SELF MANAGEMENT OF PATIENTS WITH ANKYLOSING SPONDYLITIS THROUGH A PERSONAL HEALTH SYSTEM

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ABSTRACT

SELF MANAGEMENT OF PATIENTS WITH ANKYLOSING SPONDYLITIS THROUGH A PERSONAL HEALTH SYSTEM

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Today, the growth in the number of aged people in the European population imposes an increasing burden on the healthcare systems. Accordingly, the number of people suffering from chronic conditions continues rising, which leads to an increasing demand for health care services and the subsequent cost pressure on the systems. In this environment, the citizens', especially chronic patients', contribution to their own treatment is crucial to ensure future health care supply in ageing society.

Patient empowerment integrates multiple concepts that allow a patient to effectively self-manage his disease, which are accessing to health information, education, bi-directional communication between patients and healthcare professionals, self-care support, chronic disease management support and shared decision making. Patient empowerment is considered as a potential tool to reduce healthcare costs and improve efficiency of the healthcare systems. Although there has

been significant research in the field and there are important pilot studies in place, the ultimate implementation of patient empowerment is not yet a reality.

In this thesis, we present a Personal Health System (PHS), namely PHS4AS, addressing all the concepts involved in patient empowerment in order to achieve the ultimate implementation of it. PHS4AS is developed for patients suffering from ankylosing spondylitis (AS), which is a rheumatismal chronic disease with high prevalence and incident rates in Turkey.

The developed system has been used and evaluated by 131 patients and 3 healthcare professionals in a pilot study in Turkey within the scope of European Commission supported CIP-ICT-PSP-297260 PALANTE Project.

Keywords: Personal Health Systems, Personal Health Records, e-Health, Patient Empowerment, Ankylosing Spondylitis, Interoperability

ÖZ

ANKİLOZAN SPONDİLİT HASTALARININ KİŞİSEL SAĞLIK SİSTEMİ İLE KENDİ SAĞLIKLARINI YÖNETMESİ

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Günümüzde Avrupa popülasyonundaki yaşlı insan sayısındaki artış, sağlık hizmetleri üzerinde büyük bir yük oluşturmaktadır. Benzer şekilde, kronik hastalıklarla mücadele eden insanların sayısı da artmaya devam etmekte ve bu da sağlık hizmetlerine olan talebi, dolayısıyla da sistemler üzerindeki maliyet baskısını arttırmaktadır. Böyle bir ortamda, vatandaşların, özellikle de kronik hastaların, kendi tedavilerine dahil olmaları, yaşlanan toplumdaki sağlık hizmetlerinin devamlılığı için çok önemlidir.

Hastaların kendi sağlıklarının yönetimine dahil olması fikri hastaların hastalıklarını kendi kendilerine yönetebilmelerini sağlayan farklı bir çok kavramı bir araya toplamaktadır. Bunlar sağlık bilgisine erişim, eğitim, hastalar ve sağlık uzmanları arasında çift yönlü iletişim, kişisel bakım desteği, kronik hastalık yönetimi desteği ve ortak karar almadır. Hastaların kendi sağlıklarının yönetimine dahil olması sağlık hizmeti harcamalarını azaltmak ve sağlık hizmetlerinin verimliliğini arttırmak için potansiyel bir araç olarak görülmektedir. Günümüzde bu alanda bir çok önemli araştırma ve pilot çalışması olmasına rağmen, bu fikrin nihai uygulaması henüz yapılamamıştır.

Bu tezde, hastaların kendi sağlıklarının yönetimine dahil olması fikrindeki kavramların tamamına değinen bir kişisel sağlık sistemi sunulmuştur. PHS4AS isimli bu sistemin amacı bu fikrin nihai uygulamasını yapabilmektir. PHS4AS, romatizmal bir kronik hastalık olan ve Türkiye'de görülme oranı yüksek olan ankilozan spondilit hastalığını taşıyan hastalar için geliştirilmiştir.

Geliştirilen sistem, Avrupa Komisyonu tarafından desteklenen CIP-ICT-PSP-297260 PALANTE Projesi kapsamında Türkiye'de yapılmış olan bir pilot çalışmasında 131 hasta ve 3 sağlık uzmanı tarafından kullanılmış ve değerlendirilmiştir.

Anahtar Kelimeler: Kişisel Sağlık Sistemleri, Kişisel Sağlık Kayıtları, e-Sağlık, Hastaların Kendi Sağlıklarının Yönetimine Dahil Olması, Ankilozan Spondilit, Birlikte İşlerlik

To my family...

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TABLE OF CONTENTS

LIST OF TABLES

TABLES

LIST OF FIGURES

FIGURES

LIST OF ABBREVIATIONS

AS Ankylosing Spondylitis

ASQoL AS Quality of Life

ASTM American Society for Testing and Materials

BASDAI Bath Ankylosing Spondylitis Disease Activity Index

BASFI Bath Ankylosing Spondylitis Functional Index

CCD Continuity of Care Document

CCOW Context Management Specifications

CCR Continuity of Care Record

CDA Clinical Document Architecture

CDA R2 Clinical Document Architecture Release 2

CHAS Centralized Hospital Appointment System

COPD Chronic Obstructive Pulmonary Disease

CRUD Create, Read, Update, Delete

ebXML e-Business XML

EHR Electronic Health Record

EU European Union

EULAR European League Against Rheumatism

FHIR Fast Healthcare Interoperability Resources

FMIS-T Family Medicine Information System of Turkey

GP General Practitioner

HIS Hospital Information System

HL7 Health Level Seven International

ICD International Classification of Diseases

ICT Information and Communication Technologies

IDE Integrated Development Environment

IHE Integrating the Healthcare Enterprise

ISO International Organization for Standardization

ITS Implementation Technology Specification

JDBC Java Database Connectivity

JNDI Java Naming and Directory Interface

JTA Java Transaction API

MLLP Minimal Lower Layer Protocol

MoH Ministry of Health

MVC Model-View-Controller

NHIS-T National Health Information System of Turkey

OASIS Advancing Open Standards for the Information Society

ORM Object-Relational Mapping

OSI Open System Interconnection

OSGI Open Services Gateway Interface

PAM Patient Activation Measure

PHR Personal Health Record

PHS Personal Health System

RIM Reference Information Model

SDK Software Development Kit

TAM Technology Acceptance Model

TLAR Turkish League Against Rheumatology

UI User Interface

UML Unified Modelling Language

VACS Virtual Arthritis Clinical Service

WHO World Health Organization

WS Web Service

XML eXtensible Markup Language

XPHR Exchange of Personal Health Record Context

CHAPTER 1

INTRODUCTION

The ageing of the European population is imposing an increasing burden on today's healthcare systems. By 2050, the number of people in the European Union (EU) aged 65 and above is expected to grow by 70% and the number of people aged over 80 by 170% [14]. Furthermore, the number of people suffering from chronic conditions will continue rising, which will lead to an increasing demand for healthcare services and the subsequent cost pressure on the systems. This poses important challenges for the 21st century. In this environment, the citizens' contribution to their own prevention and treatment is crucial to ensure future healthcare supply in an ageing society. This is particularly relevant for chronic patients, who will have to be enabled for self-management with better access to personal health data. In a context of increasing health costs and decreasing number of care workers, the benefits that the technology can offer are needed to be maximized in order to ensure the sustainability of healthcare systems.

Patient empowerment has become an element of high priority in the EU health strategy [20], supported both by national and regional health authorities as well as by the European institutions. The concept of patient empowerment describes a situation where an individual is an active member of his own disease management team. The perspective behind this concept is that care is more effective when patients become active participants in the healthcare process, that is, when they are well involved and informed. Patient empowerment integrates multiple concepts that allow a patient to effectively self-manage his disease. It begins with information and education and includes actively participating in treatment decisions. Indeed, shared decision making between physician and patient is the ideal goal of patient empowerment. Unlike traditional patient education that focuses on imparting disease specific knowledge to the patient, empowering means that the patient is also educated in making good decisions about their health and in managing how their condition affects their life as well as the emotional impact of the disease. Patient empowerment is considered as a potential tool to reduce healthcare costs and improve efficiency of the health systems by reinforcing healthcare quality. Although there has been significant research in the field and there are important pilot studies in place, the ultimate implementation of patient empowerment is not yet a reality.

The deployment of Information and Communication Technologies (ICT) is becoming a critical element in the process of implementing patient empowerment. ICT applications already help to empower patients and address challenges faced by EU healthcare systems. However, there is considerable potential to develop e-Health much further in the future and its promotion is a key objective of the Digital Agenda for Europe.

Healthcare systems are using different instruments and mechanisms for implementing patient empowerment. There is no clear classification of the empowerment models and quite often there are mixed mechanisms involved in the process. However, most authors agree that there are a number of key elements in patient empowerment, that is:

- Access to health information
- Education
- Bi-directional communication between patients/citizens and physicians and healthcare professionals
- Self-care support
- Chronic disease management support services

It is widely accepted that the access to their own health information empowers patients and increases their control in their healthcare. However, access to the personal health records is just the first step in the process of patient empowerment. The ultimate goal is the evolution to a system where bi-directional patient-caregiver communication is possible and shared decisions on the disease management are made. The complexity of the tools and methodologies increase as we are approaching the ultimate level of empowerment.

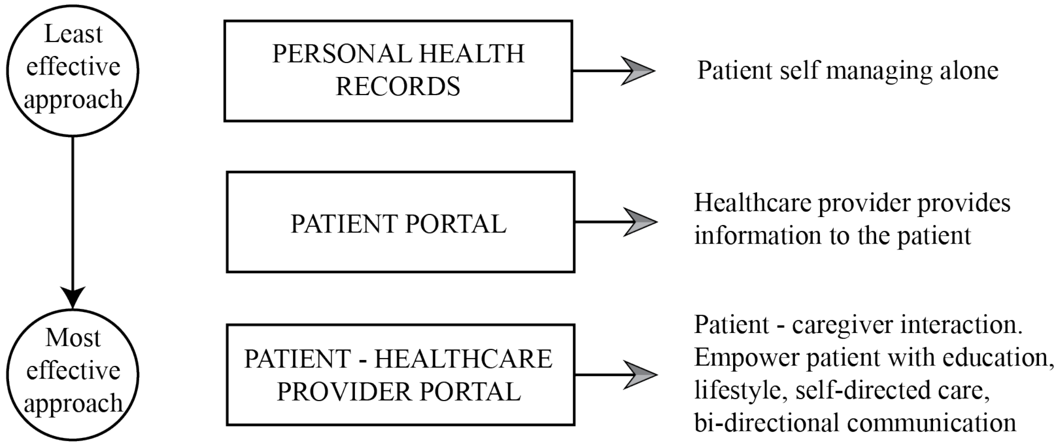

Figure 1.1: Level of Patient Empowerment [58]

Nowadays, there are many on-going studies on achieving patient empowerment through ICT. There exist several number of web and mobile applications in the field, covering the aforementioned key elements individually or partially. These applications are provided either by governments as national health systems or by vendors as mass applications in Web environment, Google Play Store or Apple App Store. Applications providing patients to access their own health information are the results of the first attempt of empowering patients. In 2004, France established the French national health record system (DMP - Dossier Medical Personnel), which is a tool for sharing and exchanging information about individual patients [65]. In December 2003, Denmark launched its public national health portal, Sundhed.dk [15], which collects and distributes healthcare information among citizens and healthcare professionals through Internet. France and Denmark are just two examples of countries providing a health portal to their citizens. Moreover, there are also some other initiatives such as Microsoft Health Vault, which is a Web-based platform to store and maintain health information [35]. As a result, there exist some systems, which provides patients access to their health information, achieving the first step of patient empowerment.

In addition, some of these systems also address some other steps of patient empowerment like education and self-care support. However, none of them provides bi-directional communication between patients and healthcare professionals, and chronic disease management support services. There are a huge number of mobile applications, which can be downloaded from Google Play Store and Apple App Store, used for managing chronic diseases. These applications, for example, are used to record the measurements measured by personal health devices such as blood pressure monitoring device for hypertension or blood glucose monitoring device for diabetes; or they are used to set reminders for the next measurement time, medication intake time, doctor appointment time etc. These features are of course very useful for patients having chronic conditions to manage their diseases but when it comes to communication with healthcare professionals and shared decision making between patients and healthcare professionals, these applications also fail to satisfy. Therefore, applications addressing all steps of patient empowerment are crucial and necessary for ultimate patient empowerment.

In this thesis, we present a Personal Health System (PHS), namely PHS4AS, addressing all the mechanisms involved in patient empowerment. Our aim is to implement the most effective approach shown in Figure 1.1 by maximizing the potential of ICT so that ultimate implementation of patient empowerment is achieved. PHS4AS is developed for the use of both patients and healthcare professionals. While developing the system, each key element in patient empowerment is individually considered. Access to health information among these five key elements is for the use of every patient/citizen. The other four elements, however, are related to chronic diseases, hence should be specialized according to disease. In other words, there need to be some specific features or modules for each disease. For this study, which can be considered as a prototype for the first ultimate implementation of patient empowerment through ICT, it would not be possible to focus on all chronic diseases. Considering its prevalence rate and characteristics, ankylosing spondylitis (AS) is chosen as the main focus of this study.

Ankylosing spondylitis is one of the many forms of arthritis that primarily affects the spine. It causes inflammation of the spinal joints that can lead to severe, chronic pain and discomfort. In advanced cases, this inflammation can lead new bones to be formed on the spine, sometimes creating a forward-stooped posture. For example, Prof. Dr. Ahmet Mete Işıkara, who was a Turkish geophysicist and earthquake scientist, lived with advanced ankylosing spondylitis and had a forward-stooped posture as illustrated in Figure 1.2.

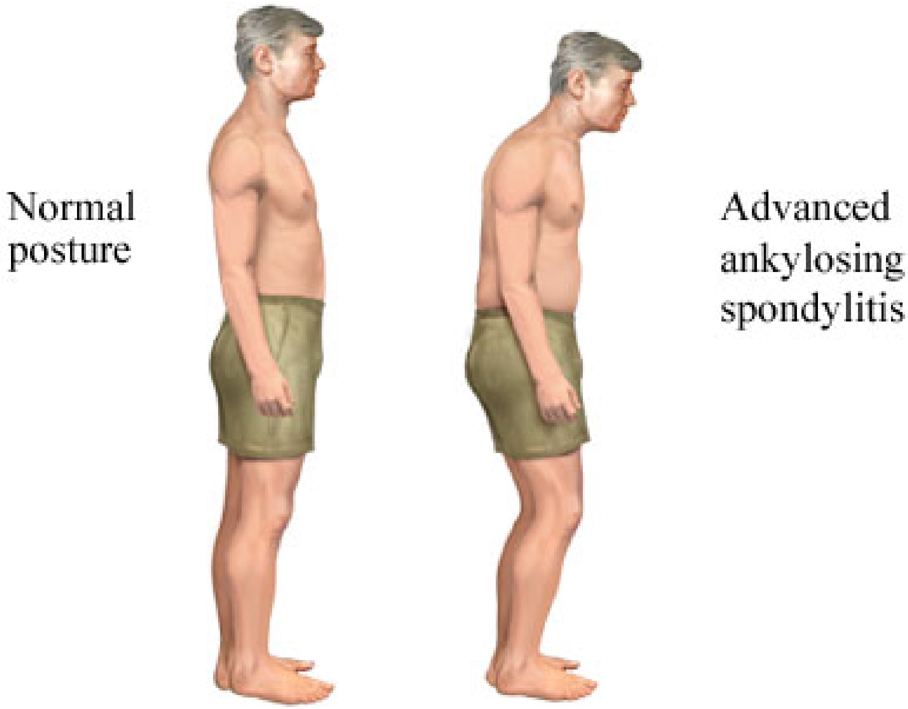

Figure 1.2: Normal Posture vs. Forward-Stooped Posture [37]

There are several reasons that why empowerment is important in AS and in parallel, why AS is selected as the main focus of this study.

1. **High prevalence and incidence of AS in Turkey:** The prevalence and incidence of AS in the Western world are estimated as 0.2% and 6/100,000, respectively [64]. In Turkey, the prevalence of AS is 0.49%, which seems to be similar to the prevalence of 0.55% observed in Germany [63, 52], and incidence is approximately 5,000 new cases each year.

2. **AS is chronic disease:** As like the other chronic diseases, AS patients

visit their healthcare professionals regularly, have long-term treatment process, and need to consult healthcare professionals when necessary. Today, there are more than 350.000 AS patients in Turkey. However, only a small portion of these patients are regularly visiting healthcare professionals for their treatments due to not having sufficient information to concede with the disease and treatment. In a regular treatment, patients are visiting their healthcare professionals in an average of 3-month period. This is both caused by not expecting an important change in patient's status in less than three months and by insufficient time that the healthcare professionals have for all patients. In this three months period, if patients get curious about anything related with their disease, they may not be able to consult the healthcare professional until their next visit. Even though they can use the Internet to find information, they cannot find a trusted solution for their concerns. Furthermore, patients do not have enough information about their treatments. They get the results of their laboratory tests or comments of healthcare professionals in the next hospital visit and then only have few minutes to consult their healthcare professionals. On the other hand, healthcare professionals also do not have any information about patients' disease progress during the time between two visits. Patients tell their conditions during the time period to healthcare professionals at the visit, but since the period is too long, most of the time patients forget the details that might be important.

3. **No study on empowering patients with rheumatic diseases:** There are lots of on-going studies on empowering patients with chronic diseases like diabetes, hypertension, chronic obstructive pulmonary disease (COPD) etc. To the best of our knowledge, however, there is no study in the field on empowering patients with rheumatic diseases.

PHS4AS is implemented as a Web-based shared patient-healthcare professional platform that provides treatment support and lifestyle guidance to the patients suffering from ankylosing spondylitis, and disease management according to the clinical guidelines published by national authorities/associations and European disease societies within the scope of the European Commission supported

PALANTE Project [41]. It was used and evaluated by 131 patients and 3 healthcare professionals in a pilot study in Turkey. Turkish pilot study is one of the nine pilot studies that project considers [58] and is carried out by SRDC Ltd. [45], Ministry of Health of Turkey (MoH) [36], and Turkish League Against Rheumatology (TLAR) [47].

Outcomes and achievements of the study were published in publications and presented in national and international conferences. A paper entitled "Self-Management of Patients with Severe Arthritis through a Personal Health System: the Turkish Case Study in the PALANTE Project" [58] was published and presented in international eChallenges e-2014 Conference in Belfast, Ireland [16]. A poster entitled "Evaluation Study for Self Management of Patients with Ankylosing Spondylitis (AS) through a Personal Health System" [59] was presented in international EULAR (The European League Against Rheumatism) Congress 2015 in Rome, Italy [19]. Furthermore, an abstract entitled "Ankilozan Spondilit (AS) Hastalarının Kişisel Sağlık Sistemi ile Kendi Sağlıklarının Yönetiminde Aktif Rol Alması" [60] was published and presented in national 11th Turkish Rheumatology Symposium in Antalya, Turkey [1].

The rest of this thesis is organized as follows: Chapter 2 provides information about standards and technologies used in this study. In Chapter 3, the development of PHS4AS is explained and interfaces of applications are presented. Simple usage scenario of PHS4AS is described in Chapter 4. Chapter 5 presents some statistical results about the pilot study. Finally, Chapter 6 concludes the thesis and presents the future work.

CHAPTER 2

BACKGROUND

This chapter provides information about standards and technologies used in this study.

2.1 Used Standards

2.1.1 HL7 Version 3

In 2005, the first version of HL7 V3 was released as the Normative Edition 2005. HL7 V3 represents an important departure from "business as usual" for HL7. HL7 V2.x series of messages offer a lot of optionality and flexibility, therefore they are widely implemented and very successful. Correlating HL7's V2 success with its flexibility would not be wrong but while providing great flexibility, its optionality obstructs reliable conformance testing and causes vendors to spend a lot of time for analyzing each other's interfaces. Therefore, HL7's primary goal for Version 3 is to offer a standard that is definite and testable, and provide the ability to certify vendors' conformance.

To do this, HL7 organization followed a different message development approach in version 3. As opposed to HL7 V2, HL7 V3 applies object-oriented principles to develop information exchange standards and uses Reference Information Model (RIM) [42] to specify all the messages.

An information model is a representation of concepts, relationships, constraints, rules, and operations to specify data semantics for a chosen domain [62]. It is used to present the relationships between components or parts of a system and most of the time Unified Modelling Language (UML) [49] is used to serve this presentation graphically. RIM is an abstract information model used to express healthcare data developed by HL7 organization. It is the cornerstone of the HL7 V3 development process since it is the source of all information models and structures in HL7 V3. It represents HL7 clinical data graphically through object-oriented concepts like classes, attributes, associations etc. and identifies the life cycle of a single message or group of messages.

