IMPLEMENTATION OF A PATIENT EMPOWERMENT PLATFORM FOR INTEGRATED CARE

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ABSTRACT

IMPLEMENTATION OF A PATIENT EMPOWERMENT PLATFORM FOR INTEGRATED CARE

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While the number of chronic disease patients are increasing with the aging population, their complex treatments are a burden in today's healthcare systems both economically and technically. Integrated care systems are one of the most powerful modern technologies to overcome these difficulties and provide more efficient treatments. Integrated care enables planning the chronic disease treatments in a sustainable and collaborative way for healthcare professionals from various disciplinaries. It also helps care providers to make more accurate decisions by ensuring data integrity.

While the integrated care systems help healthcare professionals in the care planning, there are just as many challenges in the patient side as well. Patients can suffer in understanding or performing their treatment plan, or they may need adjustments as their health conditions change. Patient Empowerment is an integrated care systems approach based-on active participation of patients by educating them to have self-management skills and allowing them to provide relevant information that affect the care planning.

ADLIFE is a European Commission funded integrated care solution for patients with chronic obstructive pulmonary disease and chronic heart failure. The pilot study of the project will be conducted on 7 pilot sites where 577 healthcare professionals and nearly 1000 patients will be participated. This thesis is mainly focused on the Patient Empowerment part of the ADLIFE project and the underlying technologies.

Keywords: Patient Empowerment, Integrated Care, Care Planning, Chronic Disease Management

ÖZ

ENTEGRE BAKIM İÇİN HASTA GÜÇLENDİRME PLATFORMU GELİŞTİRİLMESİ

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Yaşlanan nüfusla birlikte kronik hastalık hastalarının sayısı artarken, bunların karmaşık tedavileri günümüz sağlık sistemlerine hem ekonomik hem de teknik olarak bir yük oluşturmaktadır. Entegre bakım sistemleri, bu zorlukların üstesinden gelmek ve daha verimli tedaviler sağlamak için en güçlü modern teknolojilerden biridir. Entegre bakım, çeşitli disiplinlerden sağlık uzmanları için kronik hastalık tedavilerinin sürdürülebilir ve işbirlikçi bir şekilde planlanmasını sağlar. Ayrıca, veri bütünlüğünü sağlayarak sağlık uzmanlarının daha doğru kararlar almasına yardımcı olur.

Entegre bakım sistemleri, sağlık uzmanlarına bakım planlamasında yardımcı olurken, hasta tarafında da çözülmesi gereken birçok zorluk vardır. Hastalar tedavi planlarını anlamakta ve uygulamakta zorluk çekebilir veya sağlık durumları değiştikçe tedavide bazı değişikliklere ihtiyaç duyabilirler. Hasta Güçlendirme, hastaları kendi kendini yönetme becerilerine sahip olmaları için eğiterek ve bakım planlamasını etkileyen ilgili bilgileri sağlamalarına izin vererek aktif hasta katılımına dayanan bir entegre bakım yaklaşımıdır.

ADLIFE, kronik obstrüktif akciğer hastalığı ve kronik kalp yetmezliği olan hastalar için Avrupa Komisyonu tarafından desteklenen bir entegre bakım çözümüdür. Projenin pilot çalışması 577 sağlık çalışanı ve 1000'e yakın hastanın katılacağı 7 pilot sahada gerçekleştirilecektir. Bu tez, genel olarak ADLIFE projesinin Hasta Güçlendirme kısmına ve altında yatan teknolojilere odaklanmıştır.

Anahtar Sözcükler: Hasta Güçlendirme, Entegre Bakım, Bakım Planı, Kronik Hastalık Yönetimi

To My Family

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LIST OF ABBREVIATIONS

API	Application Programming Interface
ATC	Anatomical Therapeutic Chemical Classification
BCT	Behavioral Change Techniques
BP	Blood Pressure
CDS	Clinical Decision Support
CHF	Chronic Health Failure
COPD	Chronic Obstructive Pulmonary Disease
CRG	Clinical Reference Group
CRUD	Create-Read-Update-Delete
EHR	Electronic Health Record
FHIR	Fast Health Interoperability Resources
HL7	Health Level Seven
HP	Healthcare Professional
HTTP	Hyper-Text Transfer Protocol
ICD	International Statistical Classification of Diseases and Related Health Problems
JITAI	Just-in-time Adaptive Intervention
JSON	JavaScript Object Notation
LOINC	Logical Observation Identifiers Names and Codes
MVC	Model-View-Controller
NICE	National Institute for Health and Care Excellence
NPM	Node Package Manager
PAR	Pilot Application Requirements
PCPMP	Personalized Care Plan Management Platform
PDF	Portable Document Format
PEP	Patient Empowerment Platform
PRO	Patient Reported Outcome
PROM	Patient Reported Outcome Measure
REST	Representational State Transfer
SIS	Semantic Interoperability Suite
SNOMED-CT	Systematized Nomenclature of Medicine - Clinical Terms

CHAPTER 1

INTRODUCTION

As the healthcare sector advances, the average life expectancy increases, and infectious diseases are replaced by chronic diseases [1]. Chronic diseases became the major cause of the disability and morbidity besides being most costly healthcare expense item [2]. Furthermore, people are more likely to encounter multiple chronic diseases at the same time as they age [3]. These patients will have difficulty in understanding and self-managing their chronic conditions and complex treatments [4]. The increase in the number of patients with chronic diseases, complexity of their treatment and economic burdens brought the demand for more accessible and efficient healthcare systems. In order to overcome the complexity of the long-term treatment of multimorbid chronic disease patients and improve the patient experience, personalized and integrated care approach is employed by many modern healthcare systems as suggested by WHO [5] [6].

There are various definitions in the literature for the term integrated care. In its simplest form, integrated care can be defined as the cooperation and communication between any systems, organizations or individuals that will improve the efficiency and continuity of the provided care. For example, when a patient moves to another region or country, they will not want their current treatment routine to be disrupted or start over. If there is a communication between the health system in which the patient is registered and the health system in the place where he/she moves, the continuity of the patient's treatment would be ensured. Other than the healthcare systems, the collaboration may be between individuals as well. The quality of care for a patient with multimorbidity can be enhanced with the collaboration and information exchange between healthcare professionals from different specialties and the patients themselves.

Long-term conditions often require ongoing management to ensure the best results. Disease and treatment needs change over time, which also requires constant decision-making and adjustments on the part of the patient as well [7] [8]. In response to this need, one of the key features of health policies that address the needs of chronic diseases is the use of patient empowerment tools in integrated care [9] [10]. Patient empowerment activities include providing tools for active patient participation for care delivery for their chronic diseases, providing educational materials related to their diseases, enabling shared decision making in deciding care plans, encouraging and facilitating self-management activities such as adherence to medications, facilitating healthy lifestyle, self-

measurement activities to look after their health status, and enabling feedback and interaction between patients and practitioners [11] [12]. Empirical evidence of positive relationship between patient empowerment and better healthcare outcomes have been reported [7], several studies demonstrated increasing patient and health professionals' satisfaction, better adherence to treatment activities, and improving clinical outcomes [10].

1.1. ADLIFE Project

ADLIFE is an integrated healthcare project for management of advanced chronic diseases. It is funded by the European Commission under the Horizon 2020 program. ADLIFE consortium consists of 11 partners in 8 countries and 7 pilot sites. The patients who will participate in the study were selected among people over 55 years of age with chronic obstructive pulmonary disease (COPD) and/or heart failure (CHF) (as well as other diseases such as diabetes, chronic kidney failure). The patient empowerment tool of ADLIFE Project, which is the subject of this thesis, is developed by SRDC Corp. [13] from Turkey.

ADLIFE Project aims to provide an integrated care solution targeting early detection and assessment of deterioration, advanced and well-coordinated care planning and supportive care for patients with advanced chronic diseases, namely, chronic obstructive pulmonary disease (COPD) and/or heart failure (CHF). To achieve these goals, ADLIFE employs:

- A person-centered, outcome-based approach
- Intelligent tools to help decision making
- Active participation of patients and care givers

These concepts are realized in ADLIFE as a Personalized Care Plan Management Platform (PCPMP) supported by clinical decision support services, which acts as a chronic disease management platform served to multidisciplinary care team members, and a Patient Empowerment Platform (PEP) served to the patients and their informal care givers, enabling them to be informed, educated, and guided about their active care plan and to be active participants of their care plan activities. These platforms are served as web applications where PEP is also available as a mobile application to enable smart device integrations. Other than these two platforms, there are many underlying components to achieve the requirements such as data integrity and continuity, security and privacy, etc. as seen in Figure 1. There are middleware components to integrate the local systems and include their data in the system, security and privacy tools to enable user authorization and consent management. The description of these components is given in the Architecture section.

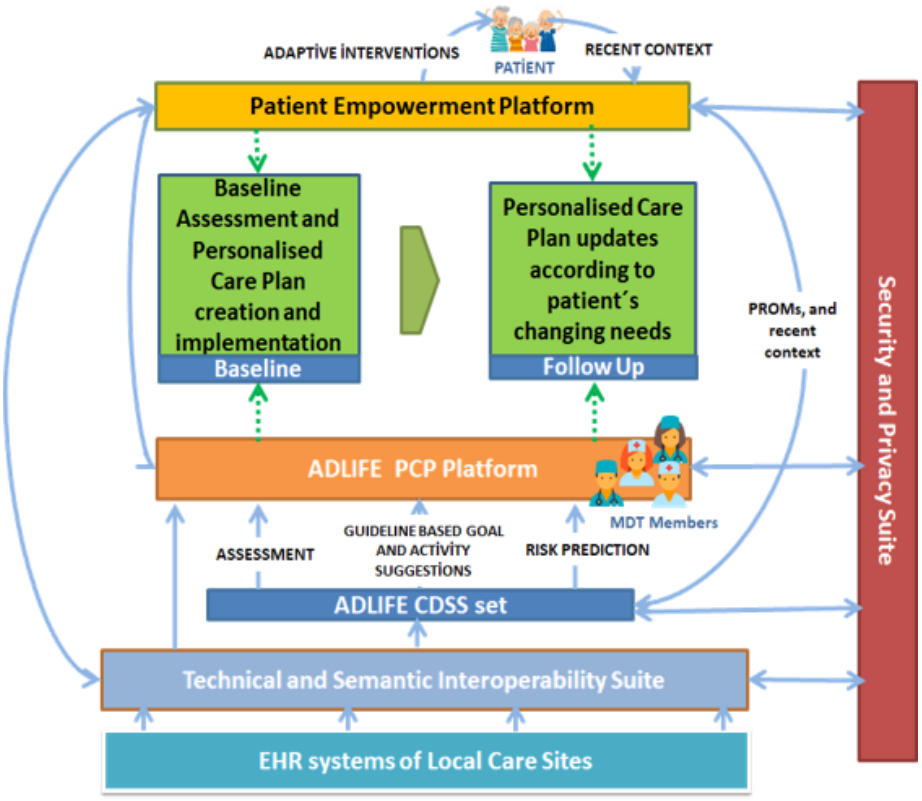

Figure 1 ADLIFE architecture [14]

1.2. Care Planning in ADLIFE

Patients with advanced chronic diseases needs long-term care. As time passes, it becomes more difficult to review and maintain previous treatment plans. It requires an accessible well-designed care pathway to not disrupt the treatment progress, which can be achieved with personalized care plans. Care planning is a key element of the person-based integrated care to deliver more personalized and targeted care by creating shared care plans that map care pathways by maximizing the role of each provider and patient in the care process [15]. The optimal treatments, goals and lifestyle interventions that fits a patient's health and social status can be organized in a care plan with the collaboration of care providers and the patient.

