



## iCARDEA

“An Intelligent Platform for Personalized Remote Monitoring of the Cardiac Patients with Electronic Implant Devices”

### SPECIFIC TARGETED RESEARCH PROJECT

**PRIORITY Objective ICT-2009.5.1: Personal Health Systems - a) Minimally invasive systems and ICT-enabled artificial organs: a1) Cardiovascular diseases**

## iCARDEA D5.3.1 Patient Feedback Mechanisms for the PHR

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## Table of contents

1	Introduction.....	4
1.1	Purpose.....	4
1.2	Definitions, acronyms and abbreviations.....	4
2	Overall Description.....	4
3	Communication between Patients and Physicians.....	4
3.1	Contact information in case of emergency.....	6
3.2	Patient Communication via remote monitoring.....	9
3.2.1	Communication through Remote Monitoring applications.....	9
3.2.2	iCARDEA Care Planner Engine Component.....	9
3.2.3	iCARDEA Patient Parameter Monitor.....	12
3.3	Limitations of patient communications.....	14
4	Communication with patients sharing similar situations.....	15
4.1	Forums for patients and health experts.....	15
4.2	Wiki-based resources for patient communities and forums.....	18

## 1 Introduction

### 1.1 Purpose

The deliverable describes issues relating to feedback mechanisms and the patient feedback mechanisms used in the PHR system, and how the PHR system and iCARDEA components support the communication between healthcare providers and patients.

### 1.2 Definitions, acronyms and abbreviations

Abbrevia- tion/Acronym	DEFINITION
PHR	Personal Health Record
PHRS or PHR system	Personal Health Record System

**Table 1 List of Abbreviations and Acronyms**

## 2 Overall Description

Electronic based patient feedback mechanisms aims to provide active and informed involvement of patients in management of their own health. These mechanisms provide the means for patients to share patient data, health related information, or create a dialog with other patients or healthcare experts. The feedback cycle is also supported over healthcare applications (external to the PHR system), such as the iCARDEA Care Planner and Patient Parameter Monitor. This cycle is facilitated by the PHR system interoperability services whereby patient information can be shared with authorised medical professionals using applications that communicate with the PHR system interoperability services.

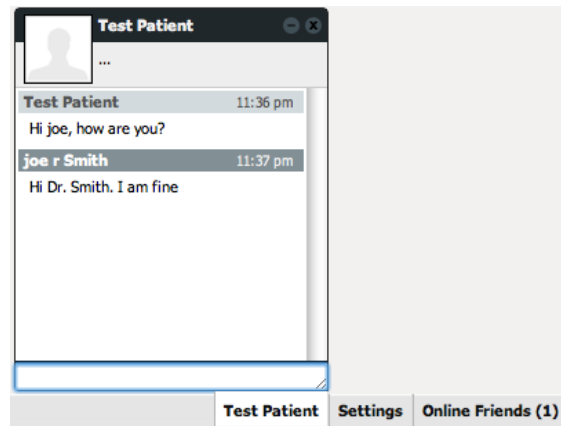
## 3 Communication between Patients and Physicians

Communication between medical professionals and patients is a sensitive area and legal, professional and hospital policies have to be respected. When patients communicate with a medical professional via a PHR system, they might expect that their data are monitored and their questions promptly answered by the medical professional – however, the PHR system is not necessarily monitored actively by a medically responsible organisation e.g. hospital or a physician. Moreover, a PHR system is an application dedicated to the patients' usages and under the patients' control. In addition, there are normally established protocols for communicating with patients e.g. telephone, email, fax, or postal mail. The

appropriate IT infrastructure or medical software supports these forms of communication and personnel comply with hospital policies especially for the patients' safety. A PHR system might also be considered external to this environment and therefore falls outside the responsibility of a hospital or physician. It is also questionable whether healthcare professionals would use a PHR system directly; that would depend on the degree of integration and interoperability with their own existing systems. The iCARDEA PHRS tries to address some of these issues in two ways: 1) provide capabilities in the web portal for users - patients and medical professionals; and 2) provide remote monitoring or data access capability to support applications in the physicians environment via the PHRS interoperability services.