As shown in Figure 2.1, there are six core classes in RIM of HL7 V3. Act is used to represent every happening like procedures or medications in healthcare domain. Acts are related through ActRelationship like composition or preconditions. The context for an Act is defined through Participation like author or subject. Roles are used to represent the participants like patient or healthcare provider and they are played by Entities like persons or organisations.

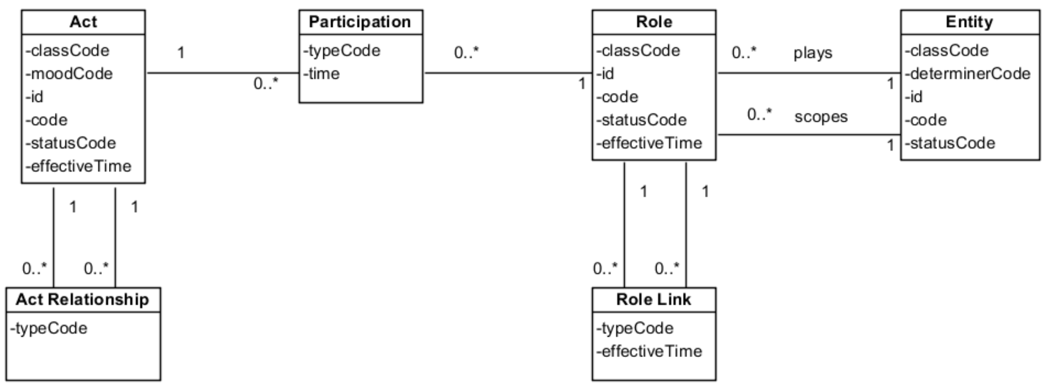

Figure 2.1: RIM Core Classes

The basis of HL7 V3 is a single model with only these six core classes. These core classes, however, are not sufficient to represent all of the elements of clinical action without their attributes. As shown in Figure 2.1, these core classes contains several attributes. It should be noted that for the sake of simplicity, not all the attributes of core classes are presented in Figure 2.1. There are four structural attributes in core classes: classCode, typeCode, moodCode and determinerCode. classCode is used to identify the meaning of class. typeCode is used to represent the type. moodCode is used to represent whether the activity has happened, is happening, will happen, can happen, or expected to happen. determinerCode is used to understand whether the class is an instance or a kind of Entity.

HL7 V3 is regarded as more of a "true standard" and less of a "framework for negotiation" [50]. Growing from the RIM base, HL7 V3 is a model-based standard containing well defined application roles and less message optionality, thus provides consistency accross the entire standard.

In addition to being promoted to more definite, testable, conformant and model-based standard, a new approach for exchanging clinical information is represented in HL7 V3: Producing messages and electronic documents expressed in XML syntax [22]. XML stands for eXtensible Markup Language that defines set of rules for encoding documents in both human-readable and machine-readable format. HL7 V3 defines Implementation Technology Specifications (ITS) [26] for the encoding rules for HL7 V3 messages based on XML and UML. The XML ITS defines data types and structures according to HL7 data types so that HL7 V3 compliant messages can easily be expressed using XML. Figure 2.2 shows an example HL7 V3 message based on XML encoding syntax.

2.1.2 HL7 V3 Clinical Document Architecture (CDA)

HL7 V3 Clinical Document Architecture (CDA) is an XML-based electronic standard that specifies the structure and semantics of clinical documents for the purpose of exchange between healthcare providers and patients [11]. CDA is developed by HL7 as being conformant to HL7 V3 ITS, based on HL7 RIM and using HL7 V3 data types. CDA Release One (CDA R1) is the first specification of CDA, which became ANSI approved HL7 standard in 2000. Focusing on semantic representation of clinical events, CDA Release Two (CDA R2) is evolved and became an ANSI approved HL7 standard in 2005 [56]. As of May 2015, the most recent version of CDA is Release 2 and CDA Release 3 is currently under development.

It is important to understand that CDA does not specify anything about trans-

```xml
<POLB_IN224200 ITSVersion="XML_1.0" xmlns="urn:hl7-org:v3"
    xmlns:xsi="http://www.w3.org/2001/XMLSchema-instance">
        <id root="2.16.840.1.113883.19.1122.7" extension="CNTRL-3456"/>
        <creationTime value="200202150930-0400"/>
        <!-- The version of the datatypes/RIM/vocabulary used is that of May 2006 -->
        <versionCode code="2006-05"/>
        <!-- interaction id= Observation Event Complete, w/o Receiver Responsibilities -->
        <interactionId root="2.16.840.1.113883.1.6" extension="POLB_IN224200"/>
        <processingCode code="P"/>
        <processingModeCode nullFlavor="OTH"/>
        <acceptAckCode code="ER"/>
        <receiver typeCode="RCV">
                <device classCode="DEV" determinerCode="INSTANCE">
                        <id extension="GHH LAB" root="2.16.840.1.113883.19.1122.1"/>
                        <asLocatedEntity classCode="LOCE">
                                <location classCode="PLC" determinerCode="INSTANCE">
                                        <id root="2.16.840.1.113883.19.1122.2" extension="ELAB-3"/>
                                </location>
                        </asLocatedEntity>
                </device>
        </receiver>
        <sender typeCode="SND">
                <device classCode="DEV" determinerCode="INSTANCE">
                        <id root="2.16.840.1.113883.19.1122.1" extension="GHH OE"/>
                        <asLocatedEntity classCode="LOCE">
                                <location classCode="PLC" determinerCode="INSTANCE">
                                        <id root="2.16.840.1.113883.19.1122.2" extension="BLDG24"/>
                                </location>
                        </asLocatedEntity>
                </device>
        </sender>
        <!-- Trigger Event Control Act & Domain Content -->
</POLB_IN224200>
```

Figure 2.2: Sample HL7 V3 Message

port mechanism, it defines clinical documents which can be read by the human eye or processed by a machine. A CDA document can be transferred within a message or can exist outside of a message. Typical CDA document could be, for example, a Discharge Summary, Diagnostic Report, or Physical Examination.

CDA is an XML document consisting of two major parts: Header and Body. Header contains the metadata required for document discovery, management and retrieval; and is also used to identify the patient, provider and document type. In header, for example, can be specified confidentiality status of the document, the time of creation, legal authenticator etc. The body part contains the clinical report and can be either structured or unstructured. Unstructured body, also known as simplest body or non-XML body, is used for wrapping some texts, images or multimedia elements. Structured body contains both human readable narrative block which is used to define the legal content and machine processable clinical statements.

The basic model of both CDA R1 and CDA R2 are essentially the same. The main difference between these two releases is that while CDA R1 uses the RIM for only deriving the header, CDA R2 uses the RIM for deriving both the header and body.

```
<ClinicalDocument>
        ... CDA Header ...
        <structuredBody>
                <section>
                        <text>(a.k.a. "narrative block")</text>
                        <observation>...</observation>
                        <substanceAdministration>
                                <supply>...</supply>
                        </substanceAdministration>
                        <observation>
                                <externalObservation>...</externalObservation>
                        </observation>
                </section>
                <section>
                        <section>...</section>
                </section>
        </structuredBody>
</ClinicalDocument>
```

Figure 2.3: Main CDA Structure

Figure 2.3 shows the major components of a CDA document. <ClinicalDocument> is the root of all CDA documents. Inside <ClinicalDocument> header is first defined. There is no specific tag for header in CDA. All the elements that are part of header are put as child of <ClinicalDocument> before the body part. Below header, structured body is defined with <structuredBody> tag, which contains one or more <section> components. The human readable narrative block is wrapped by <text> tag inside <section>. Each section can contain only one narrative block. Narrative block is followed by a number of CDA entries which are used to describe clinical statements. These CDA entries are derived from HL7 V3 RIM, which gives CDA the machine processable meaning. Within a <section>, the narrative block represents content to be rendered, while CDA entries represent structured content provided for computer processing. In CDA, narrative block is required, whereas CDA entries are optional, which means that neither the creator of CDA document has to encode all the narrative into CDA entries, nor the receiver of document has to parse all CDA entries.

In body part, <observation> is used for representing coded and other observations. <substanceAdministration> is used for representing medication related events such as medication history. <supply> is used for representing the provision of a material between different entities. All <observation>, <substanceAdministration> and <supply> are specialization of RIM Act class. CDA entries can be nested and reference external objects which exists outside the document. External references should be put in a CDA entry. In Figure 2.3, for example, <externalObservation> is used for pointing some other observation. There are also some other required components in CDA, but they are not present in Figure 2.3 for simplicity.

```
<section>                                                          Level 1
    <code code="8716-3" codeSystem="2.16.840.1.113883.6.1"
        codeSystemName="LOINC" />                                  Level 2
    <title>Vital Signs</title>
    <text>Temperature is 36.9 C</text>
    <entry>
        <observation classCode="OBS" moodCode="ENV">
            <code code="386725007" codeSystem="2.16.840.1.113883.6.96"
                codeSystemName="SNOMED CT" displayName="Body temperature" />
            <statusCode code="completed" />
            <effectiveTime value="200004071430" />                         Level 3
            <value xsi:type="PQ" value="36.9" unit="Cel" />
        </observation>
    </entry>
</section>
```

Figure 2.4: Sample CDA Observation

Figure 2.4 shows an example of a simple observation, where section is an element coded with LOINC coding system and observation is an element coded with

SNOMED CT coding system. More detail about these coding systems will be provided in the Terminologies section below.

CDA has three levels of document definition. Level 1 includes the body with only human readable content, no semantic codes. Level 1 can be non-XML or XML with no coded entries (narrative only). Level 2 includes the body with machine processable section-level semantics. Level 2 must have an XML body and at least one coded section. Level 3 includes the body with at least some clinical statements, which are machine processable and can be modelled in the RIM. Any coded entries gives Level 3.

2.1.3 ASTM Continuity of Care Record (CCR)

Continuity of Care Record (CCR) is another XML based standard used for clinical data exchange, developed by American Society for Testing and Material (ASTM) [5] in 2005. CCR is a core data set of the most relevant administrative, demographic, and clinical information facts about a patient's healthcare [13]. The main goal of the CCR is to provide both patient and healthcare professional the brief summary of recent care of patient. These include general information about patient, information about providers of patient, insurance information, patient's health status, recommendations for care plan, and the reason for transfer. By providing these information, CCR aims to enable healthcare professionals to access all necessary information of patient at the beginning of a first encounter and update it in order to assist safety and quality of patient care as well as to support continuity of it.

CCR is a concise standard based on and restricted to XML, meaning that XML coding is required to create electronic CCRs. Thanks to this restriction, it ensures the interchangeability. Although CCR is meant to address the need for continuity of care, it is not much comprehensive to serve as Electronic Health Record (EHR). Its primary function is to provide a picture of treatment and basic patient information. Therefore, it can serve as Personal Health Record (PHR).

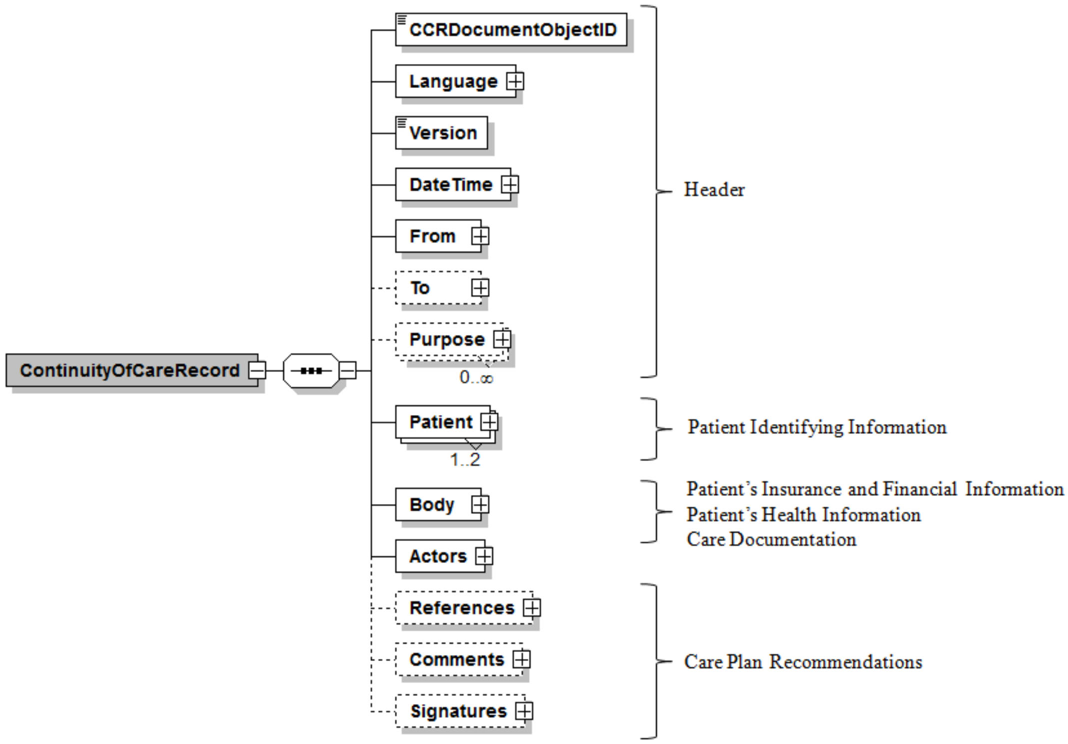

Figure 2.5: General CCR Structure

Figure 2.5 shows the general structure of CCR document on the left side and semantics of components on the right side. As shown in the figure, CCR semantically consists of six sections: Header, Patient Identifying Information, Patient's Insurance and Financial Information, Patient's Health Information, Care Documentation, and Care Plan Recommendation.

Header, or Document Identifying Information, contains general information about document like creation date, purpose, language, creator etc. Following data elements are used in header.

- **CCRDocumentObjectID:** Unique identifier of CCR document.
- **Language:** Language of CCR document.
- **Version:** Version of CCR document.
- **DateTime:** Creation date of CCR document.

- **From:** ActorLink to creator of CCR document. Answers the question "Who created it?".

- **To:** (Optional) ActorLink to receiver of CCR document. Answers the question "Who received it?".

- **Purpose:** (Optional) Purpose of CCR document. Answers the question "Why is it created?".

In CCR, any person, organization, or information system are considered as "Actor". All actors in CCR document are grouped under **Actors** element shown in Figure 2.5. Actors do not occur in other parts of the document, instead they are linked with ActorLink.

Patient Identifying Information includes the required information to identify the patient.

Patient's Insurance and Financial Information contains information about patient's insurance company, subscriber and payment provider.

Patient's Health Information is the main part of CCR and includes following data elements.

- **Advanced Directives:** Information about patient's healthcare documents and their locations.

- **Support:** Information of persons who provide support to patient during his treatment process

- **Functional Status:** Information about patient's functional status like his daily activities, ability to care himself etc.

- **Problems:** Patient's present and past diagnoses, problems, conditions and their statuses.

- **Family History:** Disease history of patient's family such as father diagnosed with diabetes.

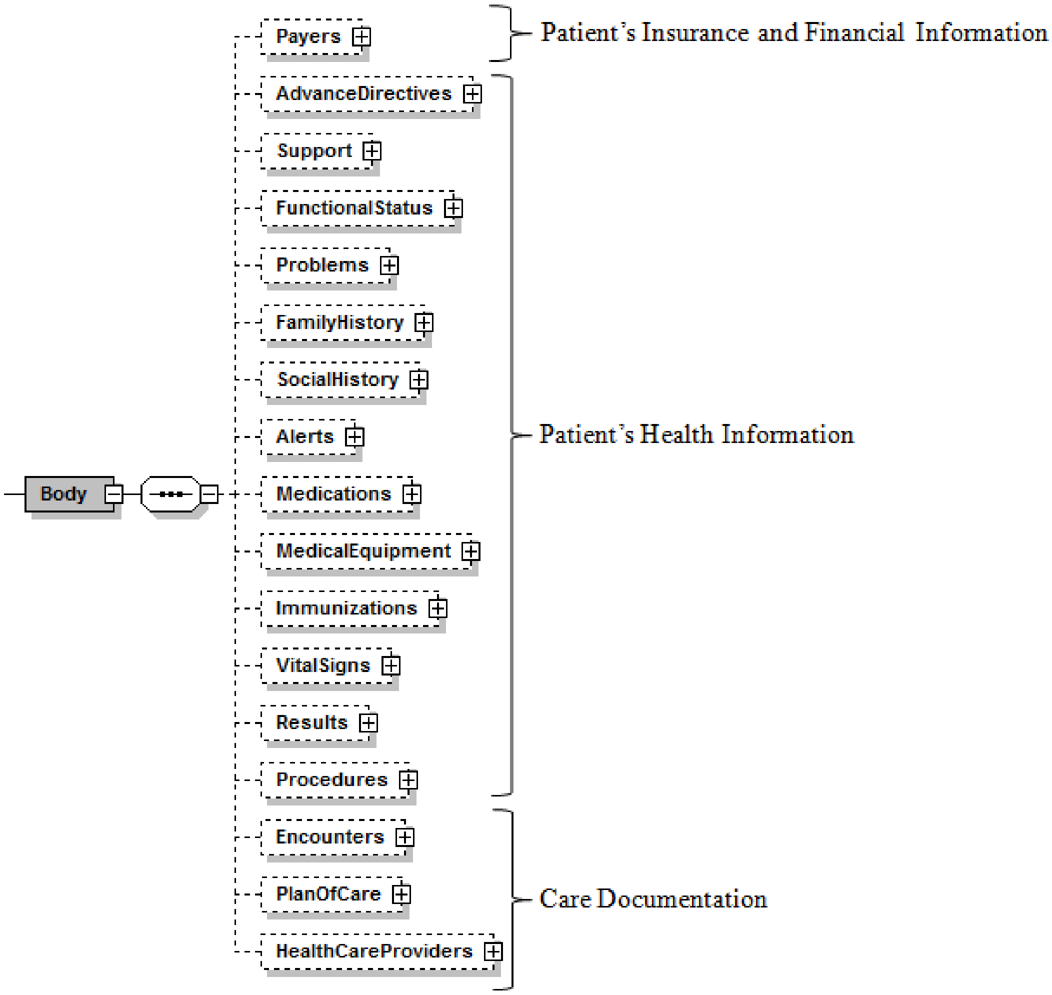

Figure 2.6: CCR Body Structure

- **Social History:** Patient's personal and social history such as alcohol usage.
- **Alerts:** Patient's present and past allergies and adverse reactions with agent, symptom, source and last reaction information.
- **Medications:** Patient's present and past medications with brand name, generic name, start date, dose, prescriber, status and comment information.
- **Medical Equipment:** Information about medical devices that patient used or is using.

- **Immunizations:** Patient's present and past immunizations with disease against which immunization is given, date that immunization is received, dose, unit and manufacturer information.

- **Vital Signs:** Basic health information of patient, which are height, weight, body temperature, blood pressure, blood type, pulse and head circumference (for infants).

- **Results:** Results of patient's laboratory tests.

- **Procedures:** Information about patient's procedures, operations, assessments with date, location, result and performed by whom information.

Care Documentation contains information about patient-clinician encounter history. It includes date, time and purposes of recent hospital visits and names of clinicians or providers.

Care Plan Recommendation is a free text entry section which includes scheduled tests and procedures.

2.1.4 Clinical Care Document (CCD)

In healthcare industry, some organizations have adopted ASTM CCR while others have adopted HL7 CDA for the electronic exchange of clinical data. In order these organizations to interoperate, Continuity of Care Document (CCD) was developed through a joint collaboration between HL7 and ASTM. CCD is an implementation guide for sharing Continuity of Care Record (CCR) patient summary data using the HL7 Version 3 Clinical Document Architecture (CDA) Release 2 [12].

CCD is built on CDA elements, but the data itself is defined by CCR. To form the standard, CCD uses CDA's detailed set of templates, which define how to use CDA elements to communicate clinical data. Within the templates, the scope of clinical data is set by CCR.

17 templates are available in CCD: Header, Purpose, Problems, Procedures,

Family History, Social History, Payers, Advance Directives, Alerts, Medications, Immunizations, Medical Equipment, Vital Signs, Functional Status, Results, Encounters and Plan of Care.

