

# PATIENT EMPOWERMENT FOR PATIENTS WITH IMPLANTABLE DEFIBRILLATORS

Manuela Plößnig<sup>1</sup>, Robert Mulrenin<sup>1</sup>, Mihai Radulescu<sup>1</sup>,  
Gökçe Banu Laleci<sup>2</sup>, Asuman Dogac<sup>2</sup>, Yildiray Kabak<sup>2</sup>

## *Abstract*

*Patient Empowerment engages individuals in taking care of their own health. This has been identified as a key element of change for improved quality and safety in healthcare. In the iCARDEA project, we aim at enabling cardiovascular implantable electronic device (CIED) patients to take a more active role in their own healthcare management by offering relevant information material and patient empowerment services in order to facilitate self-management. We present the main requirements and the design of the resulting PHR system for cardiac patients.*

**Keywords** – *Patient Empowerment, Electronic Health Records, Personal Health Record System*

## **1. Introduction**

Up to the 20<sup>th</sup> century the primary cause of illness were acute diseases and patients were inexperienced and passive recipients of immediate medical care. Over the decades of the 20<sup>th</sup> Century, chronic diseases have become the dominant medical problem and consequently, patients are required to become partners in the health care process, contributing themselves, to decision making about healthcare action. This is not only a human rights issue of patients deserving to be partners in their own health care but it is also a medical issue, because health care can be delivered more effectively and efficiently if patients are full partners in their care process [4].

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, especially in relation with chronic diseases and their management. Hence, patient empowerment solutions are gaining popularity and can be seen as "a philosophy of health care that proceeds from the perspective that optimal outcomes of health care interventions are achieved when patients become active participants in the health care process." [6]. The crucial issue is how to incorporate patient empowerment into the daily life of patients and in particular into the healthcare process, e.g. by facilitating the self-management capability of patients. There are several concepts that need to be addressed in order for patients to effectively self-manage their diseases.

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<sup>1</sup> Salzburg Research Forschungsgesellschaft, Salzburg

<sup>2</sup> Software Research, Development and Consultation Ltd., Ankara

## 2. Concepts of Patient Empowerment

Patient empowerment should lead patients to making good decisions regarding their health and their treatment [7]. Patient empowerment covers a number of issues and 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. For this reason there is no common, standardised model for patient empowerment. But there are several key issues and approaches that support patient empowerment:

- ◆ *A trustful patient-physician relationship* – close and trusting contact of patients with the physician can lead to more self-confidence and comfort. In particular, general practitioners are frequently the primary contact persons and usually play a key role in disease management programmes. For this reason physicians are often regarded as a main mediator to empower patient. In terms of patient empowerment not only the role of patients but also the role of physicians is changing. Physicians are therefore required to be better trained in communication so that they can take over the role of an advisor or a professional supervisor [8].
- ◆ *Access to relevant information* – access to relevant health information empowers patients and fosters the physician-patient relationship by facilitating patients to become a more qualified partner in their health care process. This can also increase the control that patients have over their healthcare. The challenge is to improve the patient's access to qualified and trusted information and their capacity to use it effectively [6].
- ◆ *Supporting patient education and improved decision-making process* – it is assumed that information empowers patients and that informed patients will take better care of their health [6]. Patient education refers not only to formal health education programmes, but also to education programmes using e-Learning, online support groups and electronically supported decision aids. Typically, patient education generally focuses on imparting knowledge to the patient that is disease-specific. Patient empowerment also means that the patient is educated in making good decisions about their health i.e. it refers not only to “medical” decisions. It also means that the patients are educated in managing how the disease affects their roles in life (e.g. such as parent or the way to participate in their favourite sport) as well as the emotional impact of the disease [7].
- ◆ *Managing the patient's own health data* – electronic Personal Health Record (PHR) systems facilitate the process of accessing and managing the patient's own health data and allow individuals to manage their health information. Although the implementation of electronic PHRs is still in its early stages in most European countries, the PHR is seen as having good prospects for future development and is regarded as a key component for implementing self-care and chronic care platforms [6].
- ◆ *Fostering self-management* – in particular, chronic diseases influence strongly the daily life of patients. Often, health-related decisions and actions can and will be done by the patients themselves. Many of these decisions involve routine activities of daily living (e.g. nutrition, physical activity). Hence, patients should be more involved in decisions about their care, health conditions, treatments and their lifestyle. Consequently patient empowerment should integrate multiple concepts that allow patients to effectively self-manage their disease. This can include strengthening problem solving capabilities, facilitating the decision-making process for patients, offering multiple resources which a patient can use (e.g. social

communities, information material, Internet) or providing supportive tools for changing behaviour and lifestyle in reasonable steps [5].

### 3. iCARDEA – Remote Monitoring and Patient Empowerment

In 2007, there were more than 800.000 patients in Europe with a cardiovascular implantable electronic device (CIED) causing more than 5.8 million follow-up visits for patients per year [10]. Both numbers are rising quickly. The iCARDEA project<sup>3</sup> aims at developing an intelligent platform to semi-automate the follow-up of CIED patients using adaptable computer interpretable clinical guideline models for the physicians and a Patient Empowerment Framework for CIED patients. iCARDEA assists cardiologists in remote monitoring and decision support tools for follow-ups of CIED patients and CIED patients are supported by multiple services for self-management and managing their own health data. The iCARDEA pilot application will be deployed in Salzburg, in SALK premises<sup>4</sup>. The prototype will be validated in a clinical setting including CIED patients and physicians as end-users. We report on the Patient Empowerment Framework that is being developed in iCARDEA.