There are two general approaches in the PHR portal for providing communications services to healthcare providers and their patients. One approach to facilitate communication is using the PHRS collaborative features for messaging. Messaging includes:

- Supporting Chat features, between patient and healthcare provider or other portal patients.
- Supporting IMAP<sup>1</sup> or Google mail configuration. A patient could receive or forward copies of mail from or to their private mail accounts. This requires a mail server. This way existing email addresses and established communication services are not replaced. Communication might be perceived to be closer to patient context in the PHRS.



**Figure 1 - Chatting between portal users**

The other pragmatic approach for providing communication services is via the PHRS interoperability services. Non-PHRS applications utilize PHR interoperability services to share the patient data with healthcare providers who then use their own means of communicating with their patients e.g. telephone, email, postal. Alternatively, their software might send alerts to the patients. For example, if a patient enters an unhealthy blood pressure in the PHRS, then the appropriate hospital application, such as the iCARDEA Patient Parameter Monitor<sup>2</sup> (section 3.2.3), could subscribe to patient's information in the

<sup>1</sup> IMAP Internet Message Access Protocol URL: <http://www.imap.org/>

<sup>2</sup> D7.1.1 Personalized Follow-up Parameter Assistant

PHR system and then receive patient information. Feedback to the physician can then be supported by the appropriate reports and alerts based on the updates from the PHR system. Based on this information, physician can provide feedback to the patient if necessary.

Communication with medical professionals can be enhanced when PHR information is shared with applications used by medical professionals via the PHR interoperability services. Data created or changed by the user is made available for sharing with other applications depending, however, on the consent of the patient. There are three kinds of information that the PHR system handles:

- Patient data created by other persons that cannot be modified (e.g. physicians) such as medical reports or laboratory results
- Patient data created by other persons that can be updated by the patient e.g. EHR data for medication dosage
- Data created and/or modified by the patients e.g. contact information, observations, (structured) data collected by services

Health related applications might then use the interoperability services. The iCARDEA Care Planner or the iCARDEA Patient Care Monitor (PCM) are two such applications that consume data from the PHR system over the interoperability services.

Because of both professional and organisational policies, electronic messages between a patient and physician might only be possible using established communication protocols and by using authorized email addresses, and not via the PHR system. However, to bring the patient context closer to the communication services, the PHR portal might be used to receive or forward mails to or from other mail accounts held by the patient and physician.

### **3.1 Contact information in case of emergency**

The patient can utilize a contact list of their physicians or other medical professionals e.g. physician, general practitioner, dentist, dietician, dermatologist or other specialists. Each medical professional can have:

- Name (required)
- Primary phone number (required)
- Role of the medical professional (required)
- Role note to describe specialty or reason
- Address label
- Electronic mail address
- Web site address
- Start or end dates of the healthcare relationship
- Primary organization e.g. affiliated hospital or clinic
- Optional note fields for remarks
- Optional name of assistant or secretary (agent)

Schema specifications were derived from current web standards, Portable Contacts<sup>3</sup> schema and its base vCard<sup>4</sup> schema, to support basic interoperability of contact information. Using Portable Contacts, additional extensions can be included now and in the future.

Briefly, Portable Contacts supports access to web-based address books and friends lists and it is based on various standards such as vCard and OpenSocial<sup>5</sup>. It also provides container elements and attributes for defining and organizing contact data that can also be used for storing, exchanging and exporting data in XML or JSON formats. Container elements provide groupings of contact elements e.g. telephones, addresses. Software conversion tools<sup>6</sup> are also available to transform contacts among formats such as Portable Contacts, vCard, and microformats<sup>7</sup>.

The most important elements of the contact model based on Portable Contacts and vCard card elements are outlined in Table 2. Additional elements were also defined such as the start and ending dates of the healthcare relationship between the patient and medical contact.