Figure 2.7 shows an example CCD which maps the CCR elements into a CDA representation.

```
<Results>
    <Result>
        <CCRDataObjectID>
            2.16.840.1.113883.19.1
        </CCDDataObjectID>
        <DateTime>
            <Type>
                <Text>Assessment Time</Text>
            </Type>
            <ExactDateTime>
                200004071430
            </ExactDateTime>
        </DateTime>
        <Type>
            <Text>Hematology</Text>
        </Type>
        <Description>
            <Text>CBC WO DIFFERENTIAL</Text>
            <Code>
                <Value>43789009</Value>
                <CodingSystem>SNOMED CT</CodingSystem>
            </Code>
        </Description>
        <Status>
            <Text>Final Results</Text>
        </Status>
    </Result>
</Results>
```

CCR Element

```
<section>
    <templateId root="2.16.840.1.113883.19.1"/>
    <code code="30954-2"
        codeSystem="2.16.840.1.113883.6.1"
        codeSystemName="LOINC"/>
    <title>Laboratory Results</title>
    <text>
        CBC (04/07/2000) : HGB 13.2; WBC 6.7; PLT 123
    </text>
    <entry>
        <organizer classCode="BATTERY" moodCode="EVN">
            <templateId root="2.16.840.1.113883.10.20.1.31"/>
            <id root="2.16.840.1.113883.19"/>
            <code code="43789009"
                codeSystem="2.16.840.1.113883.6.96"
                codeSystemName="SNOMED CT"
                displayName="CBC WO DIFFERENTIAL"/>
            <statusCode code="completed"/>
            <effectiveTime value="200004071430"/>
        </organizer>
    </entry>
</section>
```

CCD Element

Figure 2.7: CCR Element Mapped into CCD Element

2.1.5 HL7 Fast Healthcare Interoperability Resources (FHIR)

Fast Healthcare Interoperability Resources (FHIR) is a next generation standards framework created by HL7 organization [23]. FHIR is a new specification built on HL7's data format standards like HL7 V2, HL7 v3 and CDA. It is created to meet the requirement of more lightweight way to exchange electronic and personal health records in Web and mobile environments. In other words, it aims to provide healthcare information on variety of devices from computers to tablets and mobile phones and facilitate the development of third party mobile applications which can easily be integrated with existing healthcare systems.

For this purpose, FHIR introduces a new resource-centric approach instead of document-centric approach by exposing distinct data elements as services. FHIR solutions are built from a set of modular components called "Resources". All exchangable content in FHIR is defined as Resource. For instance, basic elements of healthcare like medications, diagnoses, laboratory results etc. can be defined in separate Resources. For a given use case, one Resource can be used by itself as well as two or more Resources can be combined and tailored. Figure 2.8 shows sample HL7 FHIR Resource.

```
<Patient>
        ... Local Extension ...
        ... Human Readable Summary ...
        <name>
                <family value="Levin"/>
                <given value="Henry"/>
                <suffix value="The 7th"/>
        </name>
        <gender>
                <text value="Male"/>
        </gender>
        <birthDate value="1932-09-24"/>
        <managingOrganization>
                <reference value="Organizaton/2"/>
                <display value="Good Health Clinic"/>
        </managingOrganization>
        ...
</Patient>
```

Figure 2.8: Sample HL7 FHIR Resource

FHIR uses modern web technologies like HTTP based RESTful protocols for data transfer [43], JSON [32] or XML [22] for data representation, OAuth for authorization [40], ATOM for query results [8]. By courtesy of using modern web technologies and its new resource-centric approach, FHIR is easier to implement standard. Its full normative specification is expected to be published by HL7 organization through 2015 [23].

2.1.6 Terminologies

In healthcare, terminologies are formal representations of entities and defines universal meanings of concepts. For example, "abnormal hearth rhythms", "cardiac arrhythmia", or "dysrhythmia" are all semantically the same and used to refer the irregular heart rates. No matter which term is used, healthcare professionals can understand the patient's problem. However, when it comes to healthcare systems, there is no way for a software to understand this, unless the terms are correlated with a unique code from a coding system. Therefore, clinical terminology systems are used to express the semantics of different terms. For example, SNOMED CT, one of the most widely used clinical terminology systems in the world, represents abnormal heart rhythms with concept code "698247007". If two healthcare systems use the SNOMED CT clinical vocabulary, regardless of their choice of concept name, there will be no ambiguity between them and they can interoperate.

Currently, there exist quite number of medical terminologies used to define patient's medical records. Among them, most widely used terminology standards are Systemized Nomenclature of Medicine Clinical Terms (SNOMED CT) [46], Logical Observation Identifiers Names and Codes (LOINC) [34], RxNorm [44], and International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) [28]. Details of these medical terminologies are explained in the subsections below.

2.1.6.1 Systemized Nomenclature of Medicine Clinical Terms (SNOMED CT)

SNOMED CT is the most comprehensive, multilingual clinical healthcare terminology in the world [46]. It is developed to represent the clinical content in electronic health records such as symptoms, diagnoses, procedures, pharmaceuticals etc. in computer processable manner. It enables data entry for EHRs, meaning-based retrieval of clinical information from EHRs, provides opportunity for clinical decision support and data analysis.

Figure 2.4 above shows sample usage of SNOMED CT to define "body temperature" observation, while Figure 2.7 shows the usage of SNOMED CT to define "complete blood count without differential" laboratory test result.

2.1.6.2 Logical Observation Identifiers Names and Codes (LOINC)

Logical Observation Identifiers Names and Codes (LOINC) is a universal code system for representing laboratory tests, measurements, and observations [34]. As its name suggests, it provides universal identifiers to denote medical laboratory observations. LOINC was used by several standards such as IHE and HL7. In fact, in 1999, HL7 identified LOINC as the preferred code set for laboratory test.

2.1.6.3 RxNorm

RxNorm provides normalized names and unique identifiers for medications and drugs to enable software systems to exchange drug related informtion unambigously [44]. It contains all generic and branded clinical drugs and drug packs available in US market. It also provides a tool to support semantic interoperability between drug terminologies and pharmacy knowledge base systems.

2.1.6.4 International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10)

International Statistical Classification of Diseases (ICD), maintained by World Health Organization (WHO), is a system used to classify diseases, signs, symptoms, abnormal findings, complaints, social circumstances, and external causes of injury or disease for epidemiology, health management and clinical purposes. ICD-10 is 10th and latest classification of ICD, which was completed in 1992. It is adopted by many countries including Turkey.

2.2 Used Technologies

2.2.1 Open Services Gateway Interface (OSGI) Framework

Founded in 1999, OSGI Alliance is a non profit world wide consortium that defines a set of specifications to enable modular assembly of software built with Java technology [39]. OSGI technology facilitates componentization of software modules and applications. Component-based software development appeared as a new paradigm in software development at the beginning of 21st century [53]. The main idea is to divide the different parts of software into separate components and reuse the already created components when necessary. Componentization not only provides loose coupling, but also reduces the development and maintenance costs. OSGI is the first technology that implemented the componentization approach successfully.

OSGI is developed to create a collaborative software environment where different reusable components that have no prior knowledge of each other are put together and dynamically assembled. Today, there are many open source implementations of OSGI such as Apache Felix [6], Eclipse Equinox [18] and Knopflerfish [33], which enable developers to divide their applications into multiple modules and manage dependencies among them.

From the developer's point of view, one of the most important advantages of OSGI is the enablement of installing, starting, stopping or uninstalling a module dynamically at runtime without restarting the application and disrupting the operation. It also makes possible to run different versions of the same module at the same time. These features make OSGI the perfect choice for server side development.

OSGI defines six layers as illustrated on Figure 2.9.

- **Bundles:** In OSGI, every component is defined as a bundle. Bundles are considered as OSGI components developed by the developers and consist of group of Java classes, libraries, configuration files and services. There are two main elements of a bundle: "Activator.java" and "MANIFEST.MF".

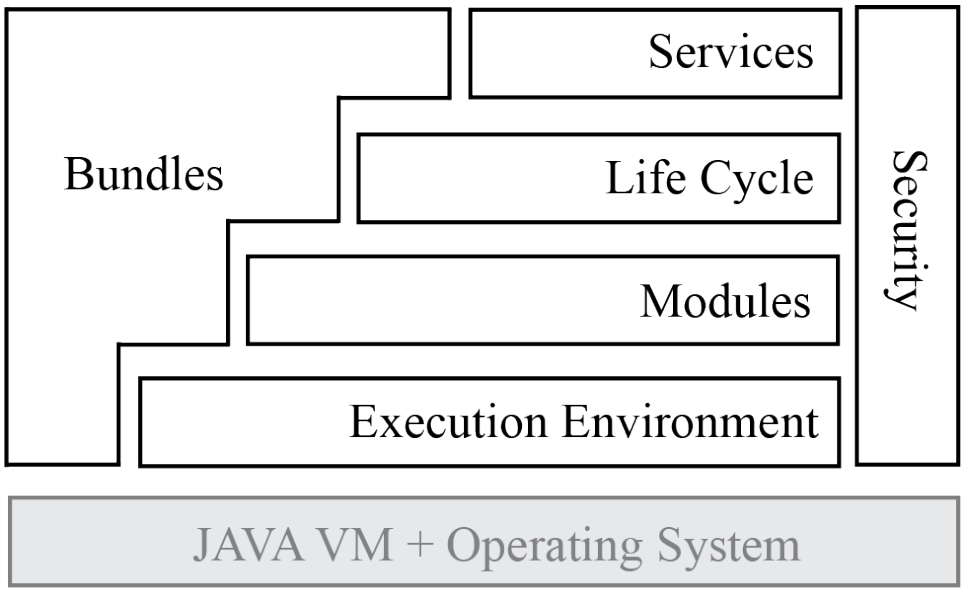

Figure 2.9: OSGI Layers

Activator.java is used to intervene in when bundle state changes. When it is implemented, OSGI framework invokes related method when state changes. More information about states are provided in life cycle layer below. *MANIFEST.MF* is a configuration file which contains the deployment information of the bundle such as bundle name, symbolic name, version, activator, import package and export package.

- **Services:** Services are used to connect bundles in a dynamic way. OSGI service layer enables bundles to export services that can be imported and used by other bundles without knowing any other information about exporting bundle.

- **Life Cycle:** Life cycle is the API used to install, start, stop, update and uninstall the bundles. In OSGI, a bundle can be in six states:

  - INSTALLED - The bundle has been successfully installed.
  - RESOLVED - The bundle is either ready to be started or has stopped.
  - STARTING - The bundle is being started.

  - ACTIVE: The bundle has been successfully activated and is running.
  - STOPPING - The bundle is being stopped.
  - UNINSTALLED - The bundle has been uninstalled

- **Modules:** Bundles are distinct components and in OSGI, no bundle can see the classes of other bundles by default. However, it is sometimes necessary to access a class of a bundle from another bundle. OSGI allows bundles to export and import codes so that target bundle can import and use the exported classes of source bundle.
- **Execution Environment:** Execution environment is the layer where application is connected to operating system and executed.
- **Security:** Security layer handles the security issues.

2.2.2 Hibernate

JDBC stands for Java Database Connectivity [29] and provides an API for Java programs to interact with SQL compliant relational databases. JDBC has a simple syntax, so it is very easy to learn and use. JDBC is perfect choice for small projects to connect with relational database. When it comes to large projects, however, JDBC becomes a burden with the increasing number of SQL statements to write. Furthermore, majority of these large projects prefer to use object-oriented approach for development and there are lots of mismatches occur between object model and relational database. For example, if the number of classes increases, the number of database tables increases too and if the database design is modified at any time, related code segments and classes are needed to be modified as well.

Object-Relational Mapping (ORM) [38] is the solution to handle these problems. ORM is a programming technique for converting data between relational databases and object oriented programming languages like Java or C# without dealing with any database implementation. In ORM, SQL queries are hidden from object oriented logic.

Hibernate is an ORM framework developed for Java language [25]. It provides mappings between Java classes and relational database tables.

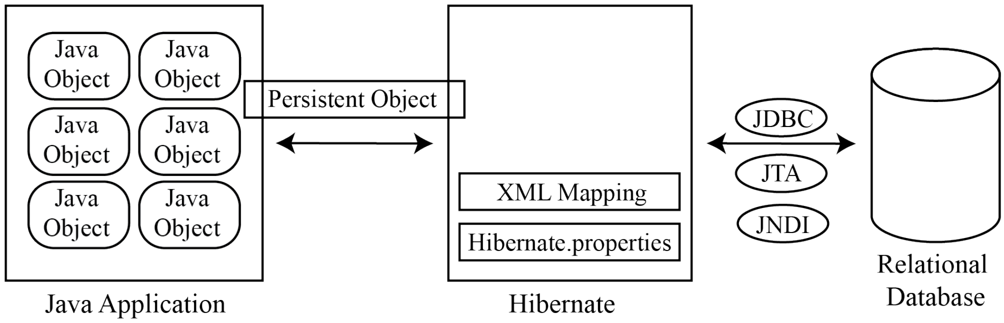

Figure 2.10: Hibernate Application Architecture

Figure 2.10 shows the high level view of a Java application using Hibernate. Hibernate handles the mapping of Java classes to database tables with XML files. It does not require any other coding for that purpose. If the database design is modified, it is only necessary to change the related properties in XML files, there is no need to change any code. Therefore, Hibernate provides perfect isolation between application code and database, hence perfect maintenance. In Hibernate, objects to be stored in database are called persistent objects. Hibernate receives persistent object from Java application and stores it in relational database according to XML mappings. Hibernate uses existing Java APIs for database connections like JDBC [29], Java Transaction API (JTA) [31], and Java Naming and Directory Interface (JNDI) [30]. Hibernate finds the related database configurations such as JDBC connection URL, username and password in *Hibernate.properties* file, as well as the list of all XML mapping files. Sample Hibernate XML mapping file is shown in Figure 2.11.

2.2.3 Adobe Flex

Flex is a powerful, open source application framework that allows you easily develop applications based on Adobe Flash platform [3] for browsers, mobile devices and desktop. It was developed by Macromedia in 2004, then acquired by Adobe. After Adobe Flex 4.6.0 [4] is released in November 2011, Adobe

```xml
<?xml version="1.0" encoding="utf-8"?>
<hibernate-mapping>
	<class name="Employee" table="EMPLOYEE">
		<meta attribute="class-description">
			This class contains the employee detail.
		</meta>
		<id name="id" type="int" column="id">
			<generator class="native"/>
		</id>
		<property name="firstName" column="first_name" type="string"/>
		<property name="lastName" column="last_name" type="string"/>
		<property name="salary" column="salary" type="int"/>
	</class>
</hibernate-mapping>
```

Figure 2.11: Sample Hibernate XML Mapping File

donated Flex to Apache Software Foundation. As of 2015, new versions of Flex is being continued to release under the name of Apache Flex [7].

Flex is a technology for client-side. It comes with a Software Development Kit (SDK) which enables developers to create expressive and interactive rich internet applications. With Flex, it is possible to

- create visually rich, dynamic and platform independent user interfaces
- interact with server-side technologies such as Spring, Hibernate and PHP through REST, SOAP, JSON and so on.
- integrate multimedia elements to UI easily

Flex applications can be developed by using standard Integrated Development Environments (IDEs) such as Eclipse [17], IntelliJ [27], FlashDevelop [24] and Adobe Flash Builder [2].

Figure 2.12 depicts how Flex applications are built. In Flex, two languages, MXML and ActionScript, are used to develop applications. MXML is an XML-based language used for designing user interfaces. ActionScript is an object-oriented procedural language used for giving logic to applications. Event lis-

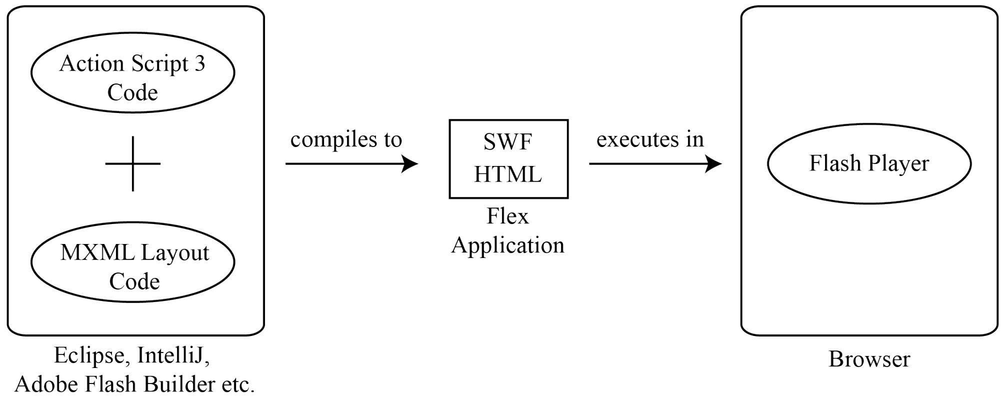

Figure 2.12: Build Process of Flex Applications

teners, event handlers, remote connections, importation of external components are all handled in ActionScript. During build process, MXML and ActionScript codes are compiled into SWF and HTML files by Flex compiler. Application server then serves these files to the outside world so that browsers, on which Flash Player is run, can display it.

There are a number of application frameworks and tools to help Flex developers to better structure their codes and communicate with remote servers easily. Among them, BlazeDS and Cairngorm are the two of the most important application frameworks.

2.2.3.1 BlazeDS

BlazeDS is a server-based Java remoting and web messaging technology that enables developers to easily connect to data on server and push data in real-time to Flex applications for more responsive rich Internet application experiences [9].

BlazeDS remoting service enables Flex applications to directly invoke methods of Java objects existing on the server-side. It provides high performance data transfer since it uses Action Message Format (AMF) binary data exchange format which is much more faster than text-based formats such as XML and SOAP. AMF is developed by Adobe and used in ActionScript and XML objects' serialization, and messages between Adobe client and remote service. **BlazeDS messaging service** enables publish/subscribe messaging between Flex clients and server, and server data push over HTTP in real time.

In order to use BlazeDS, writing both client-side and server-side code is required. Client-side code is written in MXML and ActionScript as other Flex applications whereas server-side code is written in Java.

2.2.3.2 Cairngorm

Cairngorm is Model-View-Controller (MVC) based application architecture framework for Flex applications. Briefly, MVC is a software architecture pattern that separates representation (model) from presentation (view). Cairngorm directly adapts MVC design pattern as it is. What Cairngorm adds on MVC is that Cairngorm also defines additional architecture inside Model, View and Controller as shown in Figure 2.13.

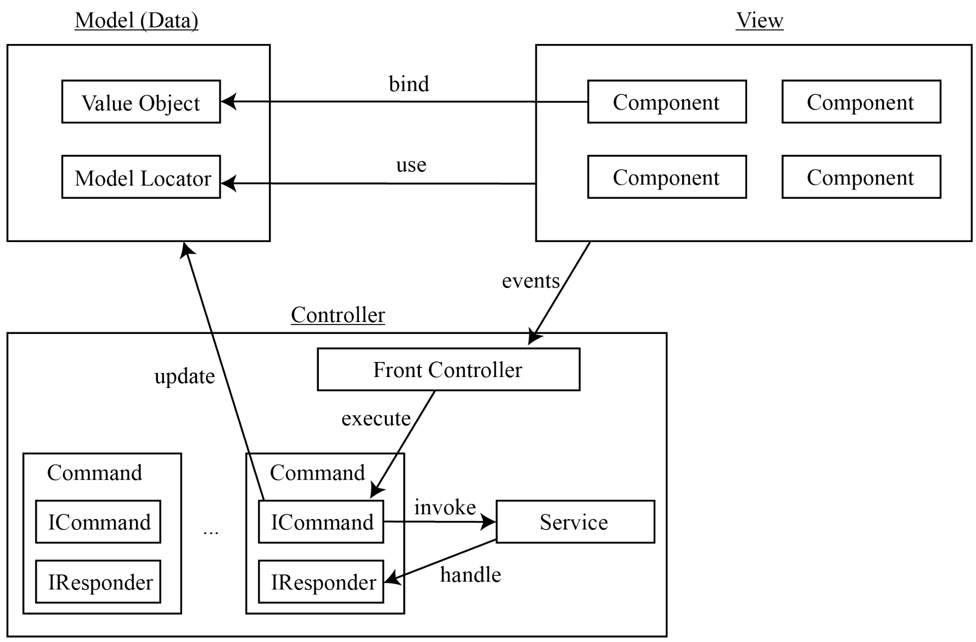

Figure 2.13: Cairngorm Architecture

In **Data layer**, data are stored in Value Objects (VOs) while simple variables and properties are stored in singleton ModelLocator class.