Multimorbidity adds another level to the complexity of the chronic disease management. The multimorbid patients' care is managed from multiple healthcare professional from different disciplines. The lack of communication between the healthcare professionals may result in conflicting, repetitive or inefficient treatment decisions. In PCPMP tool of ADLIFE, care plan is shared to all multidisciplinary care team members so they can review the activities or medications assigned by other members and plan how to proceed accordingly. In addition, the care team members share critical information by adding notes to the care plan or sending messages to other care team members.

ADLIFE toolbox is also providing Clinical Decision Support (CDS) Services integrated with the PCPMP to enhance care planning process. CDS services produce intelligent treatment, goal and intervention suggestions accordingly with evidence-based international clinical guidelines. Furthermore, CDS services helps healthcare professionals to avoid the mentioned conflicts and repetitions in care plans. For instance, a drug therapy for a disease may have serious contraindications with a condition or drug prescribed for other disease. CDS services may suggest changing or stopping a treatment according to the case.

Chronic diseases cause some physical or psychological barriers for the patients to adhere their treatment plan, especially for elderly patients. Studies show that the active participation of patients to the care planning process have positive effect on their adherence [16]. PCPMP allows shared decision-making by giving the opportunity to the healthcare professionals to offer patients set of options that they can choose which is more suitable with their health or social status. There is also a bi-directional messaging between PCPMP and PEP to provide patient-healthcare professional communication that can also be used for shared decision-making.

1.3. Patient Empowerment in ADLIFE

As mentioned, patient empowerment has significant effect on the quality of the care given for the long-term chronic diseases. Patients have to deal with difficulties of their conditions in the long time gaps between encounters with their care providers. They may have confusions that lead to discouragement and lowering their adherence to the treatment plan. There may also be need for adjustments in the care plan according to new symptoms, physical barriers, etc. Even if none of these are present, the patients may lose interest in the activities they need to perform over time.

ADLIFE follows a patient-centered outcome-based approach to empower patients for taking control over their care and affect the treatment decisions by reporting their opinions and outcomes via Patient Empowerment Platform (PEP). A study conducted on COPD patients show that patient education and participance on their treatment increased the quality of life and reduced the rate of re-hospitalization [17]. However, patients cannot be forced to take these actions and regularly use the system, but they can be encouraged. PEP provides behavior change interventions in a way that doesn’t dictate taking actions but convince and motivate the patients instead.

ADLIFE analyzed the instruments of patient empowerment and adopted some of the key concepts to educate and motivate patients for self-assessment and self-management of their care:

- Educational Materials
- Patient Reported Outcomes (PROs) and Patient Reported Outcome Measures (PROMs)
- Just-in-Time Adaptive Interventions (JITAI)

1.3.1. Education Materials

While the shared-decision making and self-management are crucial in the patient-centered care, it comes with the necessity of ensuring patient has enough understanding about their conditions. Evidence shows that, well informed people are more concerning about their health, and as they become more concerned, they tend to make more accurate decisions. As pointed out, long-term treatment of chronic diseases requires self-management very often. Thus, well-educating the patients with chronic diseases is essential in patient-centered care solutions.

In ADLIFE study, suitable educational materials for the empowerment of patients with COPD and CHF are identified, collected and organized by the local clinical reference groups (CRG). There are many materials covering different topics such as:

- General information about the diseases and symptoms
- Usage and side effects of the medications
- Physical and mental well-being
- Dietary suggestions
- Exercise and training

Many more materials with different topics are included in the system to inform the patients about their treatment and improving quality of life. However, the patients may still have confusions in later stages of their care. ADLIFE provides a patient forum to encourage patients ask their questions to other patients and healthcare professionals as well as direct communication with their care team.

1.3.2. Patient Reported Outcomes (PROs) and Patient Reported Outcome Measures (PROMs)

PROs are the information which directly reported by the patients about their health or functional status, effect of medications or any other aspects related to their treatment plan where the PROMs are the tools and instruments to collect them [18]. PROMs can be used to assess the quality and effectiveness of the treatment, adjust the treatment according to patient's status or make use of the population data by analyzing it to enhance care systems.

Hence the name, PROMs fit very well with the "patient-centered, outcome-based" approach of ADLIFE. They are used to design the best care plan for the patient and enhance shared decision-making. The relevant PROMs are chosen in accordance with the clinical guidelines by the local CRGs. The selected PROMs are given in the Table 1.

Table 1 PROMs used in ADLIFE

Areas	**Dimensions**	**PROMs**
Symptoms, functioning quality of life	Autonomy control	EQ-5D-5L [19]
	Symptom control	EQ-5D-5L
	Mood and mental health	EQ-5D-5L, HADS [20]
	Social context	EQ-5D-5L
	Activities of daily living	EQ-5D-5L, Lawton IADL [21], Barthel Index [22]
Clinical status	Complexity/severity	CAT [23], mMRC [24], KCCQ [25]
Healthcare responsiveness	Participation	Shared decision making: "Ask 3 questions" [26]
Care	Satisfaction	PCQ-P [27]
	Caregiver burden	ZBI-22/ZBI-12 [28], WEMWBS [29]

These PROMs are represented as electronic questionnaires in ADLIFE which can be filled via PEP and displayed by the health professionals on PCPMP.

1.3.3. Just-in-Time Adaptive Interventions (JITAI)

Although people are concerned about their health, they may not be always motivated to take necessary actions and need a little nudge. Smart watches are a good example of this. Displaying notifications such as "you've been idle for too long" or even showing a simple trophy icon on the screen when people reach their daily step goal seem to motivate people to be more active.

Similarly, JITAIs are interventions that deliver right type of support with right amount of frequency at the right time adaptively with the condition and state of the recipient, thanks to modern technologies like mobile devices and smart watches [30]. They are proven to be effective in positive behavior changing with the right design [31]. There are several studies and guidelines on designing efficient behavior change interventions published by respected organizations such as NICE [32] and OECD [33].

ADLIFE implement JITAIs as a part of the PEP mobile application to motivate the patients on daily life activities, improve their adherence on the care plan and using data collection tools of PEP such as reporting their measurements and symptoms, completing PROM questionnaires and perform exercise activities in the care plan. The intervention techniques are designed accordingly with guidelines and research studies in a way that use positive reinforcement and doesn't feel like coercion. The patients are also allowed to personalize the notification frequencies to not be disturbing. Examples JITAIs with user case and the behavioral change techniques (BCT) behind them are provided in the table below.

Table 2 JITAI examples in ADLIFE

Use case	BCT	Example message
Patient is asked to provide blood pressure measurements once a day, and the patient performed successfully for last 3 days	General reinforcement	Well done! You successfully logged your blood pressure measurements for 3 days in-a-row!
Patient is asked to walk 3km per day, and the patient performed close to the target, e.g., walked 2km	Positive comparison with population	You are almost there! Just keep up your good work and you will exceed 55% of others this week.
Patient has a planned activity of symptom reporting	Simple reminder	Just to remind you: You have an upcoming symptom logging task.
Patient assigned a daily mood questionnaire and is performing better than the last month	Positive comparison with self	You are almost there! Complete your Daily Mood questionnaire task and you will exceed your last month's performance with 30%.

1.4. Purpose

This thesis is mainly focused on the implementation of Patient Empowerment web application. The architecture of integrated components with PEP and underlying technologies are covered in Chapter 2. The designing, profiling and implemented functionalities of PEP elements are described in the Chapter 3. Finally, the conclusion and discussion on the outcomes of PEP will be given in Chapter 4.

CHAPTER 2

BACKGROUND

2.1. Technology

2.1.1. HL7 Fast Health Interoperability Resources (FHIR)

FHIR is a resource-based digital health data exchange standard created by Health Level Seven (HL7) which is designed to enhance interoperability among electronic health systems [34]. FHIR differs from its ancestors (HL7 v2, v3, CDA) by being a lightweight RESTful standard. It supports JSON and RDF data formats as well as the XML format which was restricted in the previous standards. These capabilities make FHIR the optimal solution for modern web-based and mobile health applications.

The FHIR standard's data model consists of many data elements such as Quantity, Range, Extension and more than 50 resource types (see Figure 2) to represent specific health or management related concepts. Each of these types extends the base "Resource" data type (see Figure 3) which contains the basic information to identify an element in a repository such as unique identifier and metadata. The CRUD operations of the RESTful API for resources and their query formats are described in FHIR documentation [35].