<b>vCard</b>	<b>Portable Contacts</b>	<b>Explanation</b>
	status	Status of this medical contact (active?)
N	name/familyName, name/givenName, name/middleName	Contact name. The display name (displayName) is the sum of the name elements.
TITLE	name/ honorificPrefix	Title of person
ORG	organizations/ name	Name of the primary associated organization (the hospital or private practice)
ROLE	organizations/ title	Role (e.g. physician, GP, dentist) in organization
LABEL	addresses/ formatted	Address label. Clinic or physicians private practice.
TEL	phoneNumbers /value phoneNumbers/type	Telephone
EMAIL	emails/value emails/type	Email address
URL	urls/value	Web site

<sup>3</sup> Portable Contacts <http://portablecontacts.net/draft-spec.html#schema>

<sup>4</sup> vCard <http://en.wikipedia.org/wiki/VCard> and <http://www.w3.org/2006/vcard/ns>

<sup>5</sup> OpenSocial <http://code.google.com/apis/opensocial/>

<sup>6</sup> Software converter tools

<http://wiki.portablecontacts.net/w/page/17776143/Software%20and%20Services%20using%20Portable%20Contacts>

<sup>7</sup> Microformats <http://microformats.org>

	urls/type	
AGENT	organizations/ note	Name of an assistant or secretary familiar to the patient.
NOTE	note or organizations/ note	A note added by the patient
UID	id	Unique identifier for the contact person
VERSION	published, updated	Version or expressed as two dates: the date first created and last updated

**Table 2 Relevant vCard Elements**

The patient will use a web interface for medical contact information (Figure 2) to manage their contacts or display all contacts for printing. In this particular contact form, only the primary and most relevant contact data is managed, although additional types of emails, telephones and addresses are possible.

The screenshot displays a web interface for managing medical contact information. At the top, there is a header 'Medical Contact Information' with two tabs: 'List and Manage Contacts' (selected) and 'Display All Contacts'. Below the tabs is a table listing three contacts:

Name	Role	Telephone	Active?
Dr. Mayer	Cardiologist	+43 111 222 3333	true
Dr. Kane	GP	+43 222 333 444	true
Dr. Bloom	Dentist	+43 444 343 4444	true

Below the table is the 'Medical Contact Form'. It features four action buttons: 'Add', 'Update', 'Delete', and 'Clear'. The form fields include:

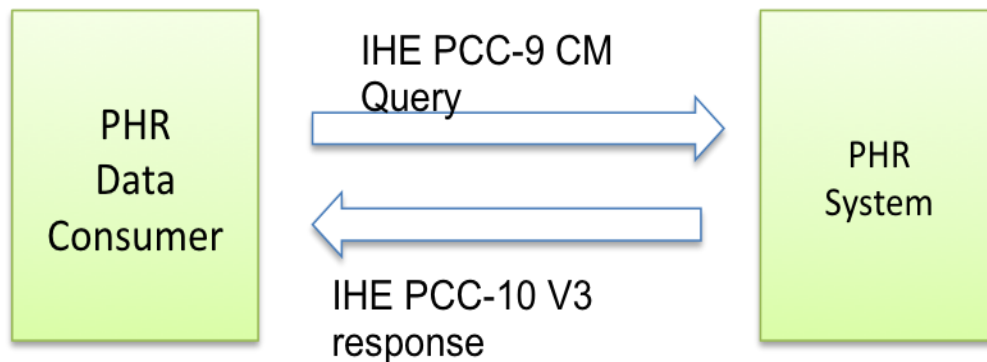
- Status:  Does this person still provide you healthcare?
- Title:
- Name:
- Telephone:
- Role:  (dropdown menu)
- Role comment:
- Clinic, Hospital:
- Email:
- Address:
- Notes:
- Website:
- The Year your healthcare began:
- The Year your healthcare ended:

**Figure 2 - Medical Contact Information**

## 3.2 Patient Communication via remote monitoring

### 3.2.1 Communication through Remote Monitoring applications

The primary means to communicate with medical professionals is through the remote monitoring of their patient information. The PHR interoperability services<sup>8</sup> provide the means for applications to subscribe to patient information (Figure 3). In iCARDEA, the remote monitoring is possible using the iCARDEA Care Planner (see section 3.2.2) or the Patient Parameter Monitor (see section 3.2.3). The physician is able to monitor PHR information directly in the Patient Parameter monitor or as input to an executable care plan. The physician and patient may then discuss any problem together.