View layer throws events and uses ModelLocator to locate the necessary data. Components in View layer bind to Value Objects in Model layer.

Controller layer is implemented as a singleton FrontController. FrontController receives events generated by components in View layer and dispatches them to the related Command classes according to its type. The event is processed through execute method of ICommand interface. During this process, Model can be updated, as well as Service can be invoked to communicate with remote server. The response retrieved from remote server are handled by onResult and onFault methods of IResponder interface.

CHAPTER 3

IMPLEMENTATION OF THE PERSONAL HEALTH SYSTEM

This chapter provides detailed information about how PHS4AS is implemented. As any other web application, PHS4AS is formed of two parts: server-side and client-side. Server-side is an OSGI Platform composed of several bundles written in Java and client-side is an Adobe Flex application composed of several small applications. Server-side handles the controller operations such as storing data, accessing remote systems, authentication, authorization and so on. Client-side contains the user interfaces that users are using to interact with the system. Communication between these two sides are handled through remote services of BlazeDS. Figure 3.1 illustrates the deployment of components in physical nodes.

In this chapter first server-side, then client-side are explained in detail. In server-side section, overall system architecture, details of the components in the architecture, usage of the technologies, and integration with Turkish National Health System are explained respectively. In client-side section, first usage of Flex to create the interfaces, then details of the each application existing in PHS4AS are explained and screenshots are presented.

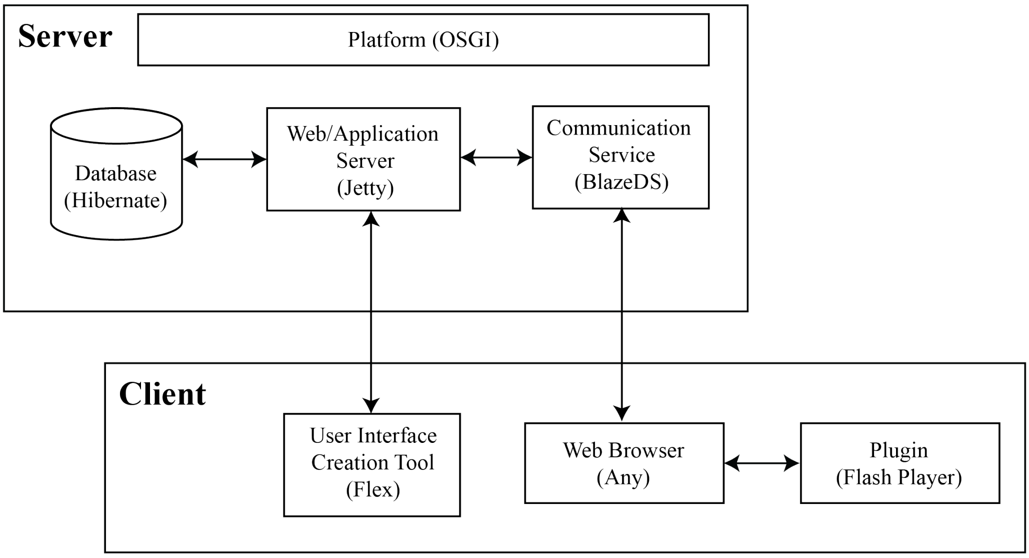

Figure 3.1: Deployment of Components in Physical Nodes

3.1 Server-side of PHS4AS

3.1.1 OSGI Platform

PHS4AS consists of several health applications, each of which are used to accomplish a different task such as displaying personal health information like diseases or medications, recording health status, conducting health care professionals etc. Furthermore, PHS4AS allows integration with various external data sources such as Turkish National Health Information System. Thanks to the OSGI framework, any health application or external data source can easily be plugged in/out to/from PHS4AS platform. As shown in Figure 3.2, PHS4AS OSGI consists of several bundles.

- **PHS4AS Manager:** It is the main bundle initializing the OSGI platform, managing configurations and providing necessary infrastructure to other bundles. It consists of several sub-managers to fulfill its purpose.
  - **Application Registry:** It registers the PHR and VACS applications' bundles. It parses the related XML files which contain the

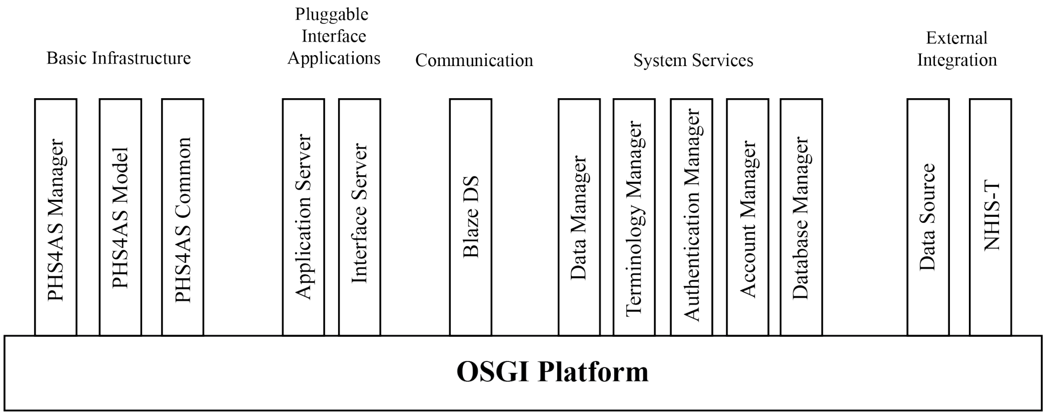

Figure 3.2: PHS4AS OSGI Bundles

list of applications and information about applications such as name, description and SWF location. This is the component enabling the applications to be plugged in/out at run time.

- **Configuration Manager:** It configures the platform and other bundles according to properties file when platform is being initialized. Properties file contains information such as application categories, port, protocol, authentication algorithm and heartbeat interval.
- **Platform Initializer:** It is the class that instantiates other classes in PHS4AS Manager. As soon as run command is executed, Platform Initializer is called.
- **Session Manager:** It manages the users' authentication together with Authentication Manager.
- **Report Manager:** It logs all users' operations in PHS4AS system and generates reports on demand of administrators.

• **PHS4AS Model:** The data model of PHS4AS is based on CCR standard. With its integration with Turkish National Health Information System, it has also mappings to HL7 CDA. Therefore, the model of PHS4AS can be regarded as the extended version of CCR model and can be used to generate HL7 CCD compliant patient health summary documents. It has the following sections:

- Alerts (Allergies)
- Documents
- Encounters
- FamilyHistory
- HealthcareProviders
- Immunizations
- MedicalEquipments
- Medications
- Messages
- PersonalInformation
- Problems
- Procedures
- Results
- SocialHistory
- VitalSign

PHS4AS Model bundle can be considered as a library that can be accessed from other bundles. It contains necessary annotations of Hibernate for database operations and methods for mapping CDA to CCR and CCR to CDA, which are necessary for NHIS-T integration. Class diagram of PHS4AS Model is shown in two parts in Figure 3.3 and Figure 3.4.

- **PHS4AS Common:** As its name suggests, PHS4AS provides common services such as utilities to other bundles. Every bundle have access to PHS4AS Common bundle.

- **Interface Server:** PHS4AS applications consist of two bundles: Application Server and Interface Server. Interface Server is the bundle that contains the interface files. After Adobe Flex generated the SWF and HTML files, they are deployed under Interface Server and served to the user.

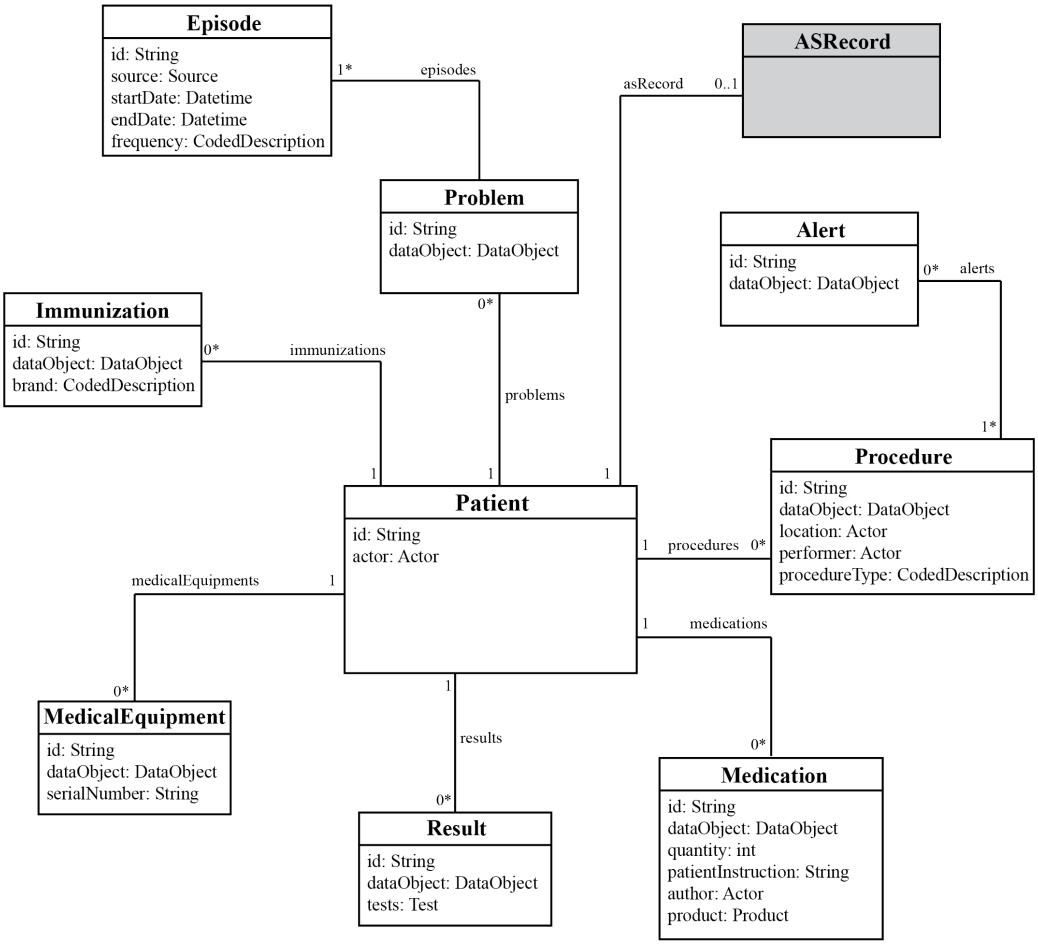

Figure 3.3: Part of PHS4AS Model Class Diagram - 1

- **Application Server:** Application Server connects the interfaces to the server through BlazeDS. According to the request retrieved from interface, it performs necessary functions such as updating records and retrieving data.

- **BlazeDS:** BlazeDS enables the communication between OSGI bundles and Adobe Flex by carrying the messages retrieved from interface to Application Server and Application Server to interface.

- **Data Manager:** Data Manager allows applications to create, read, update and delete the health records of patients. PHS4AS enables the integration of any number of different external data sources to the platform. Data Manager examines the request retrieved from application bundles and

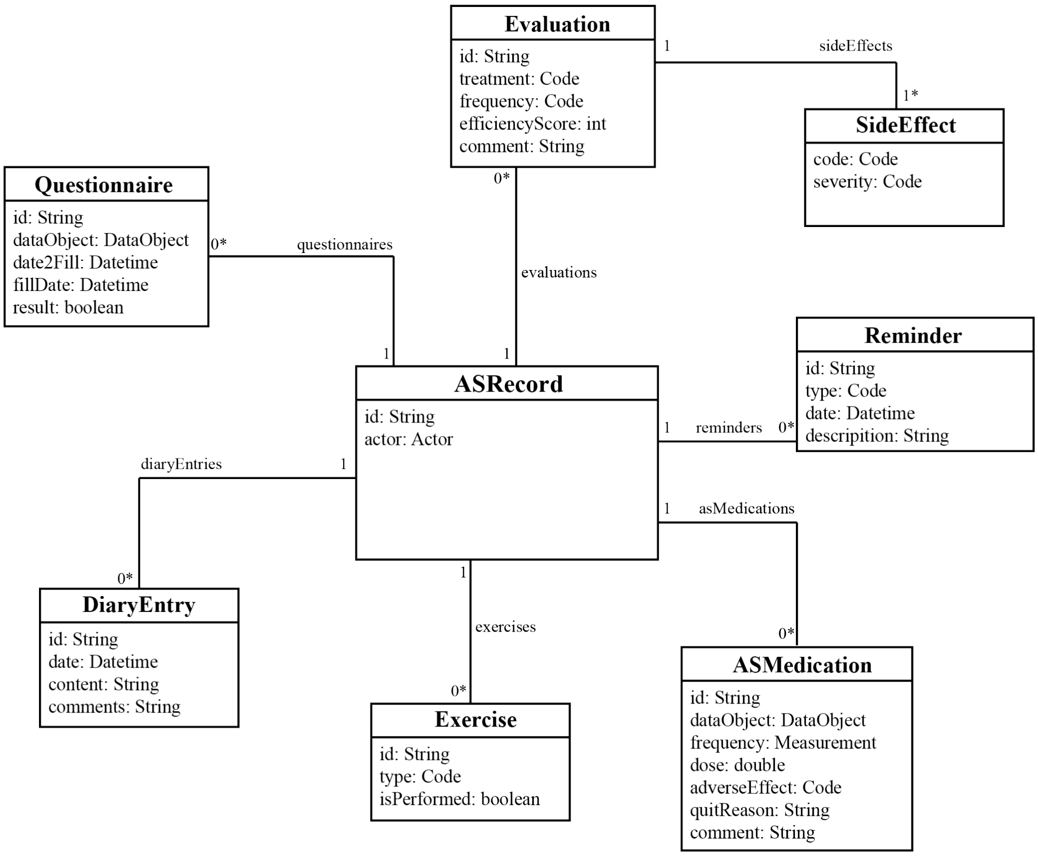

Figure 3.4: Part of PHS4AS Model Class Diagram - 2

finds the correct data source to perform the action. In this study, there are two data sources, which are PHS4AS local data source and Turkish National Health Information System.

- **Terminology Manager:** Terminology Manager allows applications to retrieve the medical terminologies. PHS4AS uses most widely used clinical terminology standards such as SNOMED CT, LOINC, RxNorm and ICD-10 to express the semantics.

- **Authentication Manager:** It provides necessary infrastructure for secure authentication and identification. PHS4AS is being accessed from Web through secure port, i.e., https. Currently, it uses username-password authentication mechanism for authenticating users. This mechanism is not very secure as there is no validation of patient's identity against a national identity verification. Since health information is very sensitive, there should be more strict authentication mechanism such as electronic signature. However, this thesis describes a pilot study, hence strict authentication is out of the scope of the thesis.

- **Account Manager:** It is used to create, access and manage the user accounts.

- **Database Manager:** PHS4AS contains two local databases, namely Terminology database and PHS4AS database. Terminology database is used to store and retrieve clinical terminology standards such as SNOMED-CT, LOINC and ICD-10. PHS4AS database is used to create, read, update and delete (CRUD) operations on personal health records. Database Manager handles the connections with these databases and utilizes Hibernate.

- **Data Source:** External data sources are connected to the PHS4AS platform by implementing the IPHRDataSource interface and registering themselves to Data Manager with related configurations. It is possible to integrate any external data source that uses CCR or CDA for data representation. In this study, Turkish National Health Information System is integrated to the system as an external data source in addition to the internal PHS4AS data source.

- **NHIS:** NHIS bundle provides services to retrieve the EHRs of patients from Turkish National Health Information System. This integration will be explained in detail in the next section.

Figure 3.5 depicts the overall system architecture and connections between components of the OSGI bundles. As shown in the figure, user interacts with the system by using a browser having Flash Player plug-in on it. Browser retrieves the HTML and SWF files existing in the application interface bundles and parses them to present to the user. Applications communicate with the PHS4AS platform through BlazeDS to perform data and terminology operations. For each application, one interface bundle and one application bundle exist in PHS4AS platform. BlazeDS enables these two bundles to communicate and exchange

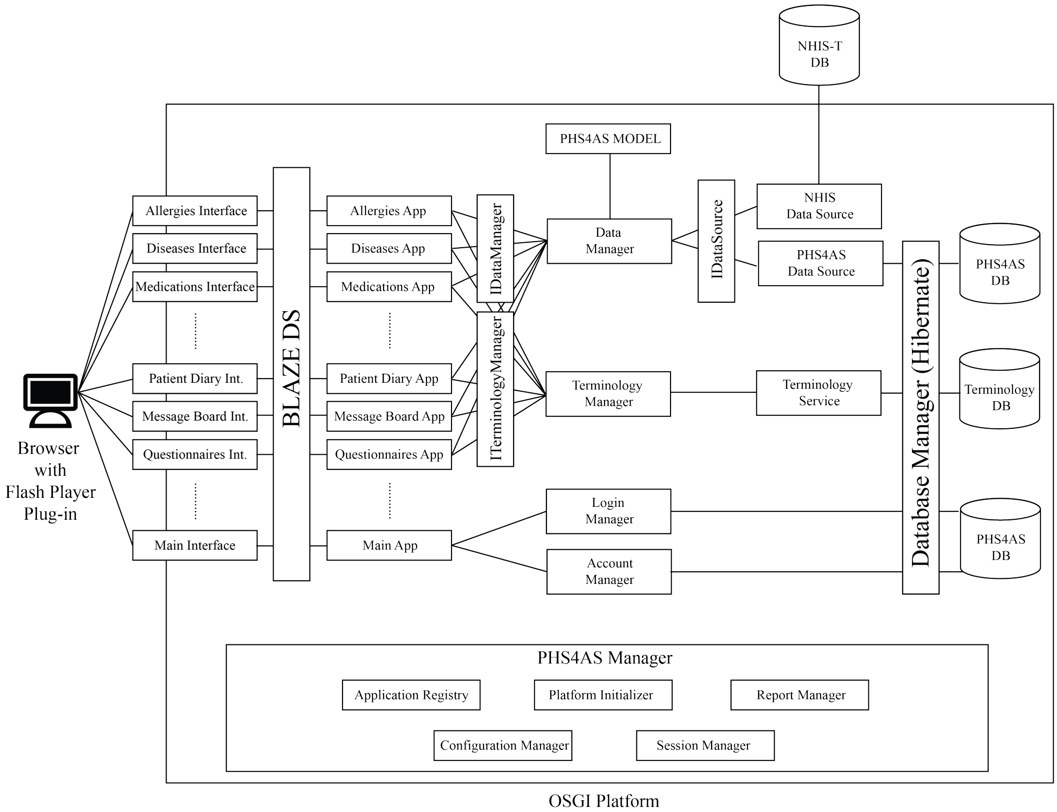

Figure 3.5: PHS4AS System Architecture

some data. The data to be exchanged is either patient's health record data or terminology. Application bundles perform terminology operations by invoking the related functions in ITerminologyManager interface, which is implemented by Terminology Manager.

Terminology Manager retrieves the medical terminologies from database through Terminology Service which connects to the database through Database Manager. The reason there is an additional Terminology Service class in the architecture is to make the system as flexible as possible so that if needed, external terminology services can be integrated to the system easily.

Application bundles perform data operations by invoking related functions in IDataManager interface. This interface is implemented by Data Manager and contains the following functions:

- *getRecords(Authentication auth, String recordType):* In PHS4AS for each type of record there is a unique identifier (UUID). Data Manager understands which records to be retrieved from a data source with this parameter. Authentication parameter is used to ensure that the request comes from a user who really logged in to the system. It contains information such as user identifier, session identifier and user role.

- *addRecord(Authentication auth, String recordType, IRecord record):* All classes in PHS4AS Model bundle implement IRecord interface. IRecord includes attributes that every model class should have such as record ID. This method stores the given record to the related database.

- *updateRecord(Authentication auth, String recordType, IRecord record):* Updates the given record.

- *deleteRecord(Authentication auth, String recordType, String recordId):* Removes the record with recordId and having the type of recordType.

Data Manager is responsible for selecting correct data source according to patient's preference. Therefore, all internal and external data sources register themselves to Data Manager. Data Manager communicates with the data sources through IDataSource interface. Any data source to be integrated to the system has to implement this interface. In this study, one internal and one external data sources are integrated. The internal one is named as PHS4AS Data Source and it is responsible for creating, reading, updating and deleting patient's personal health records (PHRs). The external one is NHIS Data Source and responsible for connecting to NHIS-T database to retrieve patient's electronic health records (EHRs). In contrast to PHS4AS Data Source, NHIS Data Source is not able to create, update and delete health records.