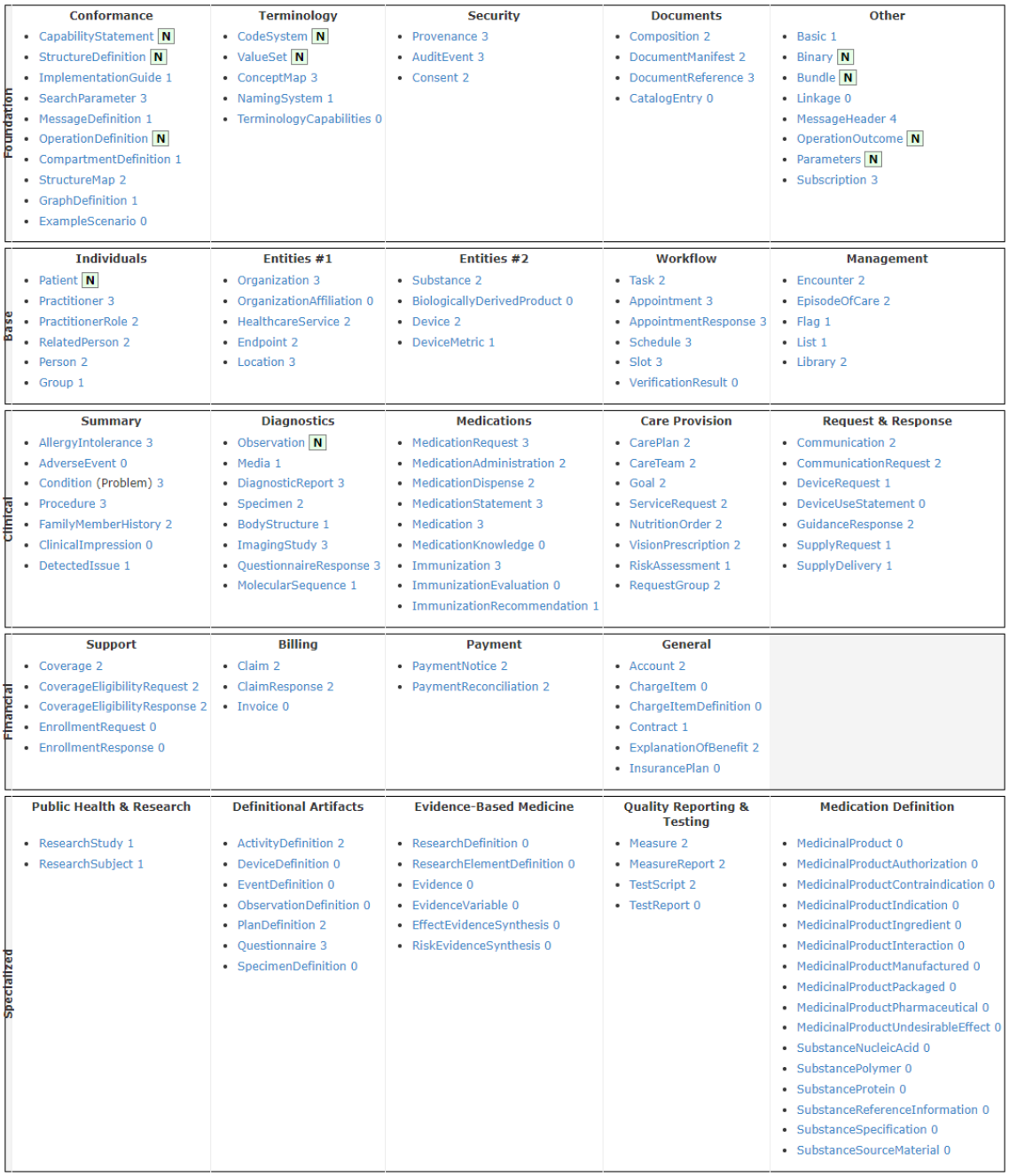

Figure 2 HL7 FHIR resource types

Name	Flags	Card.	Type	Description & Constraints
Resource	N		n/a	Base Resource
id	Σ	0..1	id	Logical id of this artifact
meta	Σ	0..1	Meta	Metadata about the resource
implicitRules	?! Σ	0..1	uri	A set of rules under which this content was created
language		0..1	code	Language of the resource content Common Languages (Preferred but limited to AllLanguages)

Figure 3 Base "Resource" data type of FHIR

While the FHIR resources target to support 80% of the common use cases rather than the 20% of exceptions (80/20 rule) [36], they have the capability of being extended to handle custom use cases. Users can define extensions (Figure 4) with a URI as an identifier of the extension and the value which can either be a primitive or other FHIR defined data types and use these extensions to represent custom elements in their data model.

Name	Flags	Card.	Type	Description & Constraints
Extension	I N		Element	Optional Extensions Element *+ Rule: Must have either extensions or value[x], not both* Elements defined in Ancestors: id, extension
url		1..1	uri	identifies the meaning of the extension
value[x]		0..1	*	Value of extension

Figure 4 Extension data type

HL7 FHIR was chosen to be the main data exchange standard of ADLIFE because of its lightweight, modern, well-defined yet extendable approach as described above. This makes the ADLIFE solution more accessible as it performs well on any desktop and mobile devices.

onFHIR Server

We have positioned an open-source HL7 FHIR Repository called onFHIR [37], which is maintained by ADLIFE partner SRDC Ltd., as the common data repository that enables seamless data exchange between EHRs and our modules. It is implemented with Scala [38] programming language and uses MongoDB noSQL database [39].

onFHIR also implements the subscription mechanism defined by the FHIR standard. It expects a Subscription resource and when the specified criteria met, it notifies the client through the specified channels. This channel can be a rest-hook service, websocket or even SMS/e-mail. In Figure 5, a FHIR subscription request example is presented where the client is requesting to be informed through a rest-hook service whenever a Blood Pressure observation greater than 140 mmHg is recorded to FHIR Repository.

```
{
  "resourceType": "Subscription",
  "reason": "A high systolic blood pressure measurement recorded",
  "criteria": "Observation?code=http://loinc.org|8480-6&value-quantity=gt140||mmHg",
  "channel": {
    "type": "rest-hook",
    "endpoint": "https://example/notification-handler-api",
    "header": [
      // optional headers
    ],
    "payload": "application/fhir+json"
  },
  "status": "requested"
}
```

Figure 5 Example Subscription FHIR resource

Subscription functionality of the onFHIR repository is used for sharing real-time data between ADLIFE modules such as notifying a patient when an update is made to their care plan or notifying the healthcare professional when the patient reports new outcomes.

Besides being FHIR compliant, onFHIR supports CDS-Hooks standard, which is described in Section 2.1.3, to allow implementing clinical decision support (CDS) services using FHIR resources.

2.1.2. Terminologies

Heath information systems represents and usually processes clinical concepts like diseases, medications, allergies, etc. These concepts may differ semantically from region to region. With the simplest example, an international healthcare system will have different representations for the same concept in different languages. To overcome this obstacle by making the clinical concepts machine processable independently from semantics and defining relationships between them, there are clinical terminologies created by different organizations such as SNOMED-CT [40], ICD-10 [41], LOINC [42] and ATC [43]. These clinical terminologies facilitate machine processing the clinical data for services like clinical decision support and improves the interoperability between distributed healthcare systems.

SNOMED-CT (Systematized Nomenclature of Medicine, Clinical Terms) is one of the most popular clinical terminologies with 300,000 structured clinical concepts. It contains a wide variety of clinical concepts like medical conditions, laboratory results, clinical professions and measurements. It also provides the translations of these concepts for more than 10 languages.

ICD-10 (International Statistical Classification of Diseases and Related Health Problems – version 10) is a terminology for coding morbidities. It classifies the diseases with child-parent relations in a hierarchical structure. Each disease is coded by adding a suffix to the code of their parent diseases. As it seen in the Figure 6, “Type 1 diabetes mellitus with coma” is coded as “E10.0” where its parent, “Type 1 diabetes mellitus”, has the code “E10”.

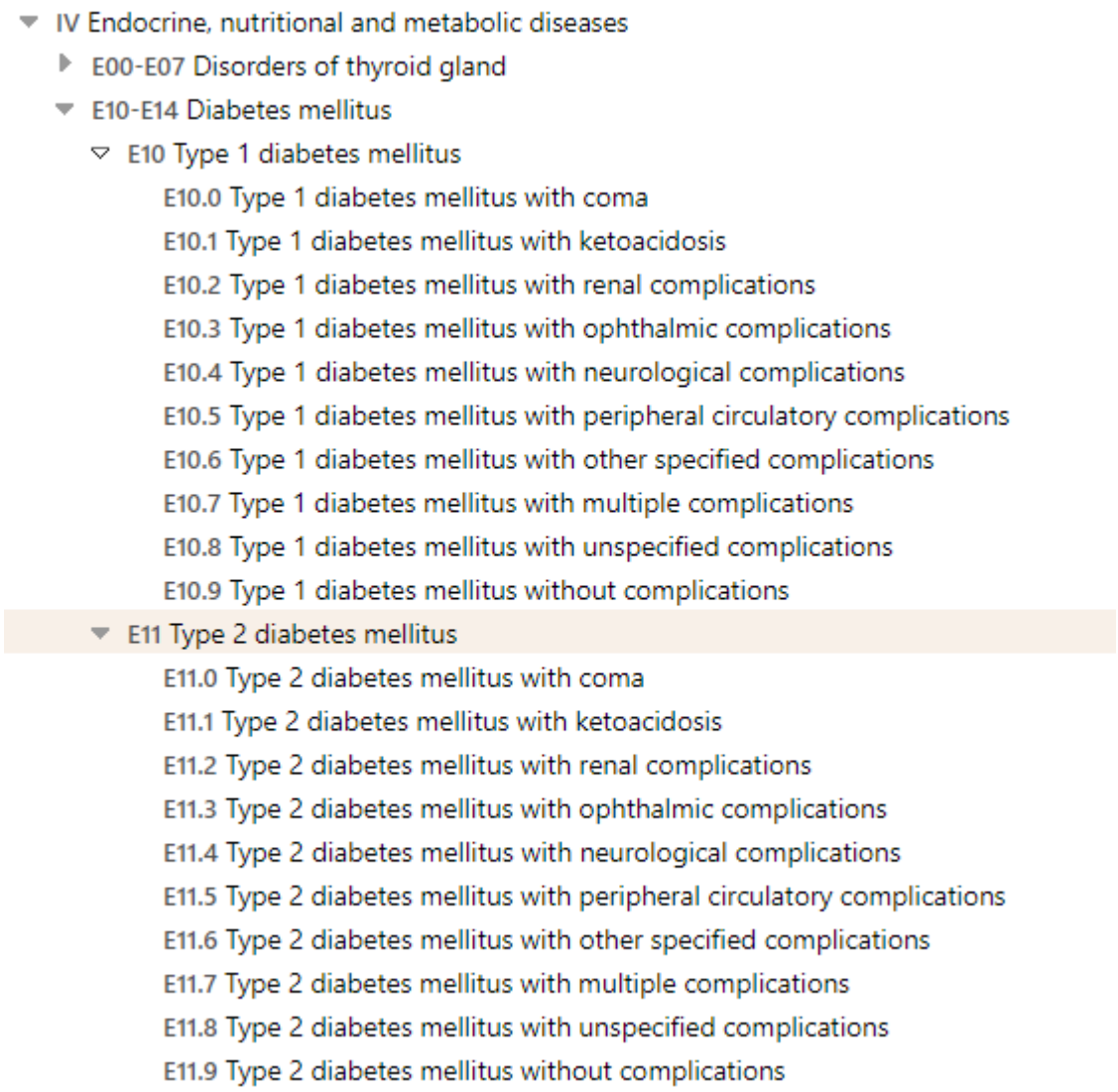

Figure 6 ICD-10 coding hierarchy for diabetes [41]

LOINC (Logical Observation Identifiers Names and Codes) is a terminology designed by LOINC Committee to identify health measurements, observations, and documents [42]. It is widely used in EHRs for the vital sign and laboratory result records.

ATC (Anatomical Therapeutic Chemical Classification) is a terminology for active substances of medications [43]. It classifies the chemicals in a hierarchy of 5 levels according to their anatomical, pharmacological, therapeutic or chemical groups. As an example, hierarchical classification of "metformin" is given in Figure 7.