**Figure 3 - Interoperability: Messaging between a PHR data consumer and the PHR System**

### 3.2.2 iCARDEA Care Planner Engine Component

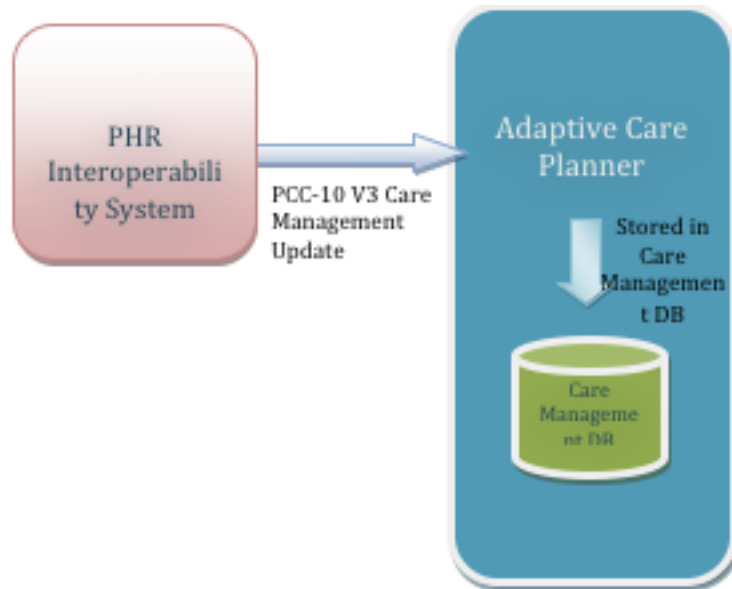
The Care Planner Engine includes data from received from PHR system via the PHR Interoperability services.

After PHR Interoperability System received a *PCC-09<sup>9</sup> Care Management Data Query* request from the Adaptive Care Planner, it sends all the recent information updated by the patient relevant to the subscription request to the Adaptive Care Planner. This is achieved through a *PCC-10 V3 Care Management Update* message as shown in Figure 4. An example *PCC 10<sup>10</sup> V3 Care Management Update* presenting the symptoms and observation of daily life activities entered by the patient in the PHR system.

<sup>8</sup> D6.3.1 Interoperability Infrastructure for Personal Health Records

<sup>9</sup> IHE PCC-09 - <http://wiki.ihe.net/index.php?title=PCC-9>

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



**Figure 4 - Care Management Update from PHR Interoperability System to Adaptive Care Planner**

Adaptive Care Planner processes the PCC-10 messages and stores the relevant PHR data in the Care Management database for use by the Care Planner Engine while an electronic care plan is being executed. While the care plan is being executed, healthcare actors, physicians and nurses, are informed about the current patient situation, which also includes the PHR data, and recommendations are presented to healthcare actors.

Apart from the Adaptive Care Planner is also able to provide feedback to the patients and their caregivers with different ways. For example if the care plan is designed in a way that it requires the caregivers of the patient to be notified when an abnormal patient reported symptom is presented in PHR data, then while the care plan is executed, the data fed by the PHR System to Care Management Database is checked by the Care Plan Engine and the necessary notifications are sent to the specified care givers. These are explained in Section 3.2.2.1 and 3.2.2.2.

### 3.2.2.1 Alarm Management via Personalized Adaptive Care Planner

After logged into the Personalized Adaptive Care Planner system, an authorised medical professional is able to adjust the Alarm Management settings by using the system. It is done through the "Alarm Management" in the Account Settings. By using this view, the medical professional can add the patients to monitor and set the urgency levels for each patient.