PHS4AS stores the patient's health data in CCR format internally. The EHR of patient, however, is retrieved in CDA format from NHIS-T. Data Manager is responsible for converting the data in CDA format to a data represented in CCR format. All of the PHS4AS Model classes contain necessary CDA-CCR and CCR-CDA mappings, hence all Data Manager needs to do is to invoke the related mapping method to perform conversion operation.

PHS4AS contains two databases: PHS4AS DB and Terminology DB. As their names suggest, PHS4AS DB is used to store PHRs of patient and Terminology DB is used to store medical terminologies. Database Manager handles all the database operations in PHS4AS platform and uses Hibernate technology.

3.1.2 Integration with Turkish National Health System

As part of its e-Health policy, the Turkish Ministry of Health has implemented main health information systems such as the National Health Information System (NHIS-T) [54], the Family Medicine Information System (FMIS) [48] and the Centralized Hospital Appointment System (CHAS) [10]. MoH has brought these systems together under the roof of Saglik-Net (Turkish for "Health-Net"), which can be defined as an integrated, secure, fast and expandable information and communication platform collecting the data produced by healthcare institutions in accordance with standards. Saglik-Net aims to increase the efficiency of healthcare services by generating appropriate information for all stakeholders from these collected data.

NHIS-T is the huge project of MoH that is responsible for collecting patients' Electronic Health Records (EHRs) from all the secondary and tertiary healthcare organizations of Turkey. NHIS-T became operational on January 15, 2009. As of November 2013, 98% of the public hospitals and 80% of the private and university hospitals were connected to the NHIS-T sending the EHRs of their patients on a daily basis [55]. The number of EHR instances that are sent by the Hospital Information Systems (HIS) to NHIS-T is 1,5 million per day on average [54], but it can reach to 4,6 million per day [55]. There are already more than 2 billion EHR instances in the NHIS-T. So far, EHRs of 78.9 million people have been created in the NHIS-T [55].

FMIS-T is another national system via which the general practitioners register their patients, observe their status, refer them to the hospitals and store their primary care records. It also includes a performance evaluation and decision support system. As of November 2013, family medicine is being applied in all 81 Turkish provinces and about 22 thousands general practitioners are using the

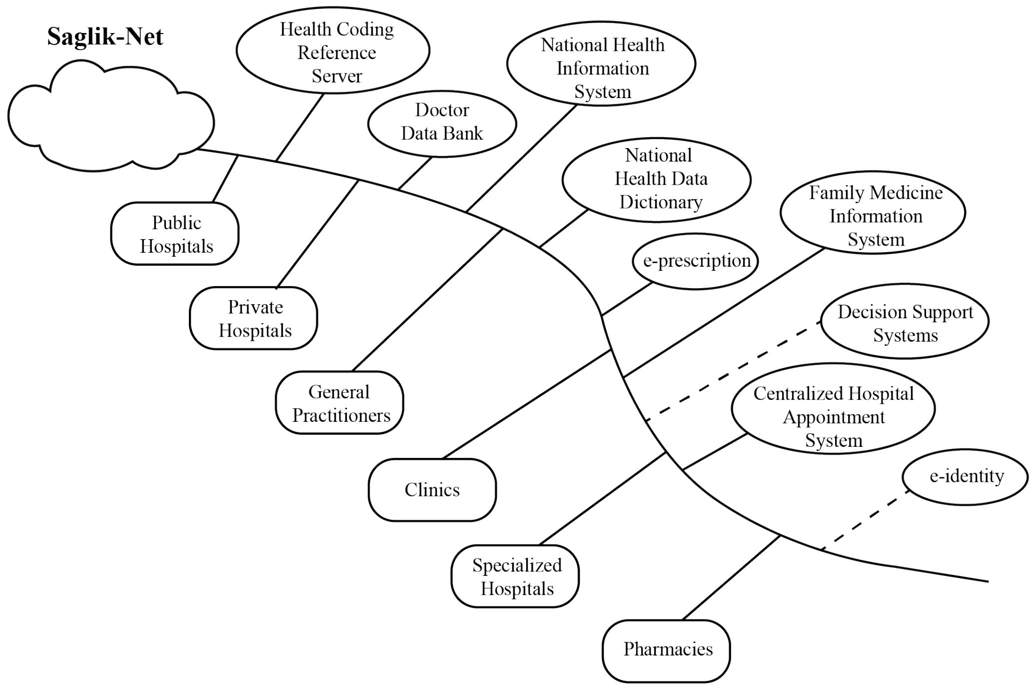

Figure 3.6: Saglik-Net Network [55]

system [55].

In the first version of the Saglik-Net, the EHR exchange templates of NHIS-T were based on HL7 CDA R2 and the transportation protocol was HL7 v3 Web Services Profile together with OASIS WS-Security. Unlike NHIS-T, however, FMIS-T was based on proprietary formats for patient data representation and custom-made SOAP Web Services for exchange of data. Having two different infrastructures was creating a crucial EHR linking problem among primary, secondary and tertiary care. In addition, NHIS-T was not totally HL7 CDA R2 compliant due to renaming of some of the attributes. In order to solve these problems, in August 2012, Saglik-Net 2.0 was released, where NHIS-T and FMIS-T systems are merged and single EHR system was provided. In the second release, NHIS-T became fully compliant with HL7 CDA R2.

PHS4AS uses CCR based data model for storing patient's health information. For each type of health record in PHS4AS, there exist a model class in CCR format and all the model classes contain two mapping functions to convert the data from CDA to CCR and CCR to CDA. These mappings make PHS4AS to be also compliant with HL7 CDA R2. Figure 3.7 shows an example code segment of a mapping function which converts the Alert data represented in CDA format to the data represented in CCR format.

```java
public class AlertTemplate extends CDATemplate{
    public static final String ALERT_SECTION_CODE_ID = "48765-2";

    public static final String ALERT_ACT_TEMPLATE_ID = "2.16.840.1.113883.10.20.1.27";
    public static final String ALERT_OBSERVATION_TEMPLATE_ID = "2.16.840.1.113883.10.20.1.18";
    public static final String ALERT_STATUS_OBSERVATION_TEMPLATE_ID = "2.16.840.1.113883.10.20.1.39";
    public static final String REACTION_OBSERVATION_TEMPLATE_ID = "2.16.840.1.113883.10.20.1.54";

    public POCDMT000040ClinicalDocument mapCCRToCDA(List<Object> records) {

    @Override
    public List<Object> mapCDAToCCR(POCDMT000040ClinicalDocument document) {
        List<Object> records = new ArrayList<Object>();

        POCDMT000040Component3 section = document.getComponent().getStructuredBody().getComponent().get(0);

        for(POCDMT000040Entry entry : section.getSection().getEntry()) {

            POCDMT000040Act act = (POCDMT000040Act)entry.getActEncounterObservationOrOthers();
            POCDMT000040EntryRelationship er = act.getEntryRelationship().get(0);
            POCDMT000040Observation observation = (POCDMT000040Observation) er.getActEncounterObservationOrOthers();
            POCDMT000040PlayingEntity playingEntity = (POCDMT000040PlayingEntity) observation.getParticipant().
                    get(0).getParticipantRole().getPlayingDeviceOrEntity();


            Alert alert = new Alert();
            alert.setDataObject(new DataObject());

            // source
            Source s = CDAUtils.createSourceFromER(act.getEntryRelationship(), false, -1);
            if(s != null) {
                alert.getDataObject().setSource(s);
            } else {
                alert.getDataObject().setSource(new Source());
            }

            POCDMT000040EntryRelationship erStatus = observation.getEntryRelationship().get(0);
            POCDMT000040Observation obsStatus = (POCDMT000040Observation) erStatus.getActEncounterObservationOrOthers();

            IVLTS effectiveTime = act.getEffectiveTime();
            IVXBTS low = effectiveTime.getLow();
            IVXBTS high = effectiveTime.getHigh();

            //description
            alert.getDataObject().setDescription(CDAUtils.ceToCode(playingEntity.getCode()));

            //time
            alert.getDataObject().setStartDate(DateUtil.parseDate(low.getValue()));
```

Figure 3.7: Sample Code Segment for CDA-CCR Mapping

Owing to compliance of both PHS4AS and NHIS-T 2.0 to HL7 CDA R2, PHS4AS is completely integrated with NHIS-T 2.0 so that patients using PHS4AS are able to display their EHRs existing in NHIS-T. The integration of PHS4AS to NHIS-T is handled by NHIS Data Source bundle existing in the PHS4AS platform. In a typical scenario, NHIS Data Source connects to NHIS-T system, retrieves the patient's EHR in CDA format, converts it to CCR format and stores in PHR4AS database. However, NHIS-T does not provide any services to the outside world for accessing the patient health data. In order to enable

PHS4AS to retrieve the patients' health data from NHIS-T, MoH implemented some proprietary Web services which send the EHRs of patients in a proprietary format within the scope of this study. Figure 3.8 shows an example document retrieved through these proprietary Web services.


```
<RIZAUCAR>
    <SURUM>v1.1</SURUM>
    <VATANDASOZLUK>
        <ADI>RIZA</ADI>
        <SOYADI>UÇAR</SOYADI>
        <DOGUMTARIHI>19.03.1978</DOGUMTARIHI>
        <CINSIYETI>ERKEK</CINSIYETI>
    </VATANDASOZLUK>
    <MUAYENELER>
        <MUAYENE>
            <TARIHI>08.03.2013</TARIHI>
            <PROTOKOLNUMARASI>OP-418023-08032013-134231765500</PROTOKOLNUMARASI>
            <ANATANIKODU>J39.9</ANATANIKODU>
            <ANATANIADI>Ust solunum yolunun hastaligi, tanimlanmamis</ANATANIADI>
            <KURUM>ANKARA POLATLI 5 NOLU AILE HEKIMLIGI BIRIMI</KURUM>
            <HEKIM>Dr. MEHMET SAĞLAM</HEKIM>
            <EKTANILAR>
                <EKTANI>
                    <EKTANIKODU>M45.9</EKTANIKODU>
                    <EKTANIADI>Ankilozan spondilit, yer tanimlanmamis</EKTANIADI>
                </EKTANI>
            </EKTANILAR>
            <MUDAHALELER>
                <MUDAHALE>
                    <MUDAHALEKODU>520080</MUDAHALEKODU>
                    <MUDAHALEADI>1.Basamak poliklinik muayenesi </MUDAHALEADI>
                </MUDAHALE>
            </MUDAHALELER>
        </MUAYENE>
        ...
    </MUAYENELER>
    ...
</RIZAUCAR>
```


Figure 3.8: Sample Part of EHR with Fake Data

3.2 Client-side of PHS4AS

3.2.1 Usage of Flex

PHS4AS is a web based personal health system developed for both ankylosing spondylitis patients and healthcare professionals (HPs). It provides different interfaces for patients and HPs with different functionalities.

In this study, Flex is chosen as the user interface development environment because Flex enables developers to create user friendly interfaces quickly, build a modular and component based architecture and communicate with the server-side through Blaze DS technology easily. There are a number of application frameworks which enable to set up application structure according to best practices. PHS4AS uses the Model-View-Controller (MVC) based Cairngorm framework for application architecture.

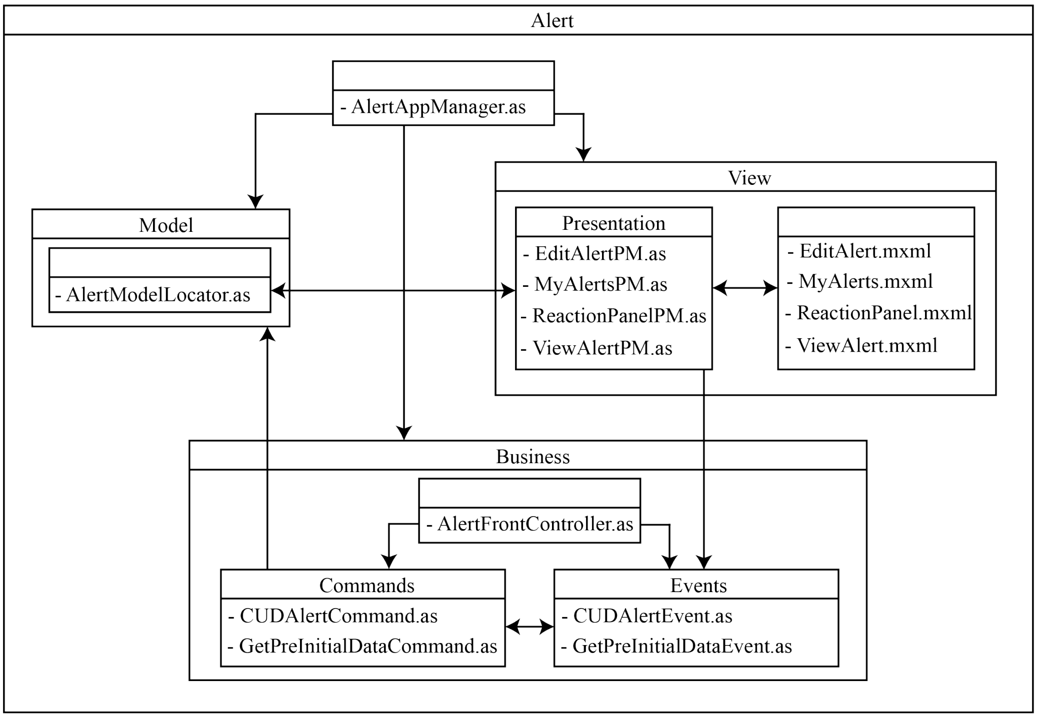

Figure 3.9: Cairngorm Architecture of Alert Application in Flex

As an example, Figure 3.9 shows the Cairngorm architecture of Alert application. Application interface resides in the mxml files at view package. For each interface file, there is a corresponding presentation file where user interactions such as button click events are managed. Interfaces are bound to the Alert data model through AlertModelLocator. AlertAppManager is responsible for initializing the components existing in the package at first run. It loads the interface files according to selected language and user type (patient or healthcare professional). It also dispatches the pre-initial data events so that patient's allergies and medical terminologies are retrieved from the server. CUDAlertEvent handles create, update and delete operations. It is dispatched by the presentation classes when user clicks on the related button. Command classes are responsible for handling the responses received from server. According to the server's response, it makes necessary updates on the model.

3.2.2 Applications

General structure of PHS4AS applications is depicted in Figure 3.10.

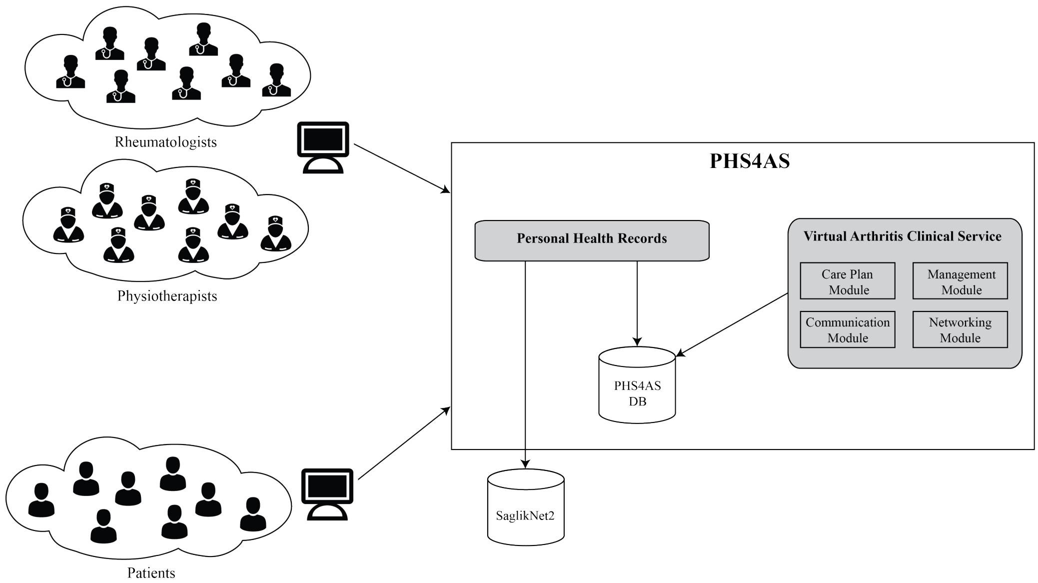

Figure 3.10: General Structure of PHS4AS Applications

As shown in the figure, PHS4AS provides different interfaces for patients and healthcare professionals. There are two types of healthcare professionals existing in AS treatment, that are rheumatologists and physiotherapists. Although the system interface is the same for both, the functionalities they have are different. For example, rheumatologists are able to ask patients to do some tests over the system, whereas physiotherapists are not able to so.

PHS4AS consists of two modules: Personal Health Records (PHR) module and Virtual Arthritis Clinical Service (VACS) module. In this section, applications in PHR module are described briefly, while applications in VACS module are explained in detail since it is the main focus of this study and first in the literature.

3.2.2.1 Personal Health Records Module

As aforementioned, access to own health information is the first step in the process of patient empowerment. PHS4AS achieves this first step of patient empowerment through PHR module since it enables both patients and healthcare professionals to access patients' basic health information. Integrated with NHIS-T, PHR module contains following basic health record applications.

- **Allergies:** Allergies application is used for displaying patients' allergies and their adverse reactions. An allergy record includes the name of allergy (e.g., cat allergy, penicillin allergy), status of allergy (active or past), start date, end date if allergy is past, reactions of allergy (e.g., weal, pruritus), severity of reaction (mild, moderate or severe), and treatment of reaction. SNOMED CT terminology codes are used for specifying the name of an allergy and its reactions.

- **Diseases:** Diseases application is used for displaying patients' diseases and their episodes. A disease record includes the name of disease (e.g., asthma, bronchitis), status of disease (active or past), start date, end date if disease is past, and disease's episodes. If patient has the same disease at another time, instead of creating new disease record, new episode containing start date and end date is added to the patient's existing disease record. ICD-10 terminology codes are used for specifying the name of disease.

- **Encounters:** Encounters application is used for displaying patients' hospital visits together with it's reason. An encounter record includes the name of clinic, visit date, practitioner name, discharged date if available, and the related problem that is the reason of visit. Related problem can be either selected from patient's diseases or created as a new one.

- **Procedures:** Procedures application is used for displaying patients' interventional, surgical, diagnostic or therapeutic procedures/treatments. A procedure record includes the name of procedure, name of clinic where procedure has been applied, date, type of procedure (surgical, laboratory or outpatient procedure), and primary provider's name.

- **Immunizations:** Immunizations application is used for displaying patients' immunizations. An immunization record includes the name of immunization (e.g., tetanus, diphtheria), and date if immunization is applied.

- **Social History:** Social history application is used for calculating patients' health risk factors according to their occupational, personal, social and environmental history. It includes records such as tobacco use, alcohol use and toxic exposure of patient.

- **Family History:** Family history application is used for recording the health problems existing in patients' family members and relatives. This information is especially valuable for healthcare professionals in a situation that patient is suspected to have the same chronic disease such as diabetes or alzheimer.

- **Medications:** Medications application is used for displaying patients' medications. A medication record includes the name of medication (e.g., Aspirin, Vermidon), date that medication is started to be used, date that medication is ended up to be used, frequency (e.g., two times per day, once a week) and dose.

- **Lab Measurements:** Lab measurements application is used for displaying patients' laboratory test results. A lab measurement record includes the name of the test (e.g., HLA B27, CRP), date that test has been applied, and its result. LOINC code system is used for specifying the name of the laboratory test.

- **Weight, Height, Blood Pressure, Pulse, Body Temperature Measurements:** These applications are used for displaying patients' basic health measurements.

All of these applications have similar user interfaces. When an application is opened, all the records are first listed with some important properties such as status, start date and information source. In PHS4AS there are three information sources: patient, healthcare professional and NHIS-T (SaglikNet2). Patients and healthcare professionals can edit the records which are created by themselves. Patients cannot edit any record that is created by healthcare professional or retrieved from NHIS-T. Similarly, healthcare professionals cannot edit any record that is created by patient or retrieved from NHIS-T. Both patients and healthcare professionals can display the details of the records by clicking on it.

Measurements applications differ from the others in a way that they not only list the records in a table, but they also draw a line chart to provide a complete picture about patient's measurements. This is especially useful to see the abnormal values measured at any time and also the progress. Figure 3.11, Figure 3.12, Figure 3.13 display some screenshots of applications in PHR module.