A	Alimentary tract and metabolism (1st level, anatomical main group)
A10	Drugs used in diabetes (2nd level, therapeutic subgroup)
A10B	Blood glucose lowering drugs, excl. insulins (3rd level, pharmacological subgroup)
A10BA	Biguanides (4th level, chemical subgroup)
A10BA02	metformin (5th level, chemical substance)

Figure 7 Example ATC hierarchy [43]

Terminology systems are represented with CodeSystem resources in HL7 FHIR. Clinical concepts in the terminologies are represented as Coding data type and included in the code systems. Coding elements consist of the fields below:

- System: Identifier URI of the terminology system
- Code: A code that refers to the clinical concept in the given terminology
- Display: Human readable definition of the concept

For example, "body weight" can be represented using the LOINC terminology as below.

```
{
  "system": "http://loinc.org",
  "code": "29463-7",
  "display": "Body weight"
}
```

Figure 8 FHIR representation of "Body Weight", coded with LOINC

While implementing a digital healthcare system, the context related concepts may be collected from subsets of different code systems. These logical group of concepts can be represented as ValueSet resources in FHIR. Using the “designation” fields, translations of the concepts to different languages can be provided. The $expand operation of the FHIR ValueSets [44] allows to collect the value set in the specified language, which make the localization and interoperability of the healthcare systems easier.

2.1.3. CDS Hooks

CDS Hooks is a RESTful API specification created by HL7 team to describe the integration between Clinical Decision Support (CDS) services and clients [45]. It provides JSON structured well-defined request and response data models to be exchanged between the APIs and clients. The health data included in the requests and responses follow the HL7 FHIR standard.

In CDS Hooks, the context information and health data required for the CDS services’ (prefetch) interior logics should be structurally defined. These definitions are accessible to the clients by the discovery endpoint. For example, the “medication-prescribe” service shown in Figure 9 requires the Patient and MedicationRequest resources of the given patient.

```
curl "https://example.com/cds-services"
```

> The above command returns JSON structured like this:

```
{
  "services": [
    {
      "hook": "patient-view",
      "title": "Static CDS Service Example",
      "description": "An example of a CDS Service that returns a static set of
      "id": "static-patient-greeter",
      "prefetch": {
        "patientToGreet": "Patient/{{context.patientId}}"
      }
    },
    {
      "hook": "medication-prescribe",
      "title": "Medication Echo CDS Service",
      "description": "An example of a CDS Service that simply echos the medica
      "id": "medication-echo",
      "prefetch": {
        "patient": "Patient/{{context.patientId}}",
        "medications": "MedicationRequest?patient={{context.patientId}}"
      }
    }
  ]
}
```

Figure 9 Example discovery response of CDS-Hooks [45]

Clients provide the requested resources to the services by querying the FHIR repository and send them to the related hook via HTTP POST request. Figure 10 represents a CDS call to the “patient-view” hook by providing the Patient FHIR resource in the prefetch.

```
curl
  -X POST \
  -H 'Content-type: application/json' \
  --data @hook-details-see-example-below
  "https://example.com/cds-services/static-patient-greeter"
```

```
{
   "hookInstance" : "d1577c69-dfbe-44ad-ba6d-3e05e953b2ea",
   "fhirServer" : "http://hooks.smarthealthit.org:9080",
   "hook" : "patient-view",
   "fhirAuthorization" : {
     "access_token" : "some-opaque-fhir-access-token",
     "token_type" : "Bearer",
     "expires_in" : 300,
     "scope" : "patient/Patient.read patient/Observation.read",
     "subject" : "cds-service4"
   },
   "context" : {
       "userId" : "Practitioner/example",
       "patientId" : "1288992",
       "encounterId" : "89284"
   },
   "prefetch" : {
      "patientToGreet" : {
         "resourceType" : "Patient",
         "gender" : "male",
         "birthDate" : "1925-12-23",
         "id" : "1288992",
         "active" : true
      }
   }
}
```

Figure 10 Example CDS-Hooks request with prefetch data [45]

The CDS services responds with a JSON object which include “Cards”. These cards may include only informative texts, or they can have suggestions which recommend some actions. The actions are given as FHIR resources and the CRUD methods that should apply to the resources. For example, to recommend the user to stop a medication, CDS may respond with an action that have the related MedicationRequest resource by changing its status to “stopped”, and the action type will be “update”. Thus, the client will understand it should send an update request to the FHIR repository with the suggested MedicationRequest resource in the body of the request.

```
{
  "cards": [
    {
      "summary": "Stop Diuretics",
      "indicator": "info",
      "source": {
        // ...
      },
      "suggestions": [{
        "label": "Stopping diuretic treatment for this patient is recommended.",
        "actions": [{
          "type": "update",
          "resource": {
            "resourceType": "MedicationRequest",
            "id": "7c2e2ccf-48e9-4385-9560-3c9b8571a6a5",
            "status": "stopped",
            "medicationCodeableConcept": {
                "coding": [
                    {
                        "system": "http://www.whocc.no/atc",
                        "code": "C03A",
                        "display": "LOW-CEILING DIURETICS, THIAZIDES"
                    }
                ]
            },
          }
        }]
      }]
    }
  ]
}
```


Figure 11 Example CDS-Hooks response

2.1.4. Angular

Angular is a component based MVC (Model-View-Controller) framework built on TypeScript that allows building scalable web applications [46]. It is developed by Google, and it has a very large community with over 1 million developers. Angular provides many integrated libraries to provide features like routing, form bindings, RESTful HTTP calls, testing, etc. Angular allows developers to easily connect their business logic to the forms and views over HTML templates with two-way data binding. The change detection lifecycles keep the UI updated seamlessly as the data changes. Since it is built on TypeScript, it allows developers to work with type-safe object-oriented models. Thus, Angular eases the collaboration among a team of developers while still preserving the flexibility of JavaScript.

Angular has a modular structure with components, templates and services. While the views are implemented in HTML templates, the business logic stands in components. The templates and their respective components can share data through two-way data binding and events. Angular also provides dependency injection infrastructure to allow developers create singleton services and inject them to the components to share data and functionality between components. Lastly, it has another concept called "pipes" to allow data manipulation in templates such as text manipulation, array sorting and pagination, etc.

The pipes are very essential and useful especially in localization. One of the most used pipes provided an easy-to-use internationalization library of Angular called "ngx-translate" which eliminates the difficulty of maintaining UI translations. The translation service expects translation files for different languages in JSON format that consists of labels and translations as key-value pairs. Then, by using the labels in templates instead of static textual content and binding them to translation pipe, translations are automatically retrieved for the given language. Another library "ngx-moment" provides pipes for date manipulation which is also used for localization as displaying dates in the local format of the country/region.

2.1.5. NPM

Node Package Manager (NPM) is a platform that provide a registry of libraries with command line tools to import and manage these libraries into JavaScript based projects as dependencies [47]. Angular libraries and build tools are provided as NPM packages and used in ADLIFE to develop the web applications.

2.2. Architecture

ADLIFE project has two complementary platforms for the use of healthcare professionals and patients: Personalized Care Plan Management Platform (PCPMP) and Patient Empowerment Platform (PEP). These two platforms are sharing data through the FHIR server. The patients from different pilot sites have their data also in the local EHR systems. To include these data into the system, local EHRs are integrated to the FHIR repository through Technical and Semantic Interoperability Services (TIS and SIS). The guideline driven CDS services are implemented within the FHIR server to use the patient data and provide suggestions to the healthcare professionals through PCPMP. Health professionals creates a care plan for the patient with the help of CDS services and the care plan is presented to the patients on PEP.

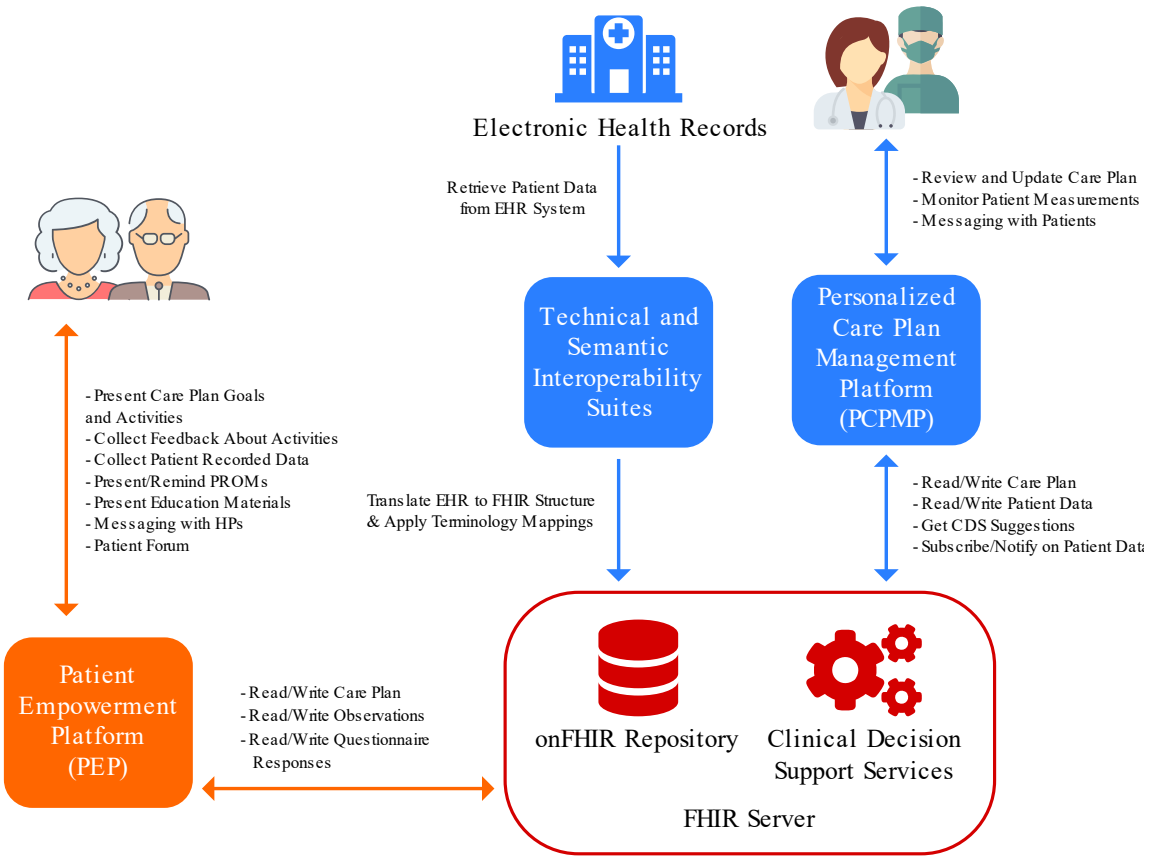

Figure 12 Integrated ADLIFE components and functionalities

The pilot healthcare systems integrated to ADLIFE have their own data formats and terminologies. CDS services need the data in FHIR format and coded with specified terminologies like LOINC and SNOMED-CT. ADLIFE partners identified the corresponding FHIR resources for data models in the source systems and their field mappings to the selected FHIR resource. Technical Interoperability Service is implemented to translate the pilot site specific data models into FHIR using these mappings. Similarly, the terminology mapping of the clinical concepts in the pilot EHRs to the desired terminologies and their translations to other languages are prepared. Semantic Interoperability Service uses the prepared datasets and provides terminology mapping over an API. Combining both TIS and SIS, inconsistent formats from different EHR systems are provided in a standardized format to be used in ADLIFE platforms.