The screenshot shows the iCARDEA Alarm Management interface. On the left is a navigation menu with sections for 'iCardea' (Home Page, FAQ, Account Settings) and 'Tools' (Careplan Definition Tool, Careplan Monitoring Tool, Patient Management). The main area displays 'User Info' and 'Alarm Management' sections. Below these is a table of 'Registered Patients' with columns: Name, Surname, Gender, Birth Date, Add, and Urgency Level. The table contains two rows: Andreas Schmidt (M, 1953-01-04) and Jane Mayr (F, 1973-04-22). The Urgency Level for Andreas Schmidt is 'Send SMS' (Red), and for Jane Mayr, it is 'Send E-Mail' (Yellow). A legend at the bottom indicates the meaning of the colors: Red for Send SMS, Yellow for Send E-Mail, and Green for Do Nothing. An 'Update' button is located at the bottom right of the table.

Name	Surname	Gender	Birth Date	Add	Urgency Level
Andreas	Schmidt	M	1953-01-04	<input checked="" type="checkbox"/>	Send SMS
Jane	Mayr	F	1973-04-22	<input checked="" type="checkbox"/>	Send E-Mail

**Figure 5: Alarm Management**

As it can be seen from Figure 5, three different urgency levels are adjusted for each patient. These urgency levels are:

- Red - "Send SMS": This urgency level demonstrates that emergency messages are sent to the patient via SMS while execution if medical professional wants.
- Yellow - "Send E-Mail": This urgency level demonstrates that emergency messages are sent to the patient via e-mail while execution if medical professional wants.
- Green - "Do nothing": This urgency level demonstrates that emergency messages are not sent to the patient while execution.

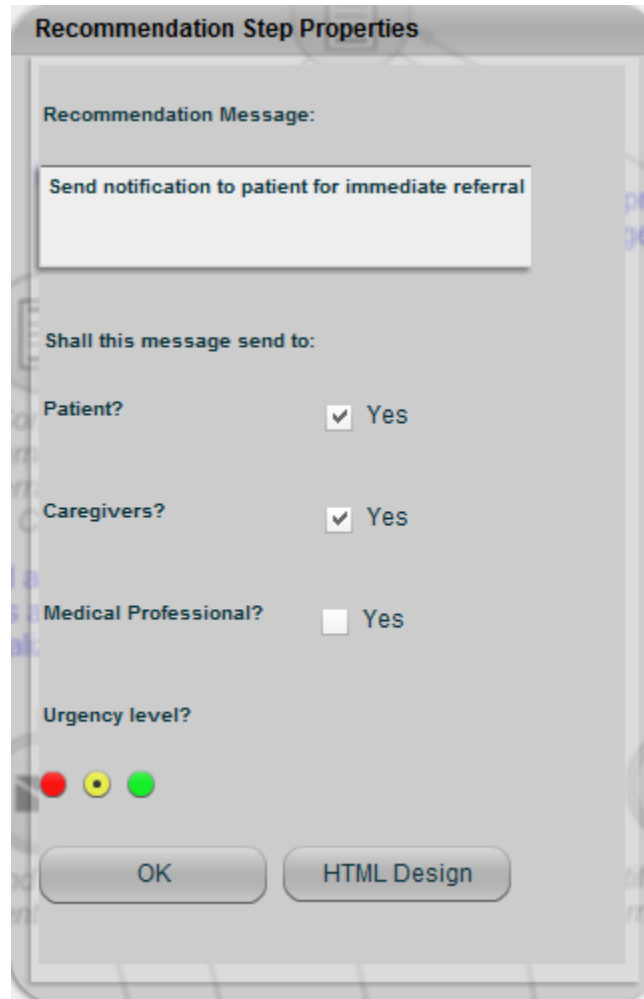
The caregivers of the patient can be added when the new patient is registered by the medical professional and the urgency levels for them are fixed as:

- "Yellow - Send E-Mail".

After alarm settings, a medical professional is able to choose the specific messages to be sent to the patient/caregivers by using Personalized Adaptive Care Plan Definition Tool. The details of this process are explained in detail in Section 3.2.2.2.

### 3.2.2.2 Personalized Adaptive Care Plan Definition Tool

Through this view, a medical professional can choose the specific messages to be sent to the patient/caregivers with the urgency levels adjusted before. By selecting the desired receivers, the messages are sent based on the urgency levels of each patient and their caregivers.



**Recommendation Step Properties**

Recommendation Message:

Send notification to patient for immediate referral

Shall this message send to:

Patient?  Yes

Caregivers?  Yes

Medical Professional?  Yes

Urgency level?