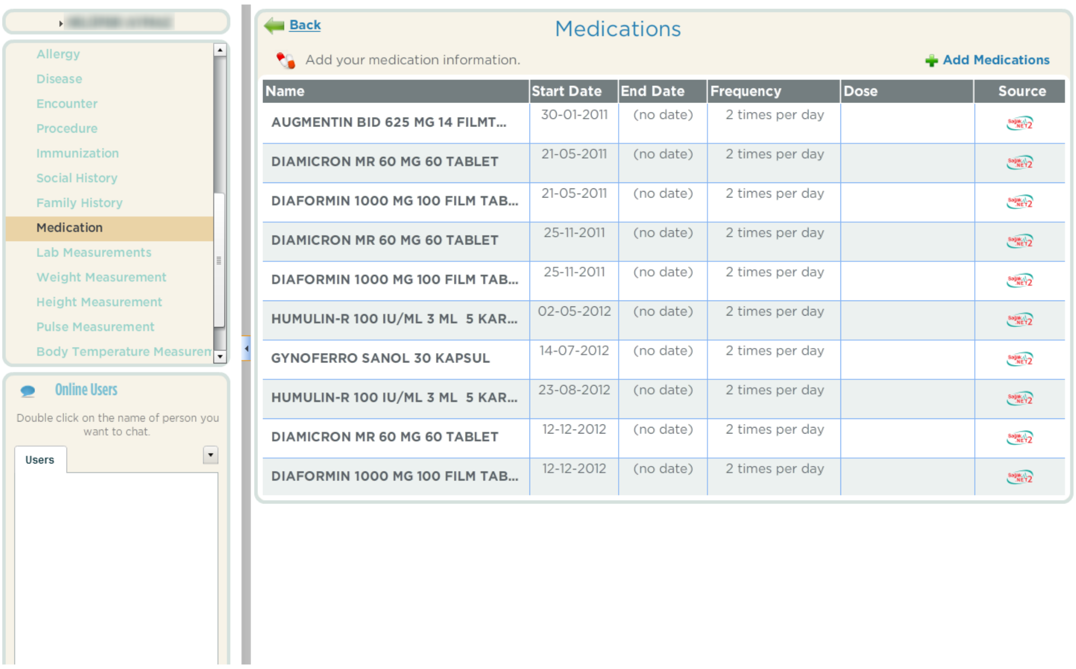

Figure 3.11: List of Patient's Medications

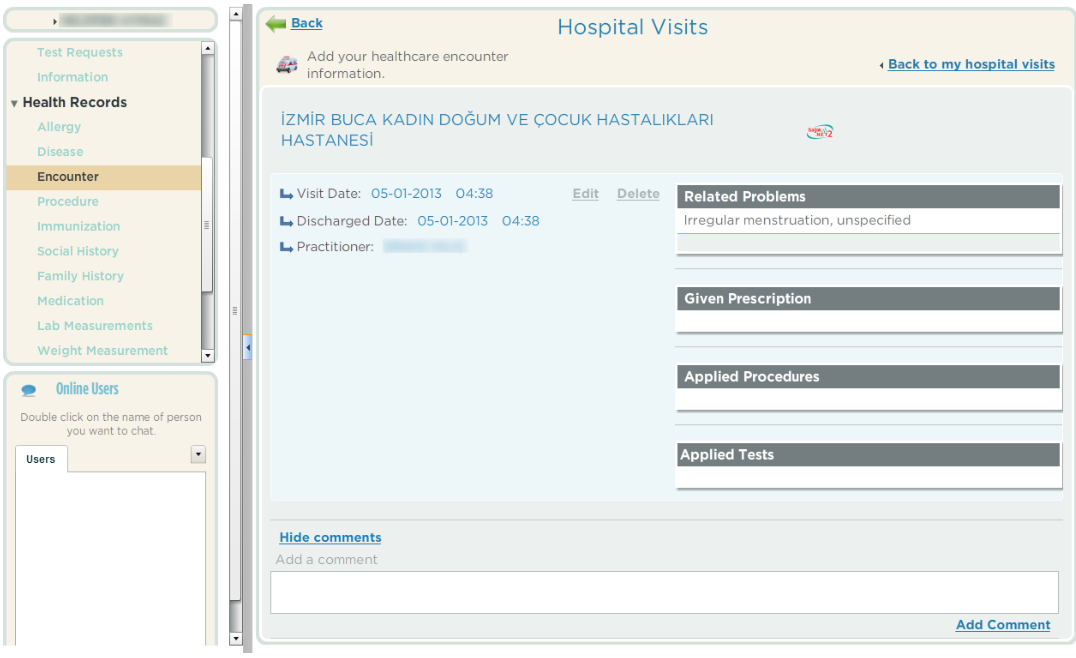

Figure 3.12: Details of Patient's Encounter

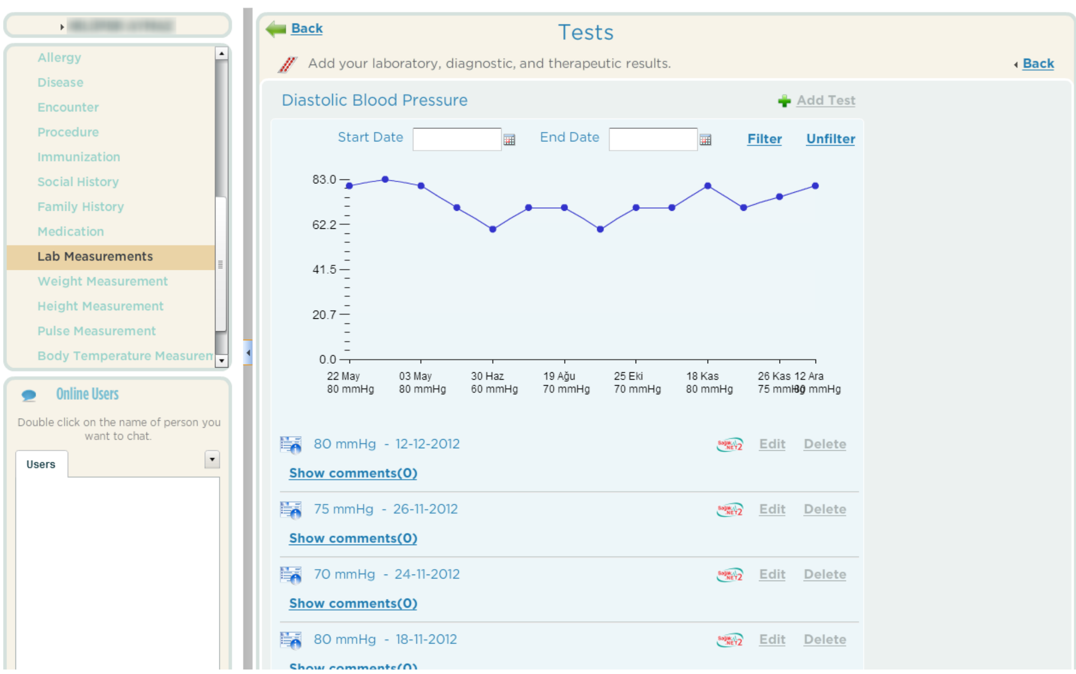

Figure 3.13: Patient's Diastolic Blood Pressure Measurements

3.2.2.2 Virtual Arthritis Clinical Service Module

Aiming to provide treatment support and lifestyle guidance to the patients who suffer from ankylosing spondylitis, VACS module contains several chronic disease management applications, such as patient diary, message board, questionnaires, reminders, evaluations, arthritis medications, workouts, test requests, information and videos. Through these applications, VACS module aims to enable the following functionalities:

- Remote follow-up
- Information access
- Chronic disease management
- Remote consultation
- Disease and treatment education
- Medication and non-pharmacological treatment follow-up
- Medication and non-pharmacological treatment benefit analyse
- Reminders

All the applications under VACS module are developed under the supervision of Turkish League Against Rheumatology (TLAR) [47], which is the Turkish patient organization aiming to reduce the burden of rheumatic diseases on the society, improve the treatment and support education and research in the field of rheumatology. Having the necessary clinical, social and legal expertise, TLAR provided necessary clinical guidelines and requirements for the development of VACS module. These well-accepted clinical guidelines and care plans are created by TLAR according to the publications of European League Against Rheumatism (EULAR) [21] and TLAR.

As illustrated in Figure 3.14, applications in VACS are grouped into four submodules according to their functionalities and different purposes.

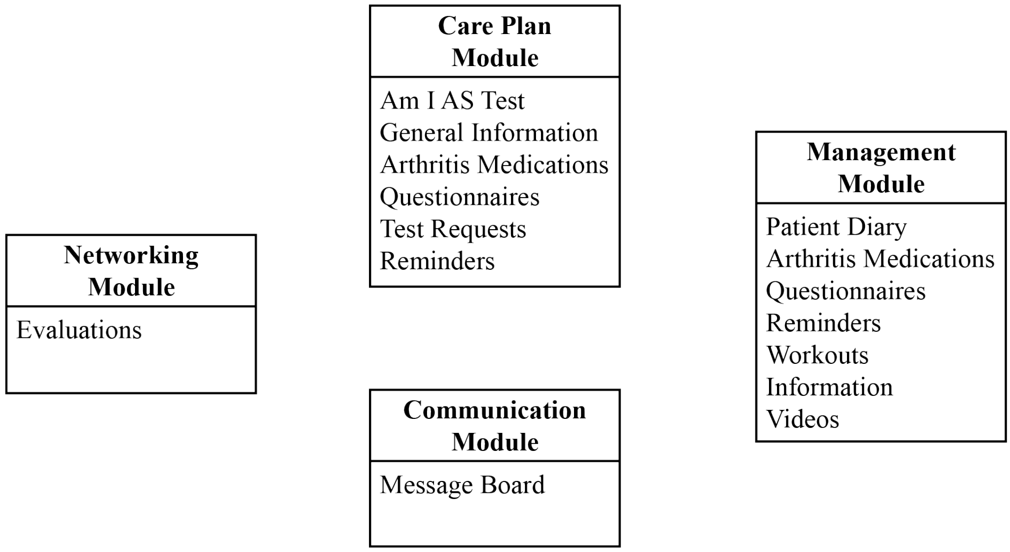

Figure 3.14: VACS Modules

Care Plan sub-module provides necessary functionalities to healthcare professionals to create care plans for their patients and monitor them. Healthcare professionals are able to view, add, update and comment to patient's information through this module. Management sub-module enables patients to follow the care plans created by their healthcare professionals. Patients are able to view the comments of the healthcare professionals through this module. Communication sub-module connects patients and healthcare professionals for remote consultation. Networking sub-module provides collaboration between patients, supporting each other and sharing experiences. It allows patients to share their information with other patients, follow similar patients' treatments and share the analyzes of different treatments. Healthcare professionals are also able to use this information to improve the treatment of patient.

3.2.2.2.1 "Am I AS?" Test

It is an informal way of understanding whether someone is AS or not. For AS diagnosis, there should be two findings. One is related to complaints and examination of patient, and the other is related to x-ray of sacroiliac joint of patient. For the first one, patients are asked three questions about their back pains, restrictions on spine movement and restrictions on expanding of chest. For the second one, patients are asked to compare their x-rays with some other x-ray pictures. If patient has answered yes to at least one of the three questions at the first part, and his x-ray resembles at least one of the x-ray pictures shown at the second part, application says that "you are ankylosing spondylitis". This is a simple application in VACS module, which is however also an important one to call patients' attention at their first time in the system.

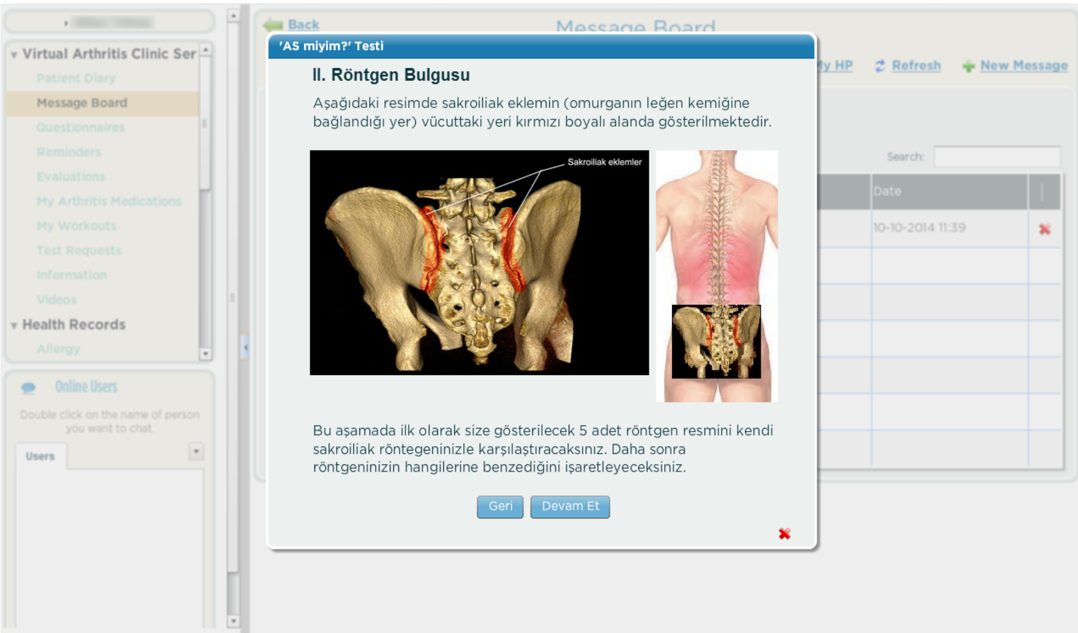

Figure 3.15: "Am I AS?" Test

3.2.2.2.2 General Information

General Information panel shows the general information about patient and also summarizes the patient's latest records related to AS. It contains several parts such as complaint history, system inquiry, previous physical treatments, laboratory results, family history, questionnaire results and AS medications. Some of these parts are filled by healthcare professionals at the first visit after diagnosis, whereas other parts are retrieved from other applications in VACS module. This panel can be considered as electronic version of patient's AS file and is only visible to healthcare professionals, not to patients.

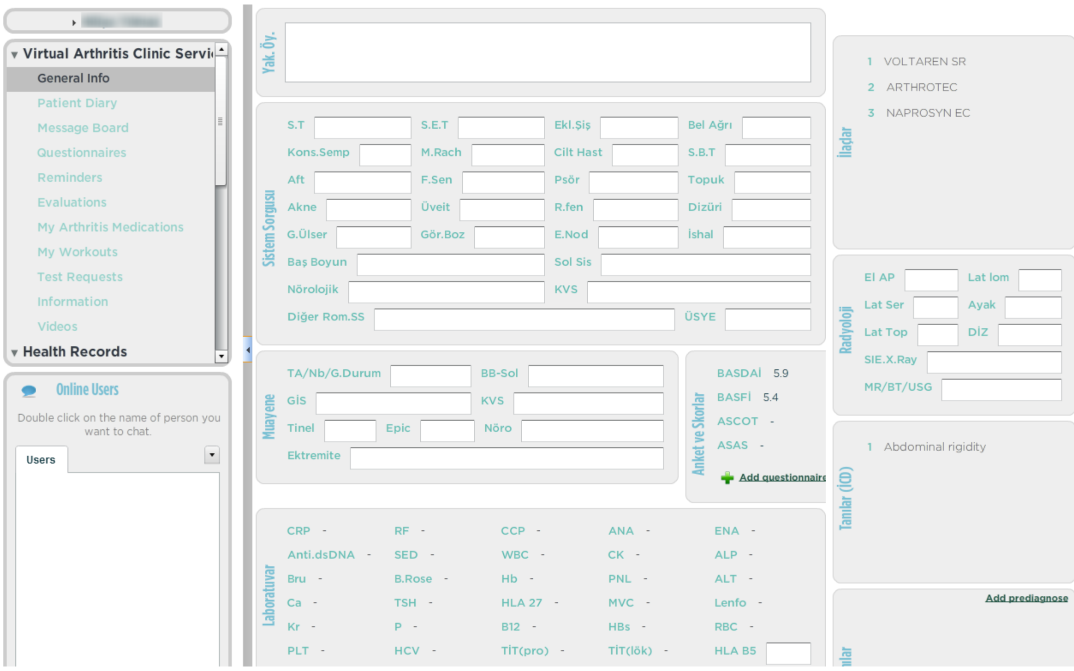

Figure 3.16: General Information

3.2.2.2.3 Patient Diary

VACS module provides Patient Diary application for patients to record their daily problems and physical and mental statuses. Patients fill the diary as frequently as they want, however they are requested to fill it at least once in three months. Healthcare professionals check these diaries whenever they want to get information about the patients' progress. HPs are able to make comments on the patients' status. This improves the communication between patients and HPs, and HPs do not need an extra remote follow-up for finding out status of the patient.

For example, AS patients usually suffer from morning pains and healthcare professionals ask patients to record their level of morning pains when they wake up. Patients take these notes to the papers, however, some of the papers usually get lost until the next visit since the time period between two regular visits are approximately three months. This causes healthcare professionals to evaluate patients' situation incompletely. Therefore, Patient Diary is an important application to get rid of this kind of problems in AS treatment.

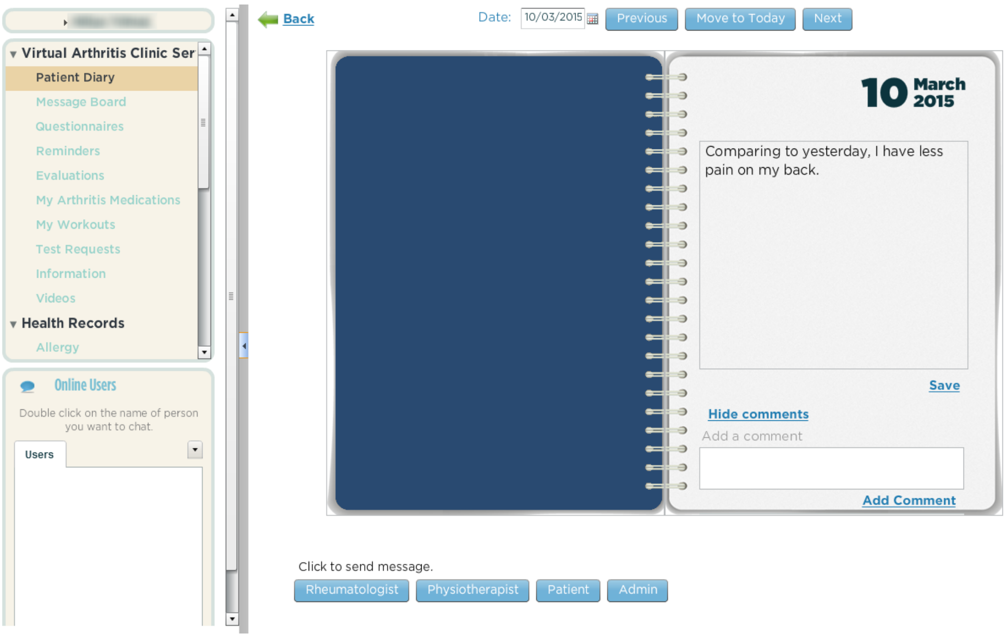

Figure 3.17: Patient Diary

3.2.2.2.4 Message Board

VACS module enables patients to consult their healthcare professionals remotely. Patients are able to consult their healthcare professionals through Message Board application, and healthcare professionals answer their questions within 24 hours. This greatly improves the patients' interest with the treatment, since most of the patients do not get involved into treatment too much because they think that treatment process is something they cannot understand. If they can find the answers to the basic questions related with disease and treatment, they will be more inclined to embrace their disease and treatment.

Moreover, in Turkey, patients are suffering from getting an appointment to make one short conversation with healthcare professionals or ask one minor question because of the high workload of the healthcare professionals. This application overcomes this problem thanks to the fact that it connects patients and healthcare professionals remotely. This not only prevents time and money loss of patients for travelling to hospitals, but it also saves healthcare professionals' time and lightens their workload by reducing total number of daily appointments.