The medical professionals from the medical partners have formed clinical reference groups (CRGs) and analyzed evidence based clinical guidelines such as NICE (National Institute for Health and Care Excellence) to extract instructions as logical flowcharts. The flowcharts are implemented as CDS-Hooks standard based CDS services that process the available patient data from the FHIR repository to produce goal and activity suggestions for the care plan of the patient.

PCPMP tool is integrated with FHIR repository and CDS services to visualize the patient's medical history for the healthcare professionals and helps them to create a care plan practically by guiding them through predefined steps with CDS suggestions. Health professionals can assign patients quantified goals, activities, educational materials and questionnaires via the care planning tools provided by PCPMP. They can add other healthcare professionals from different specialties to the patient's care team, refer the patient to other departments and schedule online or face-to-face appointments with the patient. PCPMP also provides a messaging interface for patient-HP or HP-HP communication. Healthcare professionals can communicate with patients by answering their questions on the "Patient Forum" as well.

Patient Empowerment Platform (PEP), which is the focus of this thesis, visualizes the care plan for the patients and let them take part in their own care. Patients can see their goals and activities, enter measurements, communicate with healthcare professionals and other patients through the PEP. Detailed description of the PEP functionalities will be discussed in the Chapter 3.

CHAPTER 3

METHODS AND RESULTS

In this chapter, requirement analysis, design and implementation methods for the Patient Empowerment Platform (PEP) are explained. Then, the resulting PEP user interfaces and their functionalities are demonstrated.

3.1. Identifying the Requirements

During the requirement analysis phase, end-user partners worked on detailed storyboards depicting their envisioned "to be" scenarios for integrated care solutions that meet the needs of chronic disease management. ADLIFE partners analyzed these storyboards and formalized the Pilot Application Requirements (PARs) and mapped them to the technical components of the ADLIFE architecture. A total of 19 PARs were mapped to the PEP. Next, 22 technical use cases are created which are mapped to these PARs to represent the required functionality of the ADLIFE patient empowerment platform as given in Table 3.

Table 3 PEP functionalities with related use cases

Use cases	PEP Functionalities
Care Plan Management	• PEP-1: Publish active care plan to patient • PEP-2: View active care plan • PEP-4: Flag care plan treatment interventions and the corresponding goals as achieved • PEP-5: Flag care plan treatment interventions and the corresponding goals as not achieved • PEP-6: Update a patient's active care plan • PEP-7: Mark active care plan as finished • PEP-14: Provide feedback on care plan treatment interventions and the corresponding goals • PEP-19: Respond to an unscheduled care plan review meeting invitation
Recording Patient Observations	• PEP-8: Measure and collect patient observation data (via medical devices) according to the timings defined in care plan

Table 3 PEP functionalities with related use cases (Continued)

Patient Recorded Outcome Measurements (PROMs)	• PEP-9: Complete PROMs according to the timings defined in care plan
Symptom Reporting	• PEP-10: Record symptoms
Messaging with Healthcare Professionals	• PEP-11: Communicate via safe messaging
Access to Educational Materials	• PEP-12: Access educational materials
Shared Decision Making	• PEP-13: Access Decision Aids
Delivering Just-in-Time Adaptive Interventions (JITAI) to the Patients	• PEP-3: Present care plan related treatment intervention reminder • PEP-15: Push adaptive intervention to patient • PEP-16: Configuration of JITAI delivery options • PEP-17: Configuration of JITAI content • PEP-18: Select and Push JITAI content

Table 3 PEP functionalities with related use cases (Continued)

Informal Caregiver Management	• PEP-20: Add informal caregivers to care team
Signing Consent Forms	• PEP-21: Digitally sign consent forms
Providing User Guidance for PEP	• PEP-22: Access PEP support information

3.2. Designing Prototypes

Unlike PCPMP, which will be used by healthcare professionals, since Patient Empowerment Platform will be used by people of various ages and social groups, no assumptions can be made about the users' familiarity with the technology. Thus, the user interfaces should be clear and easy to use as possible. After the identification of user requirements as key functionalities, in order to facilitate a co-design approach together with users, we have created mock-ups of the PEP via Adobe XD Tool, and shared these mock-ups with all consortium members, and specifically asked the opinion of clinical sites.

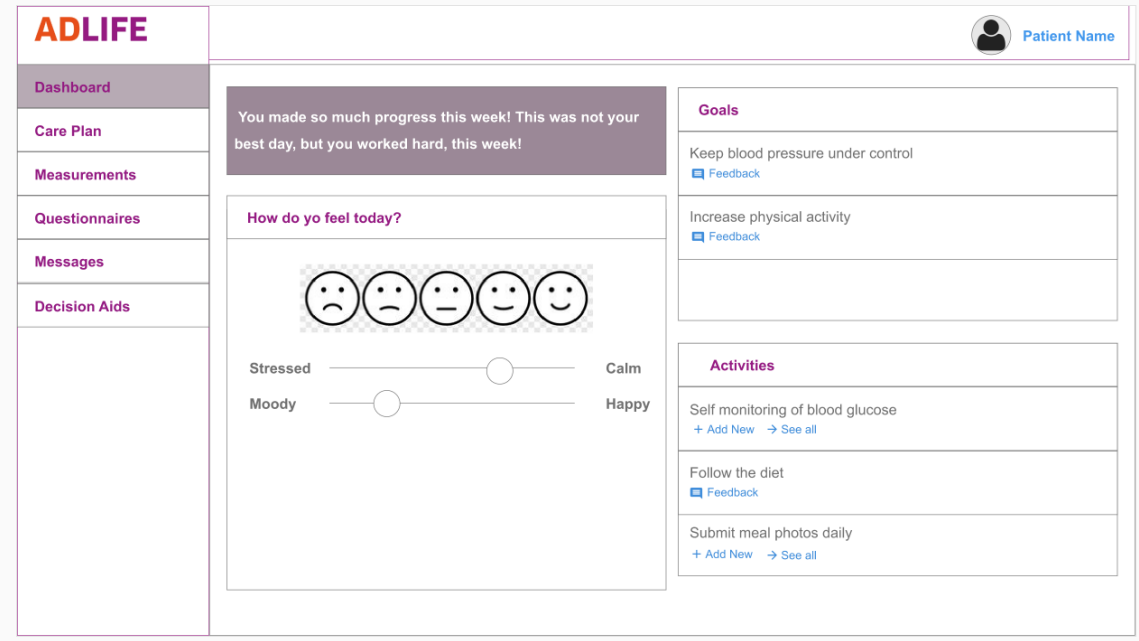

Figure 13 Example page from ADLIFE PEP prototype

The pilot sites provided very useful feedbacks in the manner of usability and functionality. The received feedbacks have been utilized for designing the PEP functionality. Collaboration with pilot sites continued during the implementation of the identified functionalities via workshops, where incremental prototypes of PEP were demonstrated to pilot sites, and further feedback was collected. After the alpha version was ready, which enabled care plan review functionalities, a video of PEP functionality demonstration was made available to pilot sites to be reviewed by the potential end users of the system. In this way, we have achieved a continuous co-design approach during the implementation phase of PEP.

3.3. Profiling

HL7 FHIR standard has clear definition of resource types that covers the representation of many clinical concepts. Relevant resources are determined to represent every component of the care planning in the ADLIFE solution.

3.3.1. Care Plan

Shared care plans are mandatory components of the integrated care environment for long-term care of chronic disease patients which includes measurable goals and treatment activities jointly agreed across multi-disciplinary care team members, by also involving patients and their informal care givers. FHIR CarePlan resource has the capability of representing goals and activities. It can also be assigned to a care team by linking a CareTeam resource.

3.3.2. Care Team

ADLIFE provides a collaborative care planning between multi-disciplinary team of health professionals as well as participating the patients themselves and their informal care givers. It is clearly defined as a part of care plan FHIR CareTeam resources covers this use case well by allowing to include all the people and organizations who plan to participate in the coordination and delivery of care for a patient.

3.3.3. Goals

Goals describe the intended objectives set as a part of care plan such as weight loss, keeping blood pressure under some threshold, quitting bad lifestyle habits. FHIR Goal resources let us to specify these goals both as free-text or in a coded way to use terminologies. It also allows specifying machine processable quantified targets like setting the upper limit of “weight loss” goal to 80kg.

3.3.3. Activities

The planned actions to occur as part of the care plan such as a medication to be used, lab tests to perform, self-monitoring activities by the patient or education materials are defined as care plan activities. The activity field of CarePlan resource can be used as embedded or by providing reference to another resource type. In ADLIFE context, the following care plan activities can be defined:

- **Appointments**: The planned appointments with care team members can be defined within a care plan by referencing to an Appointment resource. Example appointments can be the routine control appointments for COPD and CHF, where care plan is revisited and updated for the upcoming periods. In ADLIFE, it is also possible to set up online appointments as a part of care plan. The PCPMP Tool used by healthcare professionals, and PEP used by patients and informal care givers enable care team members and patients to join online appointments.

- **Referrals**: Healthcare professionals can plan the visits to specialists to take place during the next care plan period such as "visit to ophthalmologist for retinopathy control". In ADLIFE architecture, once such referrals are planned within a care plan, the referred healthcare professional is added to the care team and informed about the referral with an optional note delivered via PCPMP. Depending on the care pathways established within different pilot sites, appointments for these referrals can be initiated by the patient via PEP. For example, in one of the pilot sites, integration with the online appointment tool used within the region is planned, so that the patient can access online appointment tool via PEP to establish appointments for the specialist referrals planned within the care plan. FHIR had ReferralRequest resource type in its previous versions which is removed in release 4 thus we use ServiceRequest instead.

- **Medications**: Within a care plan, the care team members can plan the medications to be administered during the planned care plan period, till the next control visit. They are mapped to MedicationRequest resources in FHIR.

- **Lab Orders**: The laboratory tests to be carried out during the planned care plan period can be added to the CarePlan activities as ServiceRequest resources. We have defined an internal code system of activity category codes to be able to use ServiceRequest for different activities where "lab-request" code is used to identify lab order activities.

- **Diet**: Within the care plan, a specific diet can be recommended based on the conditions of the patient. We are using the ServiceRequest resource with "diet" code for these activities.

- **Patient Orders**: Healthcare professionals can suggest activities to be performed by patients in their daily life as lifestyle changes or self-monitoring activities. ServiceRequest resources with "patient-order" category is used to represent these activities. ServiceRequest resources allow setting quantities and frequencies for

the activities as “reduce alcohol consumption below 2 drinks per week” or “walk 30 minutes 3 times a day”.