OK HTML Design

**Figure 6: Recommendation Message**

As it can be seen from Figure 6, the receivers of the recommendation message can be adjusted by a medical professional in the Care Plan Definition Tool. While executing the care plan, if this step is executed, this message will send to the receivers via SMS or e-mail based on their urgency levels that are set before in Alarm Management.

### 3.2.3 iCARDEA Patient Parameter Monitor

The Patient Parameter Monitor<sup>2</sup> is accessible to medical professionals and includes PHR updates from the PHRS interoperability services. As described previously (Communications via Remote Monitoring Applications section 3.2.1), a patient's PHR information can be transferred to the PHR data consumer in the IHE PCC transaction PCC-10 message. Using this tool, medical professionals are able to monitor and discuss with patients regarding any problems and observe the latest medication information as updated by the patient from the PHR system (Figure 7 and Figure 8).

**Patient Parameter Monitor**Welcome **Nurse Allan**

Logout

Selected Patient: **Schmidt, Andreas (01.04.1953)** Last opened by Mrs. Allan (21.02.2010)

Diagnosis: Sudden cardiac death

Implantation: 20.11.2009 Battery Changed: -

ICD: Dual chamber St Jude Current excel DR Serial: 525113

Choose View:

Overview

PARAMETERS	
Battery Voltage	3,2 V (1,0 - 4,0)
Battery Impedance	-
Magnet rate	-
Charge time	9 sec
Date of last capacitor charge	na
PHR current	
	<a href="#">History</a>
Systolic blood pressure	135
Diastolic blood pressure	80
Heart rate	83
Body weight	87
Medication	Simvastatin, 1 tablet, 1x day <a href="#">More</a>
Symptom	short of breath <a href="#">Show</a>

**Figure 7 – Patient Parameter Monitor example**

**Patient Parameter Monitor** Welcome **Nurse Allan**

Selected Patient: **Schmidt, Andreas (01.04.1953)** Last opened by Mrs. Allan (21.02.2010)  
 Diagnosis: Sudden cardiac death  
 Implantation: 20.11.2009 Battery Changed: -  
 ICD: Dual chamber St Jude Current excel DR Serial: 525113

Choose View:  
 Medication

**Current Medication**

Name	Dosis	Morning	Noon	Afternoon	Bedtim	Comment	Change
Nexium	20 mg	0	0	1	0		no
Thrombo-Ass	100mg	0	1	0	0		no
Plavix	75mg	0	1	0	0	until 14.11.2010	no
Nomexor	5mg	1	0	0	0		no
Simvastatin	20mg	0	0	1	0		no

**Figure 8 – Overview of the medication from the PHR system**

The PHR system interoperability services can receive PCC-9 queries and depending on the registered query, the PHRS can share data such as patient symptoms, medication updates, activities of daily living, vital signs for body weight and blood pressure, and risk factors. For the iCARDEA WP9 pilot application, the PHRS patient information used by the Patient Parameter Monitor and Care Planner are described in more detail, including PCC-10 messages, in the iCARDEA deliverable D9.1.1 *Requirement Specifications and Scenario of the Pilot Application* (VT and AT scenarios)<sup>11</sup>.

### 3.3 Limitations of patient communications

There are normally existing and well-established communication services between patients and medical professionals. The PHRS can enhance communication by providing messaging components and by sharing data with clinical systems via interoperability services. However, it should not replace existing services for patient, such as electronic mail or telephone calls. Patients might expect a professional to answer their questions or monitor their data. Medical professionals should expect that a communication service and existing protocols ensure patient safety. Sharing data with a clinical system does help transfer the responsibility for follow-up ( from alerts, reports) directly to the medical professionals. For example, based on laws the hospital or medical professionals might be

<sup>11</sup> D9.1.1 Requirement Specifications and Scenario of the Pilot Application. Story Board for Pilot Application Scenario (Ventricular Tachycardia)

responsible for the electronic mail received from patients – depending on hospital policy or law, whoever opens a message, should take responsibility for following a particular communications protocol. These policies have to be taken in consideration when inter-linking a PHR system with existing hospital and healthcare applications.