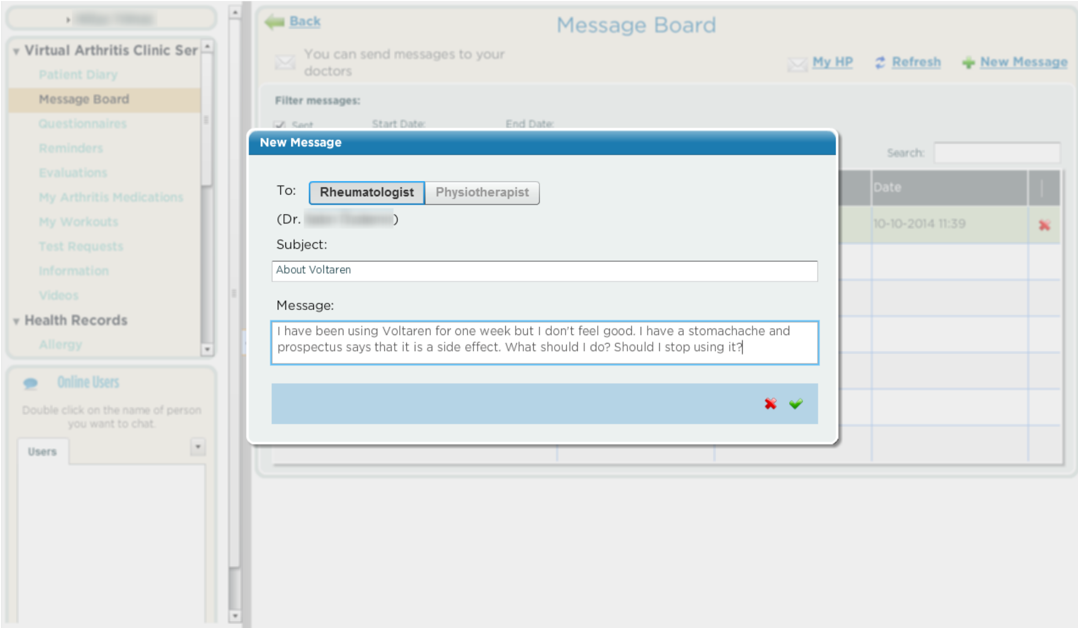

Figure 3.18: Message Board

3.2.2.2.5 Questionnaires

Questionnaires application is used for managing the questionnaires of patients specific to AS disease. It provides different functionalities for patients and healthcare professionals. It shows the previously applied questionnaires and the questionnaires that are requested to be applied to both patients and healthcare professionals. Healthcare professionals are able to request new questionnaire, and evaluate and comment on questionnaire results. Patients on the other hand can fill the requested questionnaire and read the evaluations and comments of the healthcare professionals.

In AS treatment, healthcare professionals ask patients to fill AS specific questionnaires like Bath Ankylosing Spondylitis Disease Activity Index (BASDAI), Bath Ankylosing Spondylitis Functional Index (BASFI), AS Quality of Life (ASQoL) before coming to an appointment. BASDAI is a self-administered questionnaire consisting of six questions related to five major symptoms including fatigue, spinal pain, joint pain/swelling, areas of localized tenderness, and morning stiffness [51]. The BASFI consists of eight questions related to the functional anatomy of the patients and two additional questions that assess the patients' ability to cope with everyday life [66]. ASQoL consists of 18 questions measuring the disease-specific quality of life [57]. BASDAI and BASFI are answered on 1 through 10 scale, whereas ASQoL is answered as "yes" or "no". The mean of the answers constitutes the result of the questionnaire. Normally, healthcare professionals give the questionnaire in paper format to patients and calculate the result manually. This is both waste of time during appointment and additional workload for healthcare professionals. Questionnaires application overcomes this problem by enabling healthcare professionals to ask patients to fill the questionnaire before coming to appointment. After patient fills the questionnaire, system automatically calculates its result and shows it to healthcare professional.

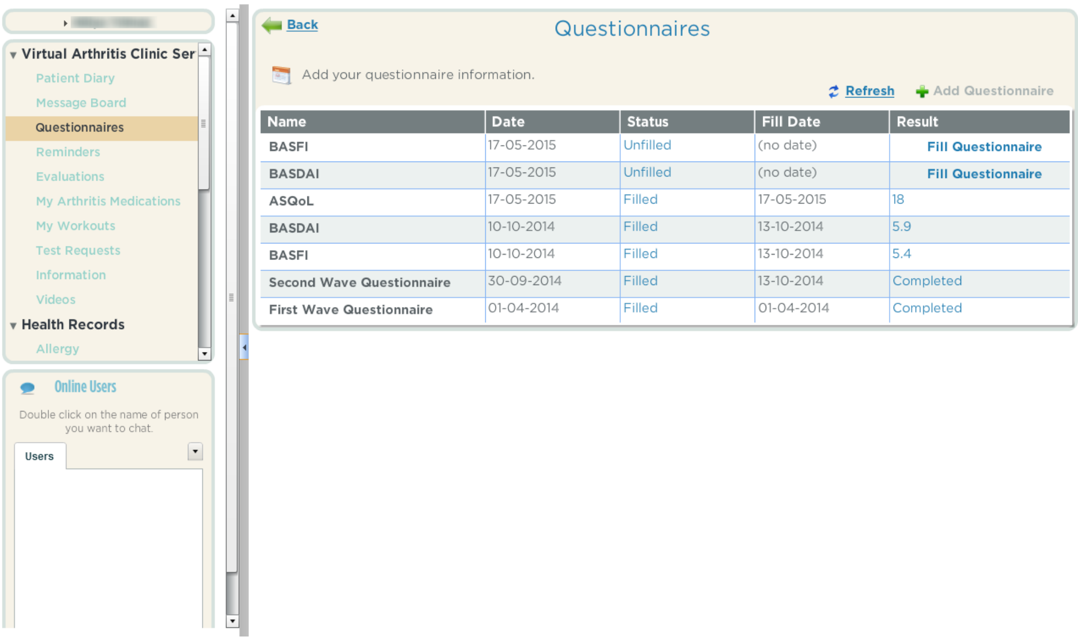

Figure 3.19: Questionnaires

3.2.2.2.6 Reminders

Patients need many reminders during the treatment process. They should follow their medication schedule, exercise schedule and also appointments. Moreover, they are requested to fill diary and questionnaires on a regular period. To follow all these jobs, reminder service of VACS is being used. Patients are able to add reminder for any of the situations stated above. VACS are able to remind the patients in three ways, i.e., SMS, e-mail or notification from the application. While adding a new reminder, patients select one of the three ways through which they want to be reminded.

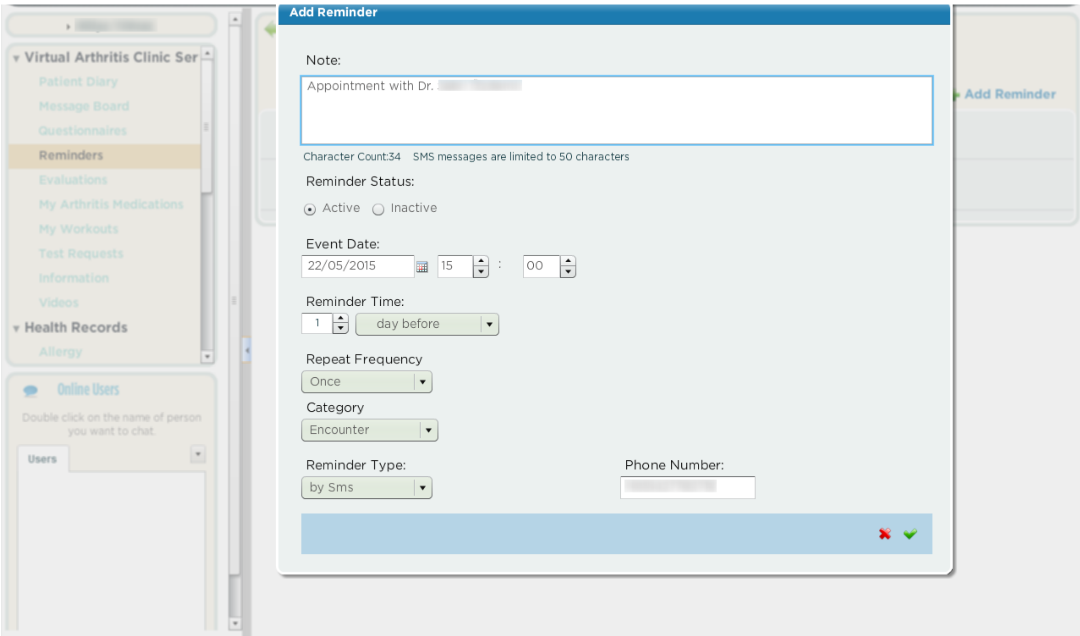

Figure 3.20: Reminders

3.2.2.2.7 Evaluations

Patients using a medication or applying any kind of non-pharmacological treatment are able to evaluate the treatment according to effects on them. For example, they are able to specify the side effect of a medication according to severity levels, rate the efficiency level of a treatment or exercise, or write comments and suggestions. They are also able to share these evaluations with healthcare professionals and other patients through this application. This provides collaboration between patients, supporting each other and sharing experiences. Moreover, thanks to the statistical results provided according to patients' evaluations, healthcare professionals are able to make more accurate decisions on the treatment of patients and this improves the quality of the care given.

3.2.2.2.8 My Arthritis Medications

My Arthritis Medications application is used for managing the medications of

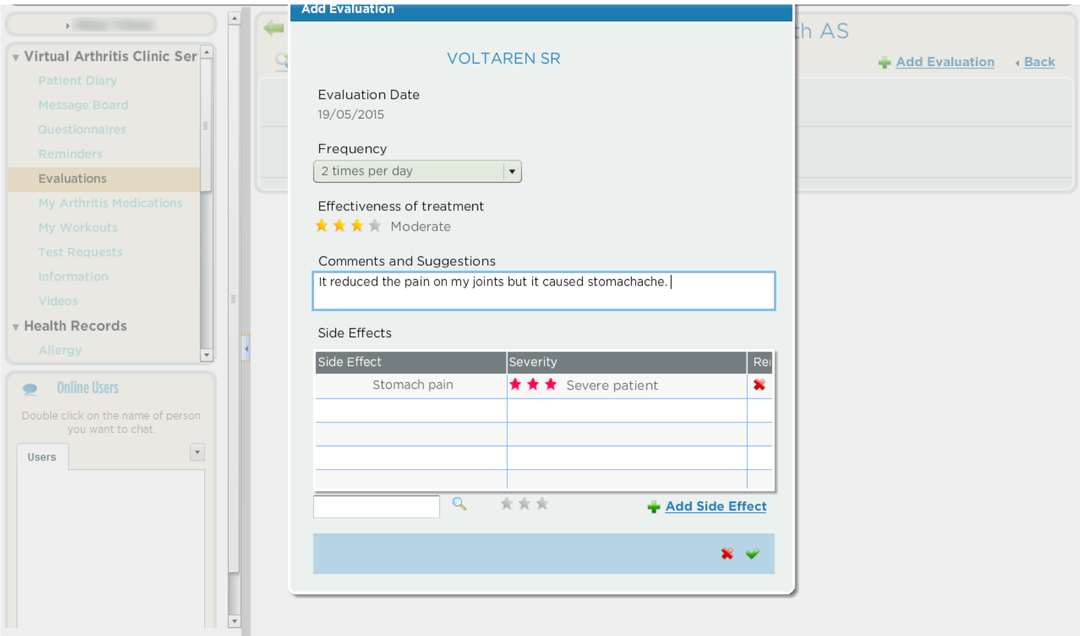

Figure 3.21: Evaluations

patients related to ankylosing spondylitis. It is exactly the same application with medications application in PHR module, except that it filters the medications of patients according to their relevance to AS. To do this, new terminology list containing the sub-list of medications used in AS treatment is created within the scope of this study. Filtering the medications is an important feature of VACS module since it eases the job of healthcare professionals to find the medications of patients related with AS.

3.2.2.2.9 My Workouts

Ankylosing spondylitis is a progressive chronic disease, meaning that it is not possible to cure and get rid of it completely. However, it is possible to prevent or slow down its progression. In order to do that, medications must be taken and exercises must be done correctly and regularly. Healthcare team of AS patients is composed of rheumatologists and physiotherapists. Physiotherapists are responsible for providing correct exercises to the patients in order to decrease their pains, while rheumatologists are responsible for dealing with all other stuff described so far. Patients record the exercises they do and physiotherapists monitor and manage them through My Workouts application.

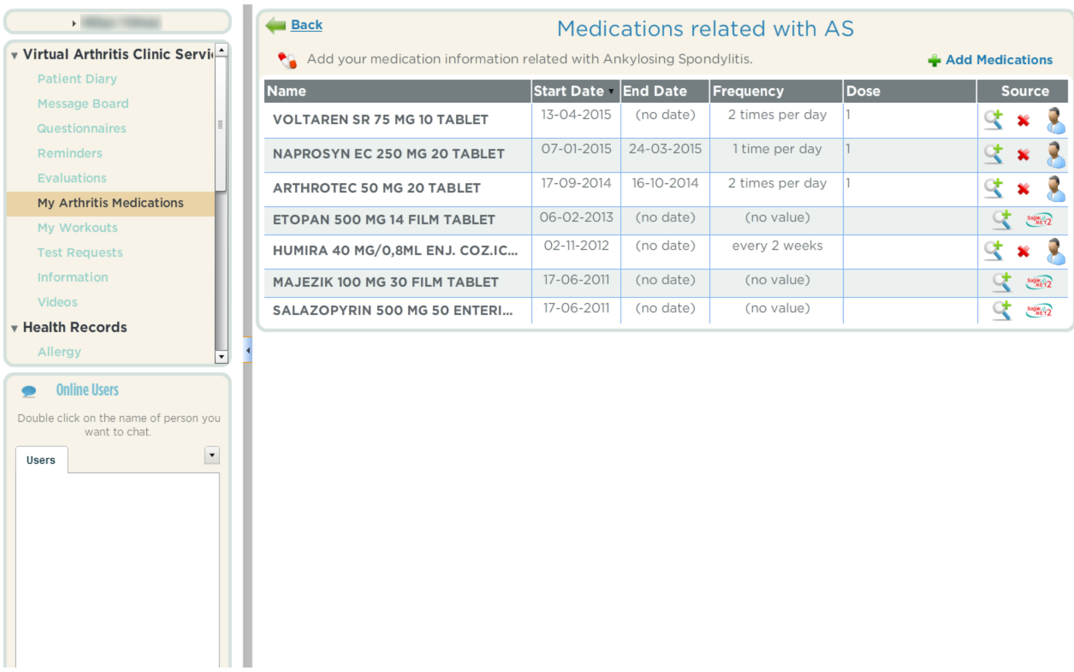

Figure 3.22: My Arthritis Medicatons

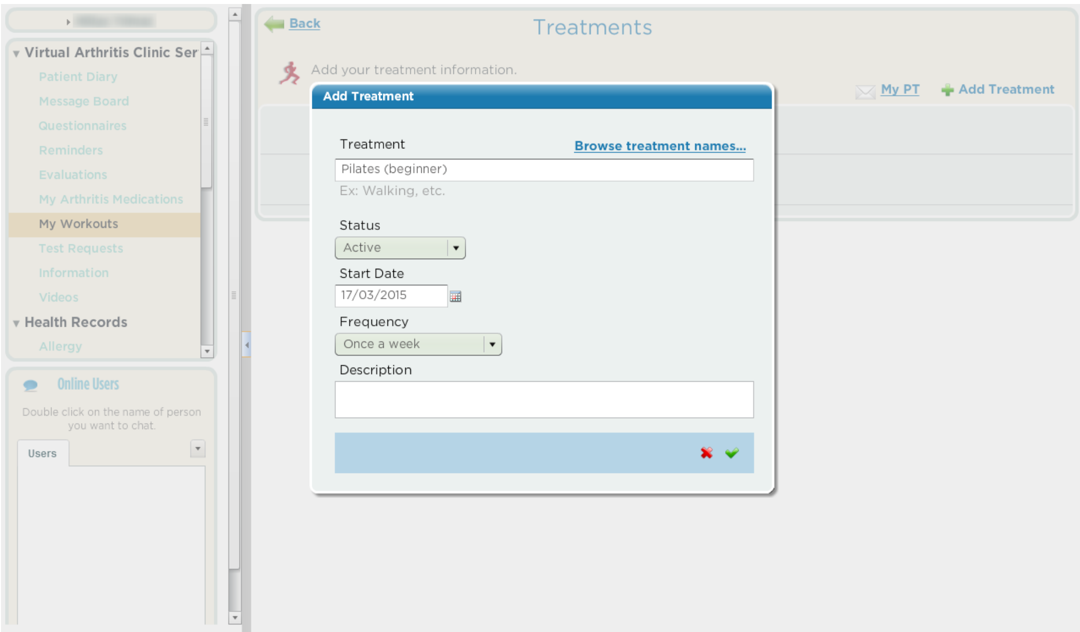

Figure 3.23: My Workouts

3.2.2.2.10 Test Requests

Test Requests application is used for managing the laboratory tests and test results of patients. It shows the previously applied tests with their results and the tests that are requested to be applied by healthcare professionals to both healthcare professionals and patients. It provides different functionalities to different actors. Healthcare professionals are able to request new test, evaluate and comment on test results, while patients are able to read the evaluations and comments of healthcare professionals.

Similar to My Arthritis Medications application, Test Requests application filters the laboratory tests according to their relevance to ankylosing spondylitis. There are 16 tests (e.g., CRP, HLA B27, sedimentation) that healthcare professionals regularly ask AS patients to apply during their treatments. To add new test, healthcare professional opens the application, selects at least one of these 16 tests and specifies the due date that test to be applied. Patients see the HPs' requests in the same application.

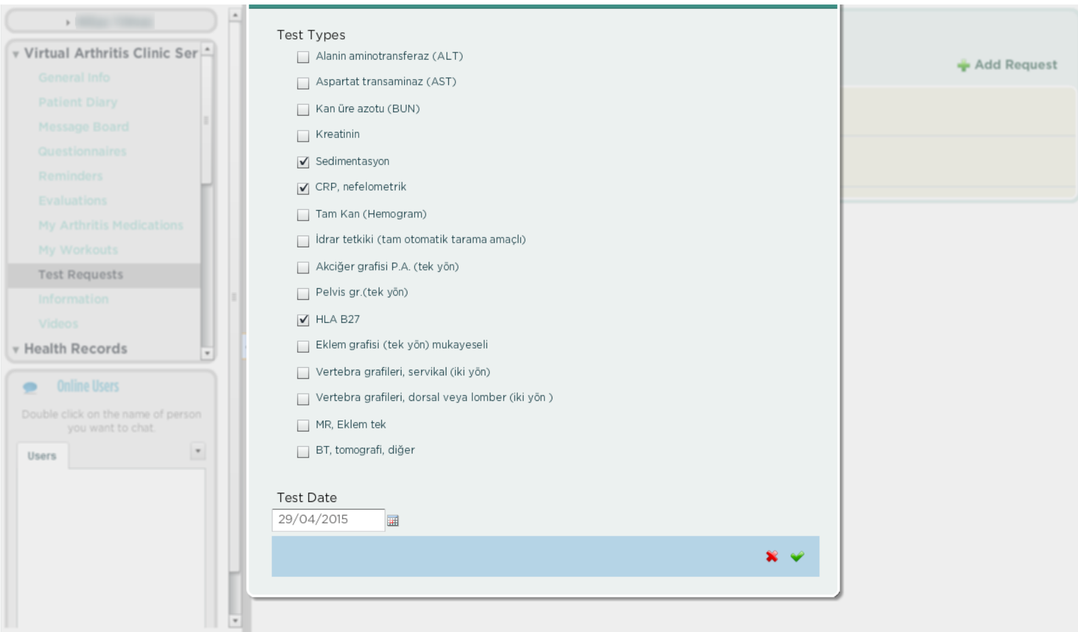

Figure 3.24: Test Requests

3.2.2.2.11 Information

All the patients are informed about the disease, treatment, actions to be taken or avoided at hospital visit of the patient after diagnosis. However, the provided information is limited because of the limited time. After this short introduction, patients generally search the Internet to find more information. However, the information on the Internet is not always 100% correct. They may get wrong information from there and applying what they learned from there would cause undesirable results. VACS module provides Information application which provides the answers of frequently asked questions about AS disease. It gives detailed information about the disease and treatment of AS, and covers most of the concerns of the patients.