- **Questionnaires**:
    - Local CRGs has identified certain questionnaires to collect patient reported outcome measures (PROM) and symptoms specific to the conditions or medications of the patient. Healthcare professionals can assign these questionnaires to be filled online via PEP within the specified time intervals. Adaptive questionnaires can be built with FHIR Questionnaire resources and added to care plan as activities.
    - Patients are enabled to report Patient Reported Outcome Measures (PROMs) and symptoms by responding the questionnaires assigned to them as a part of their care plan on PEP. FHIR QuestionnaireResponse resource is used to store the outcomes.

3.3.4. Education Materials

Healthcare professionals can include education materials related with the conditions of the patients to their care plans. These materials are identified by CRGs and stored in the FHIR repository inside CommunicationRequest resources with embedded binary documents (PDF, doc, image, etc.) or URLs of the materials.

3.3.5. Patient Measurements and Feedbacks

Care plans may include patient orders that ask patient to report measurements like weight, blood pressure, pulse, etc. Patients are able to enter measurements to patient order activities from PEP. The measurements are sent to the FHIR repository as Observation resources. Patients can also give feedbacks to goals or activities in their care plan which are stored as Observation resources as well. Observations may have quantities, attachments like images, coded values and many other data types as values. Thus, they can represent many different types of records.

3.4. Implementation

3.4.1. Data Modeling

PEP web application is developed with Angular framework and its based-on TypeScript. TypeScript extends JavaScript to an object-oriented and type safe structure. It supports type definition files (.d.ts) to provides user defined types as interfaces. The @types/fhir NPM package [48] has the type definitions for various FHIR release versions. An example definition of Patient resource would be as presented in Figure 14.

```
declare namespace fhir {
  interface Resource {
    id?: id;
    meta?: Meta;
    isRefOnly?: boolean;
    refDisplay?: string;
    implicitRules?: uri;
    language?: code;
    resourceType?: code;
  }
  interface DomainResource extends Resource {
    text?: Narrative;
    contained?: Resource[];
    extension?: Extension[];
    modifierExtension?: Extension[];
  }
  interface Patient extends DomainResource {
    identifier?: Identifier[];
    active?: boolean;
    name?: HumanName[];
    telecom?: ContactPoint[];
    gender?: code;
    birthDate?: date;
    deceasedBoolean?: boolean;
    deceasedDateTime?: dateTime;
    address?: Address[];
    maritalStatus?: CodeableConcept;
    multipleBirthBoolean?: boolean;
    multipleBirthInteger?: integer;
    photo?: Attachment[];
    contact?: PatientContact[];
    communication?: PatientCommunication[];
    generalPractitioner?: Reference[];
    managingOrganization?: Reference;
    link?: PatientLink[];
  }
}
```

Figure 14 Example type definition for Patient FHIR resource

The type-definition interfaces ensure type safety but does not provide interior logic and methods. We defined classes for the FHIR resources and data types we use in the project to implement helper methods, getters/setters or to map the extensions into custom fields. For example, an example class diagram for the Patient class which is derived from the Resource class is illustrated in Figure 15.

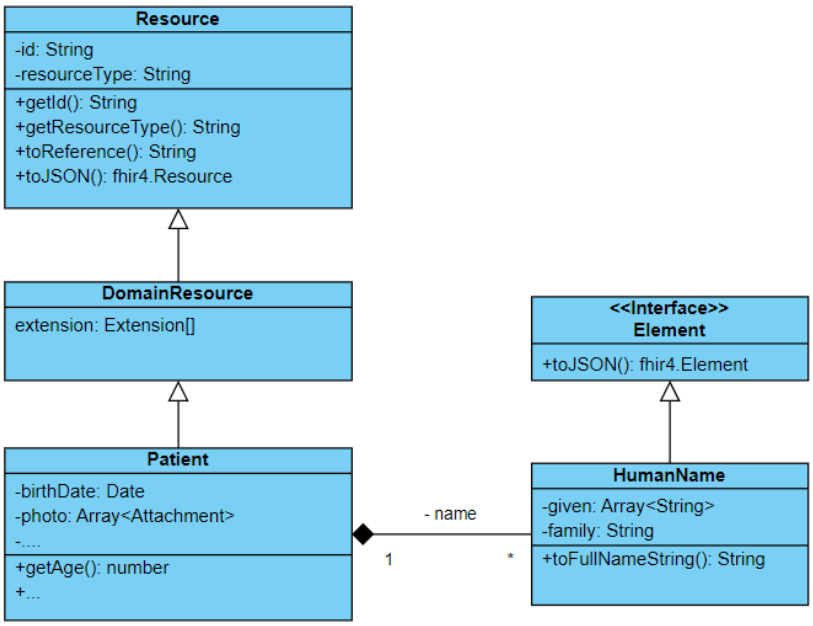

Figure 15 Example class diagram for Patient FHIR resource

A factory class is implemented to identify objects by looking their "resourceType" fields and constructing the corresponding class.

```
export class ResourceFactory {
  // ...
  public static generate(resource: fhir4.Resource): Resource {
    switch (resource.resourceType) {
      case "Patient": return new Patient(resource);
      // ...
    }
  }
}
```

Figure 16 FHIR resource factory

3.4.2. Integrating APIs

PEP is exchanging data with the FHIR repository through HTTP API calls. A service is implemented to make the API calls to the server using the injected HTTP client service provided by Angular. The retrieved JSON resources are converted to classes via ResourceFactory and they converted to JSON objects using the toJSON() methods which is implemented for each resource and data element classes while sending them to the server.

```
import { HttpClient } from "@angular/http"
import { ResourceFactory, Resource } from "./model/Resource"
import { Configuration } from "./config"

export class FhirService {
  constructor(private httpClient: HttpClient) {}

  getResource<T extends fhir4.Resource>(resource: T): Observable<T> {
    return new Observable<T>((observer: Observer<T>) => {
      this.http.get(`${Configuration.apiBase}/${resource.resourceType}/${resource.id}`)
        .subscribe((response: T) => {
          observer.next(ResuorceFactory.generate(response));
          observer.complete();
        }, error => {
          observer.error(error);
        });
    })
  }

  createResource<T extends Resource>(resource: T): Observable<T> {
    return new Observable<T>((observer: Observer<T>) => {
      this.http.post(`${Configuration.apiBase}/${resource.resourceType}`, resource.toJSON())
        .subscribe((response: fhir4.Resource) => {
          observer.next(<T>ResourceFactory.generate(response));
          observer.complete();
        }, error => {
          observer.error(error);
        });
    })
  }

  // ... other methods
}
```

Figure 17 Angular service implementation for PEP-FHIR Repository integration

The PEP client is capable of creating Subscription resources as illustrated in Figure 5 and listen to real-time events through a JavaScript Websocket connection. These events shown to the users as pop-up notifications.

Using the implemented FHIR service and subscription mechanisms, previously described PEP functionalities are implemented as designed in the mock-ups. We will walk through the PEP web application's pages to explain the functionalities in the next sections without giving the implementation details.

3.5. Functionalities of Patient Empowerment Platform

3.5.1. Care Plan

After a care plan is created in PCPMP, the health professional activates it to make it visible for the patient in PEP. The user can navigate to the Care Plan screen (Figure 18) by clicking the "Care Plan" item on the side menu. This screen contains the list of the goals, activities and education materials that are assigned to the patient. The listed items can be expanded by clicking on them to see the details (Figure 19).

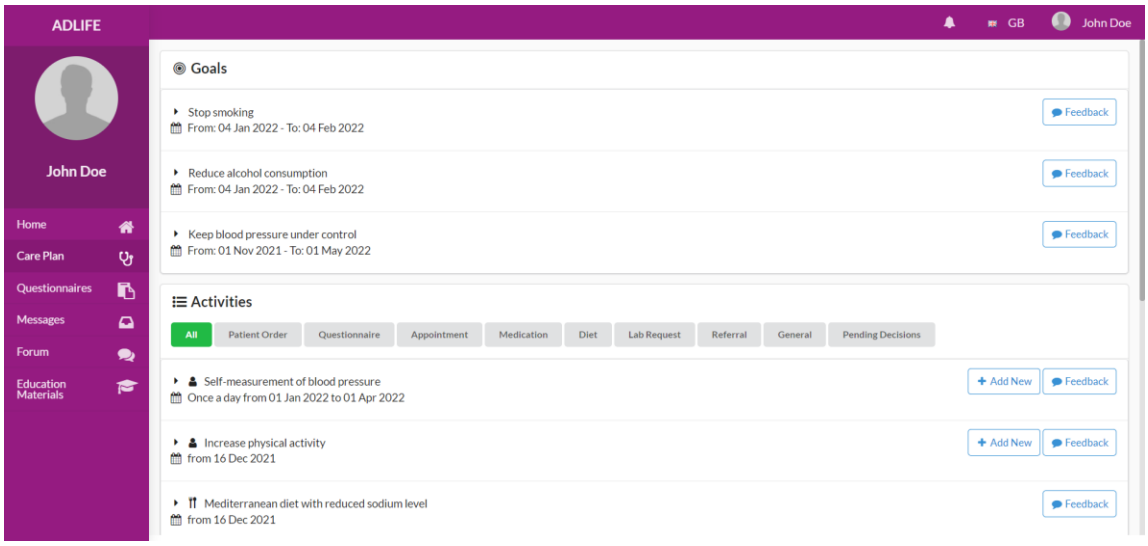

Figure 18 Care Plan page of PEP

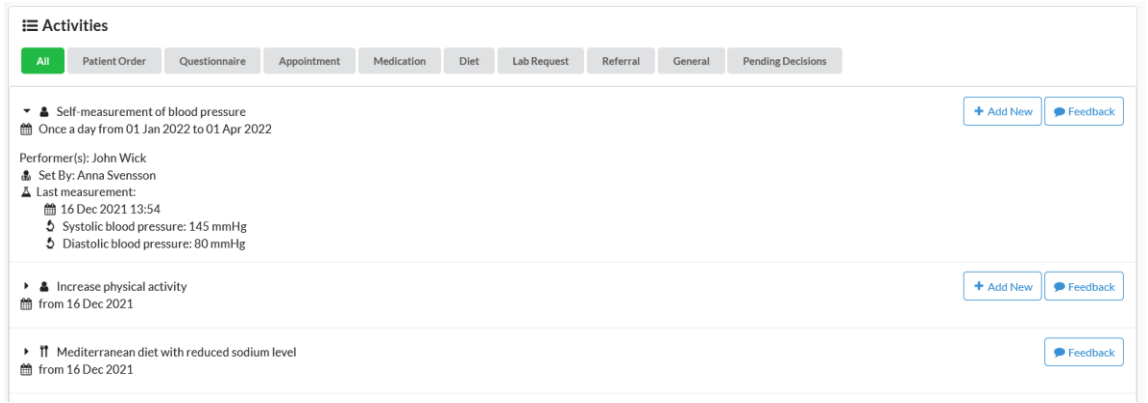

Figure 19 Expanded details of an activity

The patient may have many activities assigned to the care plan. To make the interface more usable, activity type filters are provided to the users such as Patient Order, Diet, Appointment, etc. (Figure 20)