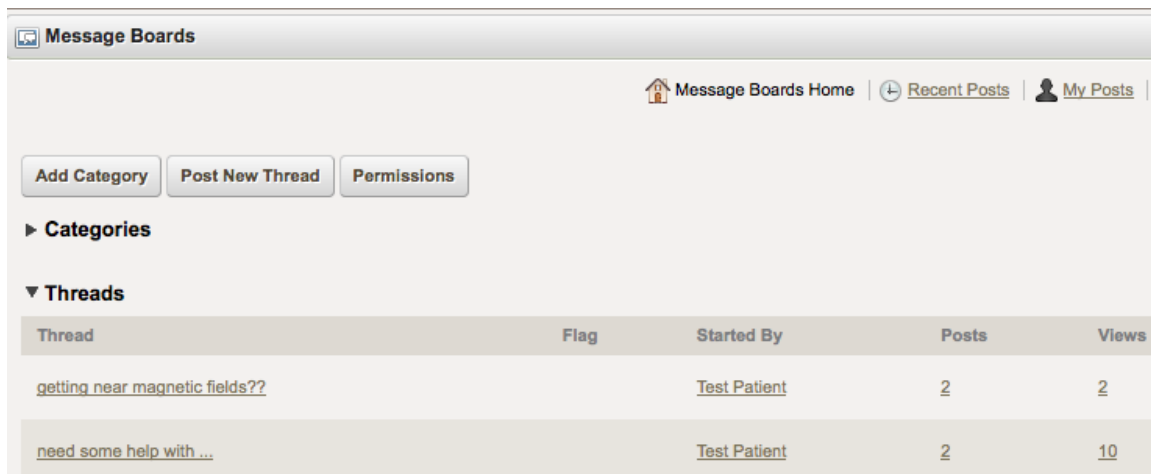
## 4 Communication with patients sharing similar situations

Patients and healthcare professionals might share their experiences or provide other information to other patients by using social media for patients.

### 4.1 Forums for patients and health experts

Web-based forums (Figure 9) provide common features for users to create a threaded discussion of forum posts by using a web-form editor (Figure 11). Users have the ability to also freely tag their posts or to categorize their post using a simple vocabulary created by the users. Example categories might include: Anxiety, defibrillator technology, depression, medication, sport, using electronic devices. Users might then select a category or subscribe to particular categories to follow posts in the forum.

Threaded discussions contain one or more posts submitted by users. An overview of all threaded discussions are shown in (Figure 9 and Figure 12).



Thread	Flag	Started By	Posts	Views
<a href="#">getting near magnetic fields??</a>		<a href="#">Test Patient</a>	2	2
<a href="#">need some help with ...</a>		<a href="#">Test Patient</a>	2	10


Figure 9 - Forum overview

Figure 10 shows a list of posts within a discussion thread that are created using editor shown in Figure 11.

getting near magnetic fields?? Test Patient 8/3/11 1:16 PM

RE: getting near magnetic fields?? Test Patient 8/3/11 1:18 PM

---

 **getting near magnetic fields??** Reply Reply with Quote Quick Reply  
8/3/11 1:16 PM

**Test Patient**  
Rank: Youngling  
Posts: 4  
Join Date: 2/25/11  
[Recent Posts](#)


Hello,

Beginner question - I already searched the internet. What actually happens with my device if I come to close to a magnetic field?  
What distance do I need to keep away from magnetic fields.  
It would help to have examples of appliances or even magnetic fields that I might encounter while traveling, buying electronics or even going to the dentist.

thanks for any help  
David

0 (0 Votes) [Flag](#) [Top](#) [Edit](#) [Permissions](#) [Delete](#)

---

 **RE: getting near magnetic fields??** Reply Reply with Quote Quick Reply  
8/3/11 1:18 PM as a reply to Test Patient.

**Test Patient**  
Rank: Youngling  
Posts: 4  
Join Date: 2/25/11

Dear David,  
Try looking at the manual "Life with the Defibrillator" at <http://www.defi-liga.com>  
Very interesting and it is now in my bookcase for quick access. I look at it first when I have questions.  
Maybe if there are still some open questions, we can organize and make a FAQ page here..  
Hope this helps you. Best regards, Carol