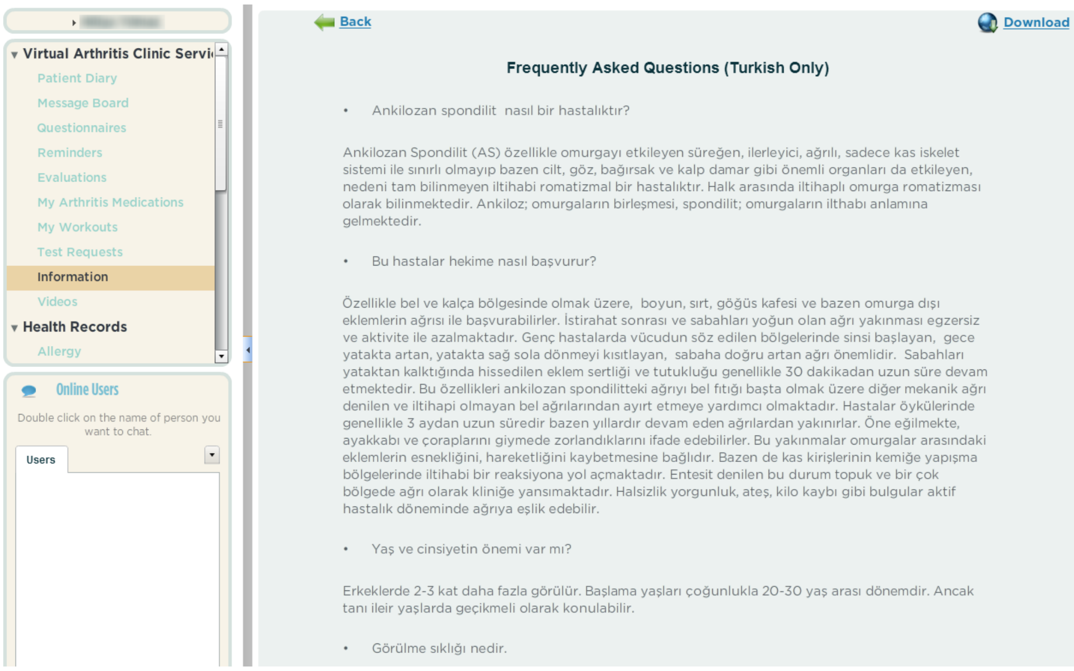

Figure 3.25: Information

3.2.2.2.12 Videos

As it is stated above, doing exercises correctly and regularly is an important part of AS treatment. In this regard, VACS module also provides Videos application which enables patients to learn how to do their exercises correctly. It presents videos about how to do exercises at desk, standing exercises and lying exercises correctly. Furthermore, it provides information videos, rheumatology videos and general health videos, supporting the Information application where patients get the information about AS through some texts. Information videos provides information about the meaning, causes, symptoms and treatments of AS, life with AS, effects of AS on human body, importance of doing exercises, meaning of tests and patients stories. Rheumatology videos informs patients about other rheumatic diseases such as psoriatic arthritis and rheumatoid arthritis.

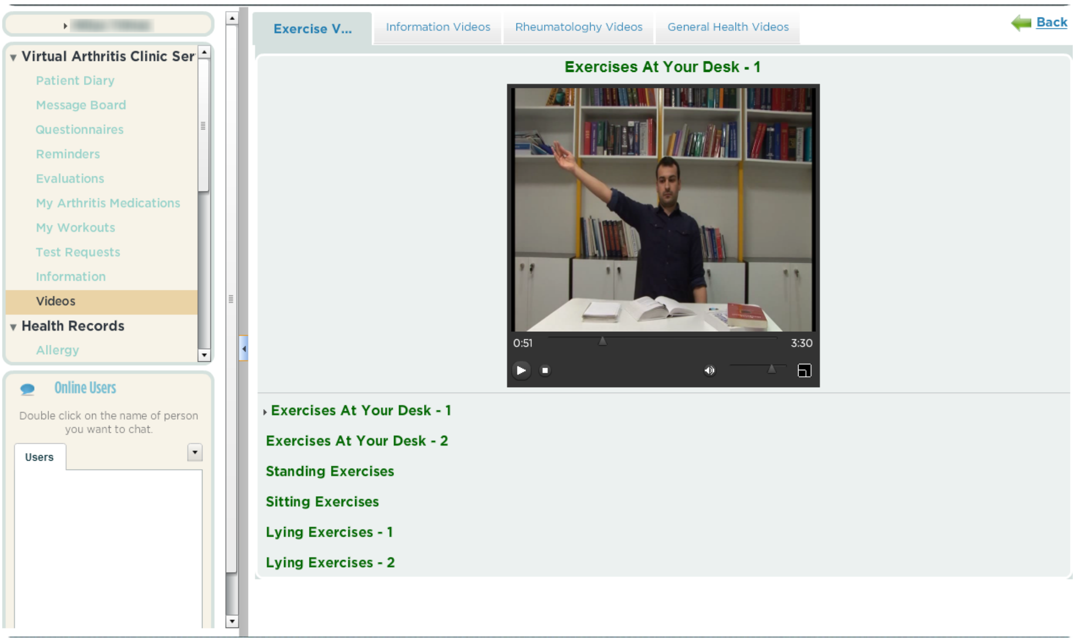

Figure 3.26: Videos

CHAPTER 4

SIMPLE SCENARIO

Mr. Gul is a 41-year-old man who visits his general practitioner (GP) with the symptoms of pain in his spinal joints for the last 6 weeks. On initial observation, the patient has restrictions on spine movement and expanding of chest. The GP orders laboratory tests as well as radiographs of hipbones. Results indicate ankylosing spondylitis and high risk of damage in the joints, so the GP refers the patient to a rheumatologist. The GP, laboratory, healthcare provider's clinic, and their information systems are all connected to the NHIS-T.

The rheumatologist confirms the diagnosis and wishes to embark on an aggressive course of treatment. He also recommends using PHS4AS for his self-management, guidance and shared decision making. Mr. Gul accepts using the dedicated PHS4AS service and gives his consent to access his records in NHIS-T.

PHS4AS provides shared decision support for the ankylosing spondylitis treatment based on "National clinical guideline for management and treatment of ankylosing spondylitis on adults". The service enables the patient and the healthcare professional to examine the treatment steps and options over the guideline workflow. The rheumatologist goes over the workflow and describes his treatment plan to the patient. He personalizes the guideline by specifying the dose regimen of the medications for Mr. Gul and requests laboratory tests every two weeks. He also wants Mr. Gul to record the symptoms and signs of the disease, his psychological state, severity of morning pains and side effects of the medications or exercises to PHS4AS system. When patient records a new event, the records directly become available to rheumatologist.

Mr. Gul adds SMS and e-mail reminders for his medications and event recordings. He confirms that he complies with the medications through these interventions. Furthermore, he uses PHS4AS system to record the symptoms, side effects and his emotional state on daily basis. After 2 weeks, the patient still has pain although he strictly follows the treatment plan, so he sends a message to the rheumatologist over the PHS4AS regarding the situation. During the virtual consultation over the PHS4AS, the rheumatologist notices that the patient still has significant ankylosing spondylitis by looking at the lab results and diary of the patient. Furthermore, he notices that patient is tolerating the medication well without adverse effects from his side-effect (evaluations) diary. Hence, the rheumatologist instructs the patient to increase the dose and prescribes a NSAID to deal with the pain.

One week later, Mr. Gul suffers from hypertension and dyspepsia, which are some side effects for NSAIDs and reports them by using PHS4AS. After the rheumatologist examines the patient's report, he replaces NSAID with COX2 inhibitor drugs and re-instructs the patient.

In the meantime, Mr. Gul applies his laboratory tests every two weeks. PHS4AS retrieves the results of these laboratory tests from NHIS-T. The rheumatologist checks the results of CRP (C-reactive protein) and ESR (Erythrocyte sedimentation rate) tests, and observes that they are around the expected range. In order to decide that disease is under control, he asks Mr. Gul to conduct the BASDAI questionnaire, which is a key indicator to measure the disease activity. Mr. Gul conducts the questionnaire through PHS4AS, PHS4AS calculates the score and shows it to both healthcare professional and patient. The rheumatologist notices that BASDAI score is also around the expected range and decides that the disease is under control. Therefore, he readjusts the medications and doses, refers Mr. Gul to physiotherapist for a suitable exercise plan and requests Mr. Gul to come for annual follow-up of the disease.

The general operative flow chart of AS treatment is shown in Figure 4.1.

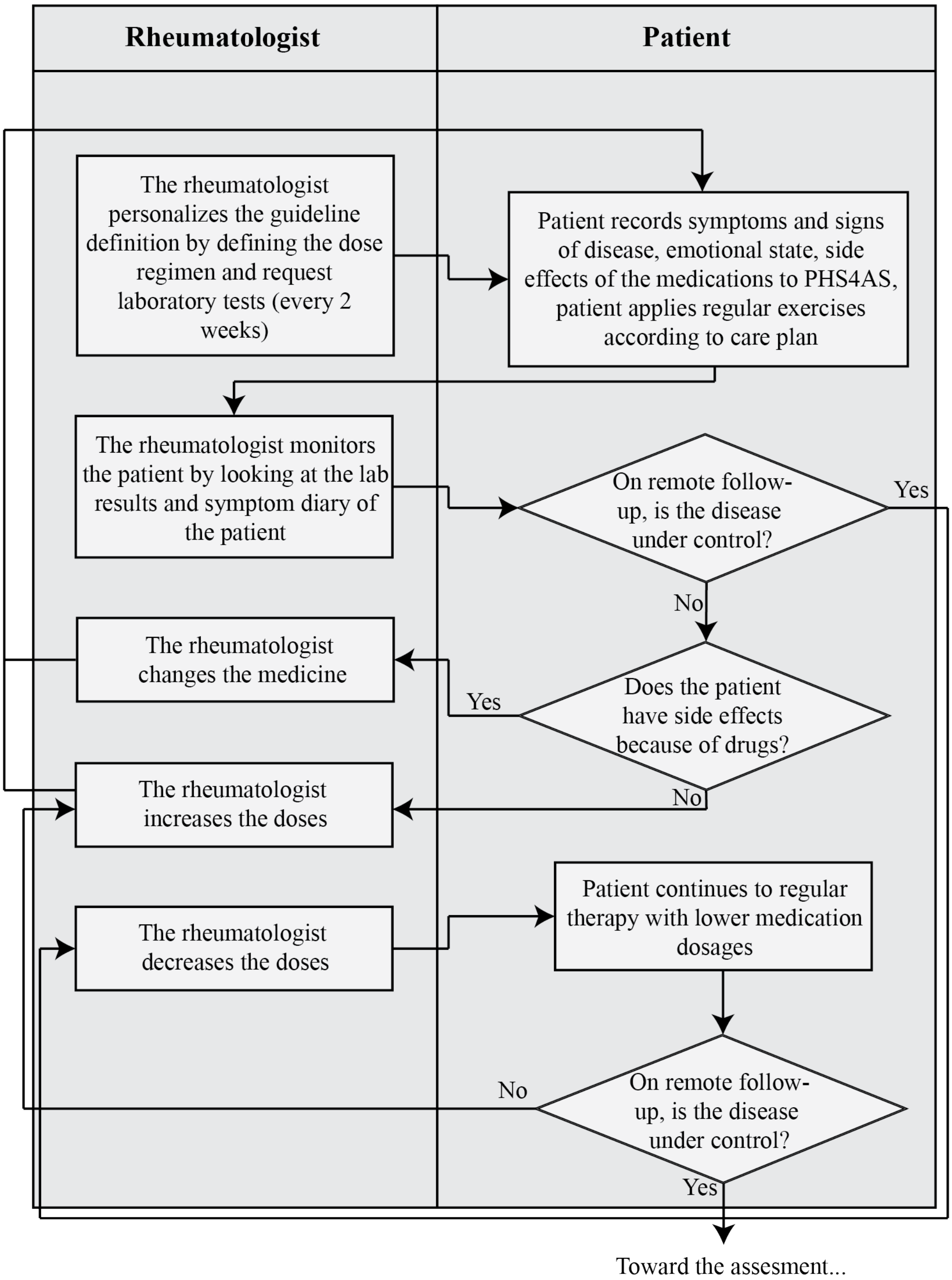

Figure 4.1: Operative Flowchart of AS Treatment

CHAPTER 5

EXPERIMENTS AND RESULTS

Within the scope of European Commission supported PALANTE Project [41], PHS4AS system has been used by 3 healthcare professionals and 131 patients for more than 6 months in a pilot study, which is conducted in three different hospitals in Ankara, Samsun and Kocaeli in Turkey.

To evaluate the success of PHS4AS system, the usage statistics of the system has been analyzed and patients filled out two questionnaires.

During the pilot study, patients used the system once a week on average, whereas healthcare professionals used it every day. During this period, 33 out of 131 patients communicated with HPs 36 times through the system. 15 patients communicated to share the side effect of medicine and result of blood test, while 18 patients communicated to share the symptom change. Only 4 of these patients were asked to come face-to-face meeting, but 2 of them were using Anti-TNF Agent. As a result, there was no need for 29 patients to go to hospital, meaning that **PHS4AS successfully decreased the number of hospital visits, thus reduced the workload of HPs and prevented the patients' spending money and time for travelling to hospitals**.

In order to assess the system from the patients' point of view, patients were asked to fill out two questionnaires. The first questionnaire is named as Patient Activation Measure (PAM) and was conducted at the phase of patient enrolment, while the second one is named as Technology Acceptance Model (TAM) and was conducted after six months period. Patient Activation Measure (PAM) is offered by Hibbard et al. in 2004 [61] and aims to measure the activation level of patient, considering patient experience and patient outcomes such as knowledge and skills of self-management before interaction with the system. Technology Acceptance Model (TAM), on the other hand, is a model built in order to predict and evaluate the acceptance of different technologies by different kind of users in the field of information technology. It is used to measure the patient satisfaction.

The features that the PHS4AS provides are grouped as communication including Message Board application, education including Information and Videos applications, and information including the other applications in PHS4AS. In the first questionnaire shown in Figure 5.1, patients were asked questions about their knowledge and skills of self-management, whether they believe that using these features would be easy and beneficial for them, their trust in healthcare systems, general use of information technology, and treatment experience. There were 64 questions in the first questionnaire, where 27 of them was related to features of the system (9 for each feature). In the second questionnaire shown in Figure 5.2 and Figure 5.3, patients were asked questions about whether using these features was easy and beneficial for them, effects of the system on their healths, and whether they want the related service to continue or not. There were 39 questions in the second questionnaire, where 27 of them related to features of the system. 70 out of 131 patients filled out the questionnaires and following responses are retrieved in summary. As shown in the Table 5.1, patients are pleased and willing to continue using such a system.

10 [PAM]

Please choose the appropriate response for each item:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know
When all is said and done, I am the person who is responsible for managing my health	○	○	○	○	○
Taking an active role in my own health care is the most important factor in determining my health and ability to function	○	○	○	○	○
I am confident that I can take actions that will help prevent or minimise some symptoms or problems associated with my health	○	○	○	○	○
I know what each of my prescribed medications does	○	○	○	○	○
I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself	○	○	○	○	○
I am confident I can tell a doctor concerns I have even when he or she does not ask	○	○	○	○	○
I am confident that I can follow through on medical treatments I need to do at home	○	○	○	○	○
I understand the nature and causes of my health problems	○	○	○	○	○
I know the different medical treatment options available for my health condition	○	○	○	○	○
I have been able to maintain the lifestyle changes for my health that I have made	○	○	○	○	○
I know how to prevent further problems with my health	○	○	○	○	○
I am confident I can figure out solutions when new situations or problems arise with my health	○	○	○	○	○
I am confident I can maintain lifestyle changes, like diet and exercise, even during times of stress	○	○	○	○	○

Figure 5.1: Snapshot from PAM Questionnaire

3 [TAM Educational]

Please answer these questions with regard to your use of the educational functionalities of VACS.

Please choose the appropriate response for each item:

	Strongly Disagree	Generally Disagree	Disagree Somewhat	Neither	Agree Somewhat	Generally Agree	Strongly Agree	Don't Know
My interaction with the educational functionalities was clear and understandable	○	○	○	○	○	○	○	○
I believe that it was easy to get the educational functionalities to do what I wanted them to do	○	○	○	○	○	○	○	○
Overall, I believe that the educational functionalities were easy to use	○	○	○	○	○	○	○	○
Learning to operate the educational functionalities was easy for me	○	○	○	○	○	○	○	○
Using the educational functionalities enabled me to accomplish my healthcare tasks more quickly	○	○	○	○	○	○	○	○
Using the educational functionalities improved my health	○	○	○	○	○	○	○	○
Using the educational functionalities improved my health indicators	○	○	○	○	○	○	○	○
Using the educational functionalities enhanced my effectiveness in managing my health	○	○	○	○	○	○	○	○
Using the educational functionalities made it easier to manage my health	○	○	○	○	○	○	○	○
I found the educational functionalities useful for managing my health	○	○	○	○	○	○	○	○

Figure 5.2: Snapshot from TAM Questionnaire - 1

9 [Rate Ed Service]Please indicate the extent to which you agree or disagree with a statement concerning the educational services by selecting one of the options to the right of the statement.

Please choose the appropriate response for each item:

	The services have improved the quality of my care	The services have improved my ideas/information about my disease	The services provided additional benefit during recovery and treatment of my disease	I want this service to continue
Strongly Agree	○	○	○	○
Generally Agree	○	○	○	○
Agree Somewhat	○	○	○	○
Neither	○	○	○	○
Disagree Somewhat	○	○	○	○
Generally Disagree	○	○	○	○
Strongly Disagree	○	○	○	○
Don't Know	○	○	○	○

Figure 5.3: Snapshot from TAM Questionnaire - 2

Table 5.1: Results of the Questionnaires

	Communication	Education	Information
Using the ... functionalities enabled me to accomplish my healthcare tasks more quickly	70%	74%	67%
Using the ... functionalities enhanced my effectiveness in managing my health	66%	73%	66%
The services have improved the quality of my care	73%	77%	77%
The services have improved my ideas/information about my disease	80%	81%	80%
The services provided additional benefit during recovery and treatment of my disease	76%	77%	76%
I want this service to continue	86%	83%	83%

CHAPTER 6

CONCLUSION

In this thesis, we present a Personal Health System, namely PHS4AS, which is developed to achieve the ultimate implementation of patient empowerment by addressing all the mechanisms involved in it. PHS4AS is developed for the use of both ankylosing spondylitis patients and healthcare professionals.

Our achievements in this study can be summarized as follows:

- Full implementation of patient empowerment has been achieved by addressing all the concepts of patient empowerment. In detail;
  - Integration with Turkish National Health System (NHIS-T) has provided patients to access their own health information.
  - Applications such as information and videos in PHS4AS have enabled patients to understand their diseases better and to learn how to do daily tasks correctly.
  - Messaging module of PHS4AS has provided bi-directional communication between patients and healthcare professionals and enabled remote consultation.
  - Self-care support and chronic disease management support services have been provided to patients through AS specific applications.
- It is the first study in the literature in the field of empowering patients with rheumatic diseases since it enables patients suffering from ankylosing spondylitis to self-manage their diseases and take an active role in their treatment process.

- The system has been developed completely standard based. CCR based data model has been used to represent patient data. Data model has also been mapped to CDA, meaning that the system also supports and conforms to CDA and CCD standards. World wide used terminology standards such as SNOMED CT, LOINC and ICD-10 are used to describe clinical information. Therefore, PHS4AS is not a system that is just for the use of Turkey. On the contrary, it is a global system based on well known standards and can be adapted by any other country.

- Owing to its modular architecture, any number of external data sources can be integrated into the system. In this study, integrator with NHIS-T has been developed.

- The system was used in real life for more than 6 months in a pilot study in Turkey and it was observed that during this period there was no need for 29 patients to go to hospital, meaning that the number of hospital visits was decreased, the workload of healthcare professionals was reduced and patients' spending money and time for travelling to hospitals was prevented.

The work presented in this thesis has been achieved within the scope of European Commission supported CIP-ICT-PSP PALANTE Project (Grant agreement no: 297260) [41]. All the applications in the PHS4AS system has been developed under the supervision of Turkish League Against Rheumatology (TLAR) [47] and according to the clinical guidelines and care plans are created by TLAR.

As a future work, we first plan to implement the mobile version of PHS4AS. We envisage that accessing such a system from mobile phones will improve the empowerment level of patients since it will provide faster access to applications, hence health information. Moreover, it will enable better reminder functionalities as well as better communication with healthcare professionals. In this regard, HL7's Fast Healthcare Interoperability Resources (FHIR) will be adapted to the system. After the mobile version is developed, we plan to extend our system in a way to comprise other rheumatic diseases such as rheumatoid arthritis (RA) and spondyloarthropathy (SpA). Treatment process of these diseases slightly differ from the treatment process of ankylosing spondylitis. By implementing additional features on top of the existing ones for these diseases, we will come up with a complete system addressing all the diseases in the area of rheumatism.

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