#### 3.1. A Patient Empowerment Framework

The iCARDEA Patient Empowerment Framework aims at enabling CIED patients to take a more active role in their own healthcare management by offering relevant information material and services. It focuses on the following conceptual components:

- ◆ *The iCARDEA PHR system* – allowing patients to access and manage their own health data. The PHR system offers multiple services in order to facilitate the self-management competences for the patients.
- ◆ *Patient Information and Feedback* – supporting the patients self-care capabilities in order to achieve high acceptance and quality of living and fostering the patient-physician relationship in order to increase self-confidence and comfort for CIED patients

The iCARDEA Patient Empowerment Framework not only offers electronic services provided by the PHR system. It additionally includes offline services such as self-help groups which can help to increase self-efficacy or to change behaviour in line with the individual health care. The Patient Empowerment Framework is a component in the iCARDEA system which can be updated with clinical data by using the IHE Exchange of Personal Health Record Content Profile<sup>5</sup> (XPHR) content profile. Additionally, medical and lifestyle data collected by the patients in their PHR system (e.g. about blood pressure, weight, sport activities) can be used as additional information and input to the decision support tools for the cardiologists.

#### 3.2. The PHR system as the core component

A Personal Health Record (PHR) is an electronic, lifelong record of health information that is maintained by individuals. These individuals own and manage the information in the PHR, which comes from both their healthcare providers and the individuals themselves [3]. A PHR gives a

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<sup>3</sup> <http://www.srdc.com.tr/icardea/>

<sup>4</sup> SALK – Salzburger Landeskliniken (Hospital system of Salzburg) - <http://www.salk.at/>

<sup>5</sup> [http://wiki.ihe.net/index.php?title=Exchange\\_of\\_Personal\\_Health\\_Record\\_Content](http://wiki.ihe.net/index.php?title=Exchange_of_Personal_Health_Record_Content)

person up-to-date information when and where he needs it. Hence, a PHR system is a tool for collecting, tracking and sharing important, up-to-date information about an individual's health such as dates of significant illnesses and surgical procedures, current medications and dosages, allergies or sensitivities to drugs or materials, results from a recent physical examination, current educational materials or web links relating to one's health, diet and exercise logs [1]. A PHR system enables the lifelong management of a consumer's healthcare records and facilitates the consumer of being responsible for the own healthcare records.

Empowered individuals would like to collect all their medical and disease-related information in their electronic PHR. In iCARDEA the core of the Patient Empowerment Framework is a PHR system which allows CIED patients to manage their PHR and enables the patients to take a more active role in the management of their own healthcare. The iCARDEA PHR Core Architecture facilitates integration with other applications and systems and provides basic services and components for a PHR system such as a Message Bus for the communication among components, a Profile Manager supporting the management of patient health profile and security issues based on authentication (single-sign-on, SAML2<sup>6</sup>), authorization, and audit trail logging (IHE ATNA profile<sup>7</sup>). Additionally, the iCARDEA PHR system comprises the following functionalities (see Figure 1):

- ◆ *Management of PHR data* – providing PHR features for managing the personal health data including semantically enhanced annotations
- ◆ *Supporting behaviour changes by an Action Plan* – a customisable action plan facilitates patient health goals and behaviour changes by involving goals and tasks that are monitored via activities such as semantically enhanced patient observations and calendar services.
- ◆ *Monitoring and Reporting Services* – this refers to general observation services such as mood or exceptional events of daily life. It also refers to patients with cardiac insufficiency, who should e.g. control their weight or blood pressure e.g. on a daily basis.
- ◆ *Consent Manager* – privacy will be supported by a pluggable Patient Consent Editor used by patients to manage access to their data e.g. by healthcare providers or family members.
- ◆ *Patient Information Services* – includes bookmarking, sharing content and sharing web feeds, and the creation of specific materials for iCARDEA CIED patients for the pilot study.

The iCARDEA PHR system is designed to complement existing PHR systems and Personal Health Applications. The PHR system's modular approach provides services and integration features supported by Enterprise Integration Patterns<sup>8</sup>. Interoperability with Personal Health Applications will be supported by standards such as on IHE Profiles<sup>9</sup> for exchanging information between Electronic Health Records (EHR), PHR or other IHE profile compliant systems. In particular iCARDEA is based on Patient Care Coordination Profiles (PCC-9<sup>10</sup> and PCC-10<sup>11</sup>) and the Exchange of Personal Health Record Content Profile<sup>12</sup> (XPHR) for interactions with EHR or other PHR systems.