**Figure 10 - Overview of forum “posts” from users in a threaded discussion**

**Message Boards**

## New Message

**Subject**  
getting near magnetic fields??

**Body**

Font [v] Size [v] **B** *I* U ~~S~~

Hello,  
Beginner question - I already searched the internet. What actually happens with my device if I come to close to a magnetic field?  
What distance do I need to keep away from magnetic fields.  
It would help to have examples of appliances or even magnetic fields that I might encounter while traveling, buying electronics or even going to the dentist.  
thanks for any help  
David

Mark as a Question

Anonymous

**Priority**  
[v]

Allow Pingbacks

**Tags**  
[v]

Add Select Suggestions

**Permissions**  
Viewable by Anyone (Guest Role) [v] [More Options »](#)

**Figure 11 - Editor for creating a post in the forum**

Categories can be used to help filter and organize posts from users (Figure 12). Categories can be added, such as: Anxiety, Medication, Using electronic devices, and Defibrillator technology.

The screenshot shows a web interface for 'Message Boards'. At the top, a green banner indicates 'Your request processed successfully.' Below this is a navigation bar with links for 'Message Boards Home', 'Recent Posts', 'My Posts', 'My Subscriptions', 'Statistics', and 'Banned Users'. There is also a search box and RSS/Subscribe options. A secondary navigation bar includes 'Add Category', 'Post New Thread', and 'Permissions' buttons. The main content area is divided into two sections: 'Categories' and 'Threads'. The 'Categories' section contains a table with columns for 'Category', 'Categories', 'Threads', and 'Posts', listing categories like 'Anxiety', 'Using electronic devices', 'defibrillator technology', 'depression', 'medication', and 'sport'. The 'Threads' section shows a table with columns for 'Thread', 'Flag', 'Started By', 'Posts', 'Views', and 'Last Post', with one thread titled 'need some help with ...'.

Category	Categories	Threads	Posts	Actions
Anxiety	0	0	0	Actions
Using electronic devices	0	0	0	Actions
defibrillator technology	0	0	0	Actions
depression	0	0	0	Actions
medication	0	0	0	Actions
sport	0	0	0	Actions

Showing 6 results.

Thread	Flag	Started By	Posts	Views	Last Post	Actions
need some help with ...		Test Patient	2	8	Date: 6/20/11 2:28 PM By: Test Patient	Actions

**Figure 12 - Category subscription**

Existing online patient forums can be accessed via the portal's Wiki pages (Section 4.2) for patient communities and forums (section 4.2). An example for an existing forum is Defibrillator-Forum<sup>12</sup>, a German forum for patients with a defibrillator. Defibrillator-Forum also includes information and contacts about self-help groups and related associations. These patient forums pages can be edited and assembled by users.

## 4.2 Wiki-based resources for patient communities and forums

Wiki-based content management in the PHR portal will enable authors to create web pages identifying resources for both online and offline communities supporting patients. These references and others might also be collected by recommendations from healthcare professionals that are shared their patients. This enables patients to contact and communicate with other patient communities and forums. With feedback from other forums as well as from the PHRS forum, the patient might bring more understanding and further questions to his/her physician, or the PHRS forum, for feedback. The portal content management supports the creation and updates to community pages by designated authors.

Alternatively these web-based iCARDEA PHR community pages can also be managed externally by authors on an external public web site and made available in the PHRS portal via an IFrame<sup>13</sup> portlet<sup>14</sup>. The IFrame allows a site to be used with a web page of the portal. The content of the externally managed site could then be viewed within an IFrame portlet. Hosting and managing particular PHR system content and resources externally

<sup>12</sup> Defibrillator-Forum <http://www.defi-forum.de/>

<sup>13</sup> IFrame description - <http://en.wikipedia.org/wiki/IFrame>

<sup>14</sup> Portlet description - <http://en.wikipedia.org/wiki/Portlet>

allows groups to work independently to create public online resources, not specific to one particular PHR system installation.