic services and components for a PHR system and facilitates integration with other applications and systems. The following highlights the most relevant core features:

- Message Bus – communication among components; utilize Enterprise Integration Patterns [11] to facilitate integration of current or new applications.
- Security – authentication (SSO, SAML2), authorization, and audit trail logging (IHE ATNA profile [8]). The iCARDEA Consent Manager and front-end will enable a patient to authorize access to their health data by particular healthcare actors from external systems (e.g. Care Manager). For example, the Consent Manager checks whether a medical professional is authorized to access patient data via a particular PCC-9 Care Manager query.
- Service registry – a central point where software actors can share information by placing or retrieving services. It includes services to support a standardized transactional model (IHE PCC-9 and PCC-10, IHE XPHR); this allows interoperation with other IHE conformant systems. Patients receive their EHR based data and or share their data with other healthcare actors.
- Health Applications front-end and presentation layer - supports integration with applications e.g. web portal, content authoring, calendars, and social software components to support patient empowerment functionalities.
- Profile Manager – supports management of patient health profile and access to portal profiles and the health profile, created by the user or from EHR systems.
- Modular Architecture / support modules – additional modules are available, such as a rule engine and rule-based process and workflow engine.

3. Discussion and future work

An important goal of chronic disease management is to help foster patient self-management. Patients have different needs depending on their conditions and their own preferences. With the technologist's expectations of future smartphones or personal sensor clouds, we will only grow more unintegrated personal health applications that might satisfy some ideas about patient empowerment, but are likely to only increase consumer confusion with the plethora of health or fitness applications together with their accompanying data silos. Future mobile applications will need to address interoperability and integration issues that provide patient empowerment features. Patient empowerment software must also integrate a diverse set of existing applications that clearly have shown benefit to patients and other users. For example, social software sites provide support or at least motivation to patients. Simply sharing one's observations is a means changing one's behaviour. For example, perhaps even the friendly competition of tracking and sharing exercise observations provides motivation. Software integration and interoperability are valuable features.

Although the focus in iCARDEA PEF is on cardiac patients, the PEF could support users with other chronic disease, e.g. diabetes or cancer, or even for personal fitness related activities. The open source PEF represents a basic infrastructure for patient empowerment services including interoperability and integration features.

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