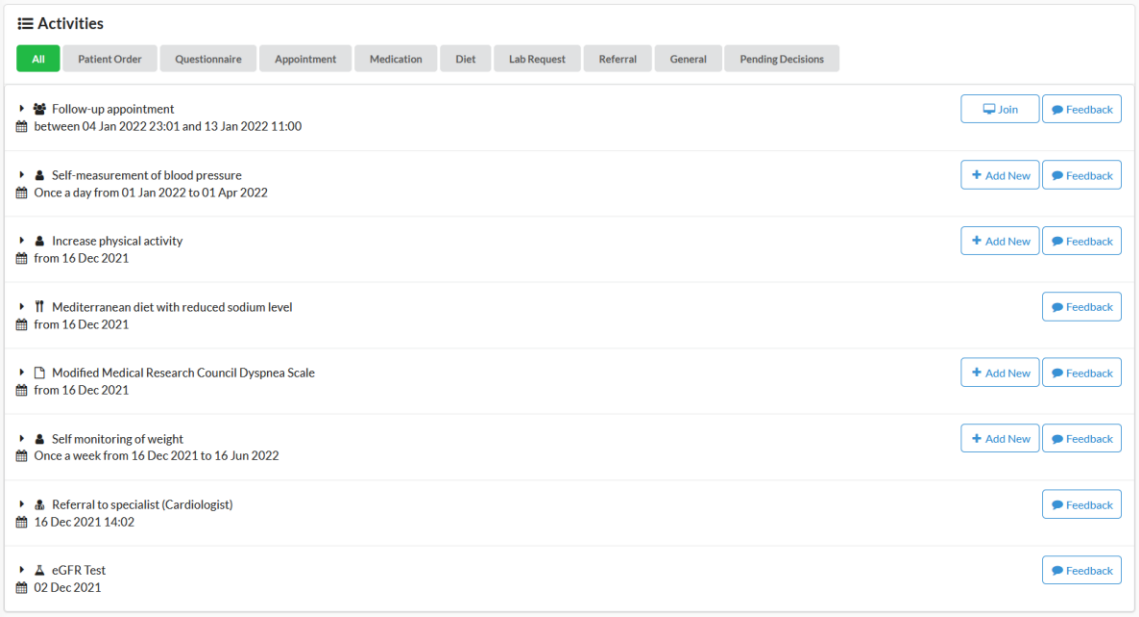

Figure 20 Activities section of Care Plan page

Using the "Feedback" button, the user can give feedback to goals and activities which may contain a reaction (sad, natural, happy) to make it easy for classifying the feedbacks in the first look (Figure 21).

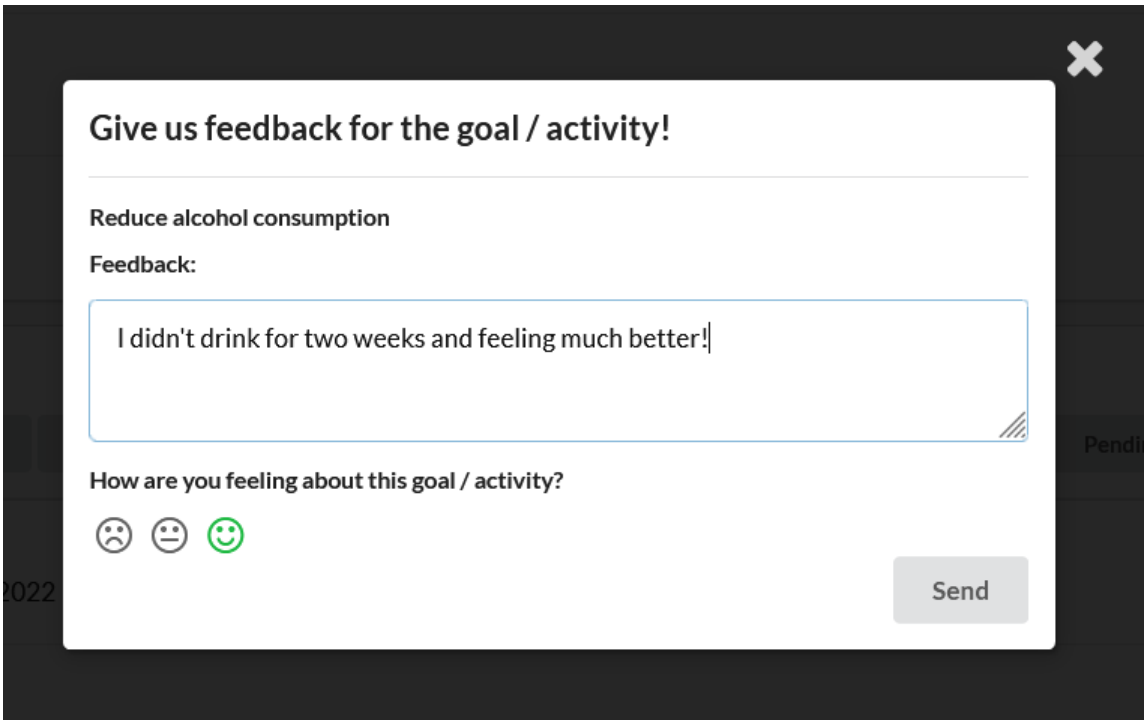

Figure 21 Patient feedback popup

Listed items have shortcut buttons next to them according to their types. For example, if an online appointment is planned and the link to the meeting is provided, the patient can join the meeting using the “Join” button (Figure 20). Similarly, for self-measurement activities, the patients can initiate adding new measurements with the “Add New” button (Figure 20).

3.5.2. Recording Observations

Care plans may include activities that asks the patients to record their vital sign measurements or upload photos of their meal. The user can provide the required information via PEP by clicking the “Add New” button on the “Care Plan” screen (Figure 20). A popup is shown to the user (Figure 22) according to the type of the requested observation. For example, there will be an upload field if the activity is asking for photos where two separate input fields as systolic and diastolic will be shown if it is a blood pressure measurement activity. Moreover, the relevant units are presented for different kind of quantified observations (mmHg for BP, kg for Weight, etc.). The user will complete the submission by clicking the “Send” button and the data will be available to care team in the PCPMP.

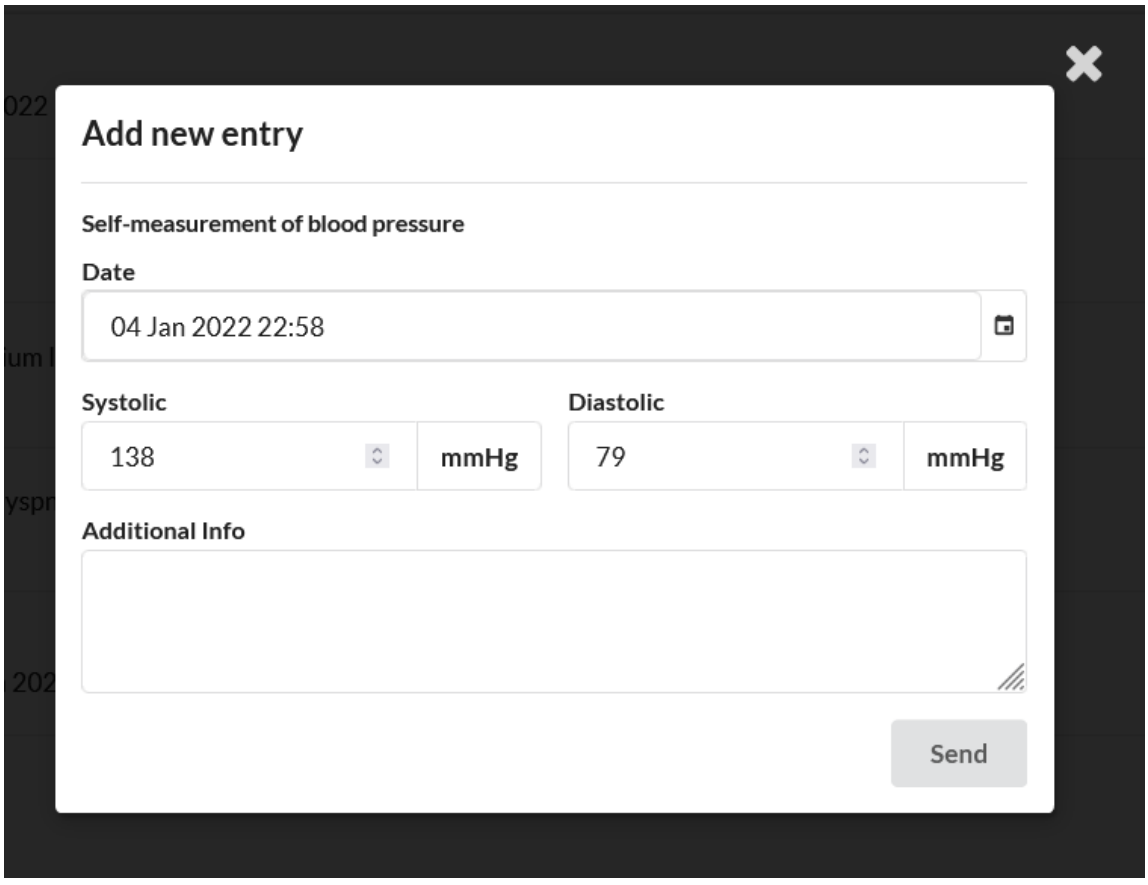

Figure 22 Measurement reporting popup

When the user clicks on the “Add New” button for an activity that requests photo type observations, a file upload input will be presented to allow submitting photos from the user’s device as shown in the Figure 23.