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<sup>6</sup> <http://www.oasis-open.org/committees/download.php/27819/sstc-saml-tech-overview-2.0-cd-02.pdf>

<sup>7</sup> IHE – Integrating the Health Enterprise <http://www.ihe.net/>

<sup>8</sup> <http://www.eaipatterns.com/eaipatterns.html>

<sup>9</sup> IHE Integrating the Healthcare Enterprise <http://www.ihe.net/profiles/index.cfm>

<sup>10</sup> <http://wiki.ihe.net/index.php?title=PCC-9>

<sup>11</sup> <http://wiki.ihe.net/index.php?title=PCC-10>

<sup>12</sup> [http://wiki.ihe.net/index.php?title=Exchange\\_of\\_Personal\\_Health\\_Record\\_Content](http://wiki.ihe.net/index.php?title=Exchange_of_Personal_Health_Record_Content)

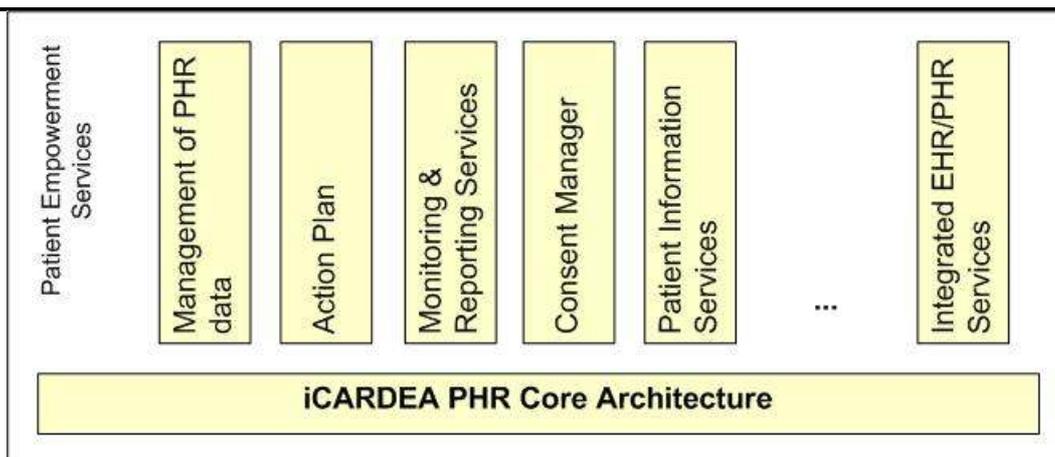


Figure 1: Major components of the iCARDEA PHR system

## 4. Conclusions

PHR systems will play a key role in patient-centred care and for patient empowerment. PHR systems can serve as a hub for information about and for patients. Today's PHRs will evolve into a suite of devices and applications enabling consumers not only to acquire, store, manage and interpret health information, but also to take appropriate health actions. And the information will be accessible whenever and wherever a patient needs it. Brennan [2] forecasts two possible paths for PHRs in the next three to five years. One will involve developing better links between health records containing a patient's observations and the records his clinician keeps. The other will entail a greater proliferation of more clinically useful home-monitoring and alert systems as home electronics mature.

iCARDEA portrays a different development route for PHR systems. Keeping patient-centred care in mind PHR systems should be devoted to patient empowerment and should - in particular - offer services supporting self-management. This will be achieved by the iCARDEA Patient Empowerment Framework in a twofold approach. On a practical level iCARDEA offers offline and online services for patient empowerment. On a technical level special services for facilitating self-management are provided – the *Action Plan* supports the changing of behaviour, information and education material aims to facilitate decision-making situations for patients and the monitoring of disease-relevant parameters such as blood pressure or body weight aims to support the self-control. Additionally, when patient-specific observations and notes about e.g. lifestyle, risk factors, cardiac-relevant symptoms or physical activity are combined with other patient-specific and disease-related data which can be collected at different stages of the health care process the benefit for decision support becomes clear. In iCARDEA, patients can allow their treating physicians to have access to specific information collected in the PHR system such as the medication changes or observations about weight gain, palpitations or shortness of breath. Such information is based on medical standards such as SNOMED CT<sup>13</sup> and LOINC<sup>14</sup> and can be included into the computerized clinical guidelines for follow-up visits for CIED patients.

With the technologist's expectations of future Personal Health Applications and in particular of mobile applications interoperability and integration issues that provide patient empowerment features need to be addressed. Patient empowerment software must also integrate a diverse set of existing applications that clearly have shown benefit to patients and other users. A first prototype of

<sup>13</sup> <http://www.ihtsdo.org/snomed-ct/>

<sup>14</sup> <http://loinc.org/>

the iCARDEA Patient Empowerment Framework will be ready by mid of 2011 and aims to complement existing PHR systems and Personal Health Applications. The PHR system modular approach provides services and integration features supported by Enterprise Integration Patterns for different purpose, e.g. monitoring and managing personal health data, medication or information material. An Enterprise information portal allows additional integration potential and communication between Personal Health Applications supporting Patient Empowerment services and non-iCARDEA PHR system.

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### **Corresponding Author**

Manuela Plößnig

Knowledge and Media Technologies, Salzburg Research Forschungsgesellschaft

Jakob Haringer Straße 5/III, A-5020 Salzburg

Email: manuela.ploessnig@salzburgresearch.at