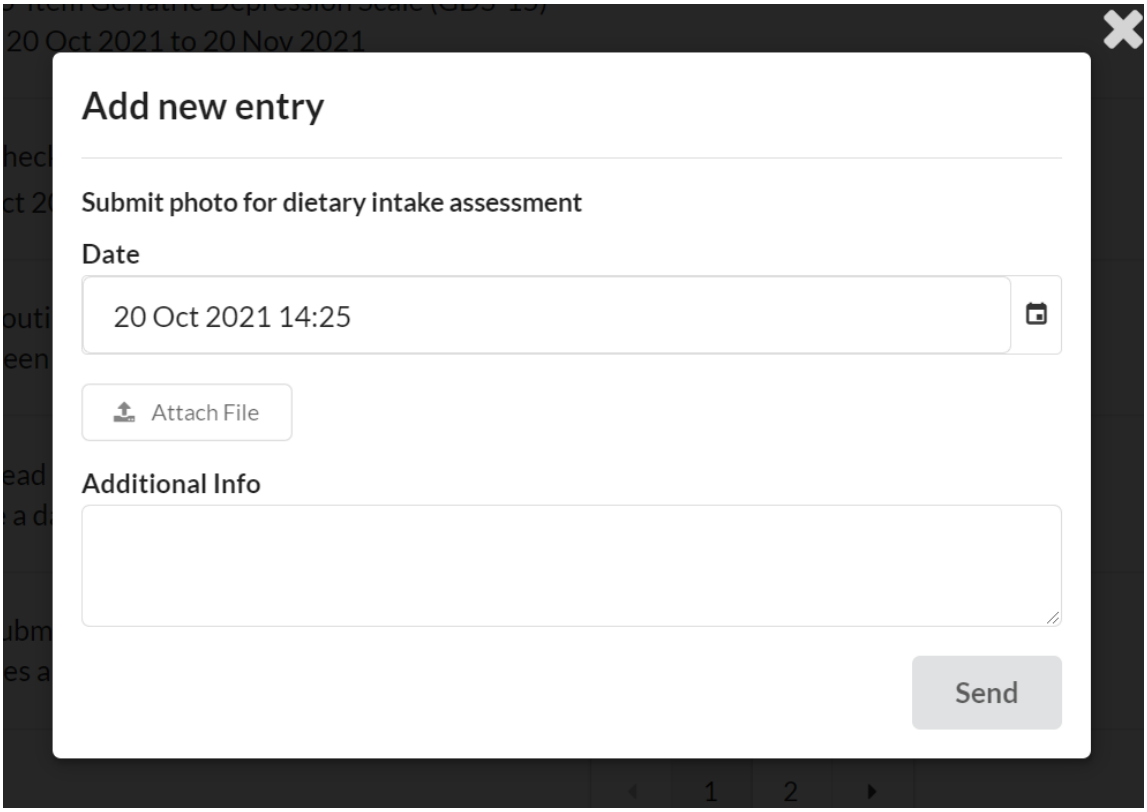

Figure 23 Image data collection popup for "Submit photo for dietary intake assessment" activity

Although this thesis is focused on the implementation of the web application, PEP has also a mobile application that can collect data from the compatible medical devices and smart watches which are capable of sharing data over Bluetooth or Wi-Fi. The users are able to configure which data to be collected when and manage their consents over PEP.

3.5.3. Shared Decision Making

Instead of assigning strict activities, HPs can offer multiple activity options via PCPMP for the patient to select amongst them. Patients can be included to shared decision making process to design their care plan in this way. For example, HP can offer different time slots for the next control appointment of the patient. The user can see the multiple-option activities in the “Pending Decisions” section of the activity list (Figure 20). Then, the user can see the options as in Figure 24 and select their choice by clicking the “Select” button next to the activity. The user can select “exactly one”, “one or more” or “at most one” activities according to the selection criterion assigned by the healthcare professional. Finally, the user clicks the “Send” button, so the selected choice(s) are saved to the care plan, and the healthcare professional is notified via PCPMP.

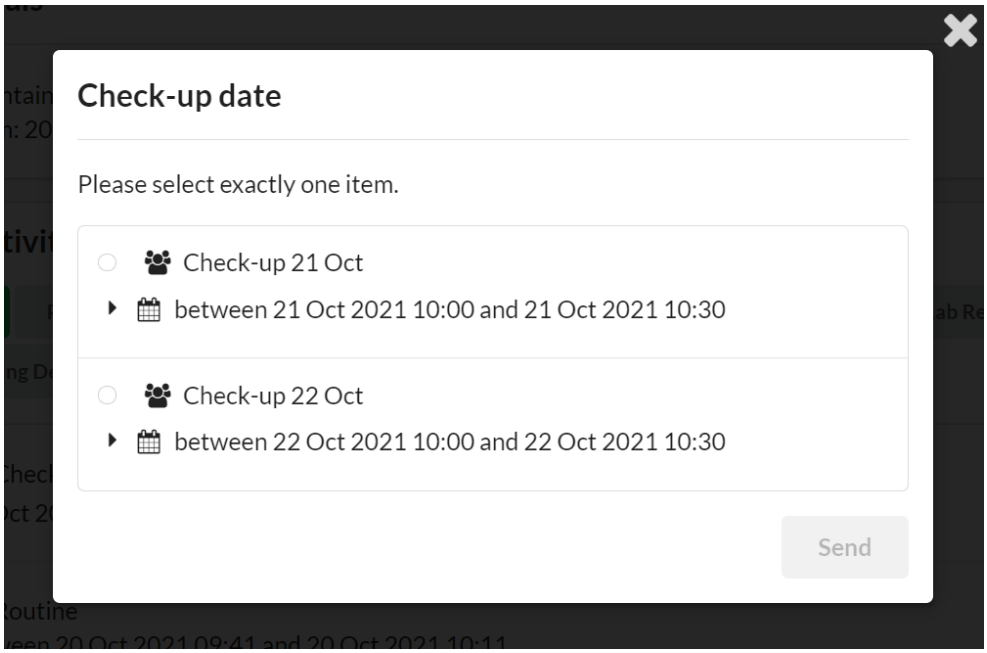

Figure 24 Patient decision-making popup to choose preferred option

3.5.4. Responding to Questionnaires

PEP has a Questionnaires screen apart from the care plan screen that contains assigned and previously completed questionnaires (Figure 25). The user can navigate to this screen by clicking the Questionnaires item in the side menu. The user can fill a new questionnaire by clicking on an assigned questionnaire or review responses of the previously completed questionnaires by clicking on them in “Completed Questionnaires” panel.

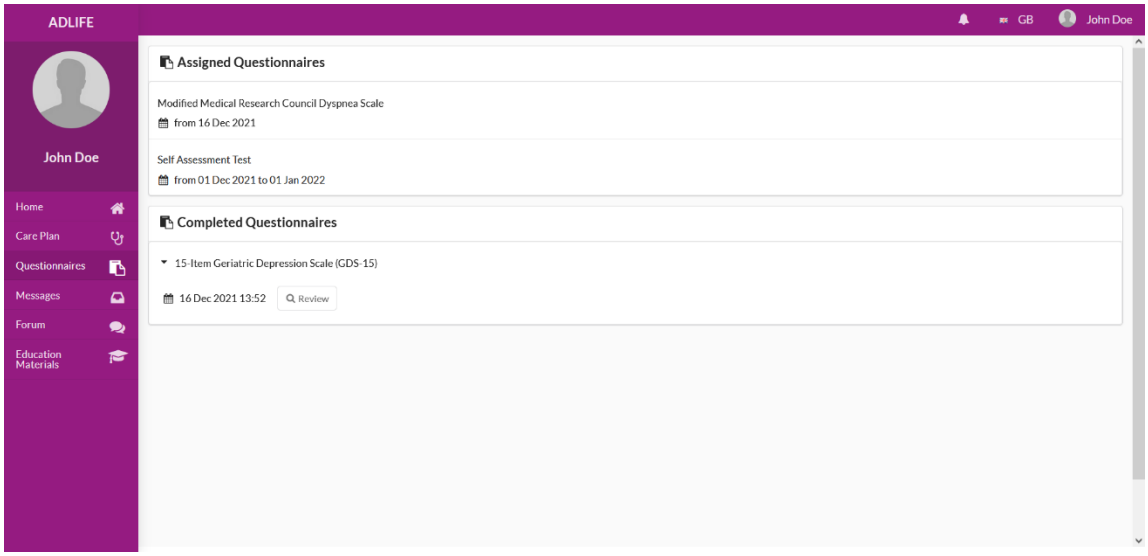

Figure 25 Questionnaires page of PEP

After clicking an assigned questionnaire, the questionnaire submission screen will open as in Figure 26. The user can answer the questions in this screen. There are two types of questionnaires as adaptive and non-adaptive questionnaires. Non-adaptive questionnaires contain fixed questions for any patient where the next question in an adaptive questionnaire is determined according to the previous answers of the user.

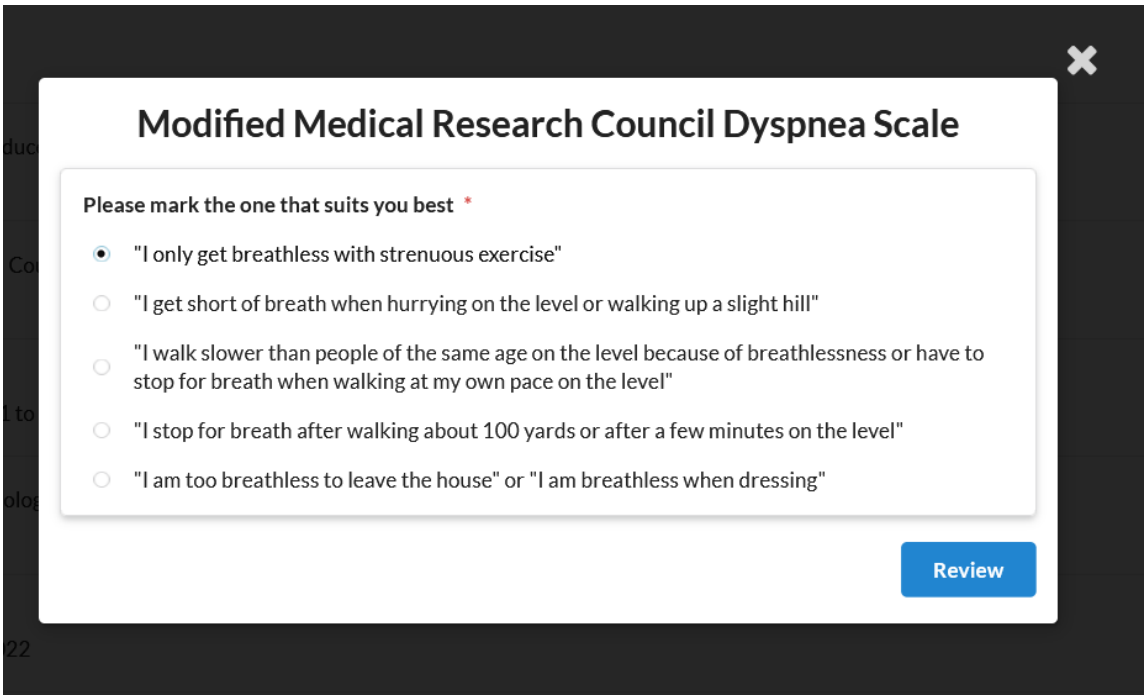

Figure 26 Questionnaire filling popup

In a non-adaptive questionnaire, there are one or more sections that include at least one question, and all questions in a section are shown at the same page. The user should click the “Next” button after answering all required questions in the section. When all sections are answered, the user should click on the “Review” button. After reviewing the answers (Figure 27), the user should click the “Save” button to submit the questionnaire response. If the user wants to change the answers upon reviewing, the user can click the “Change Responses” button.

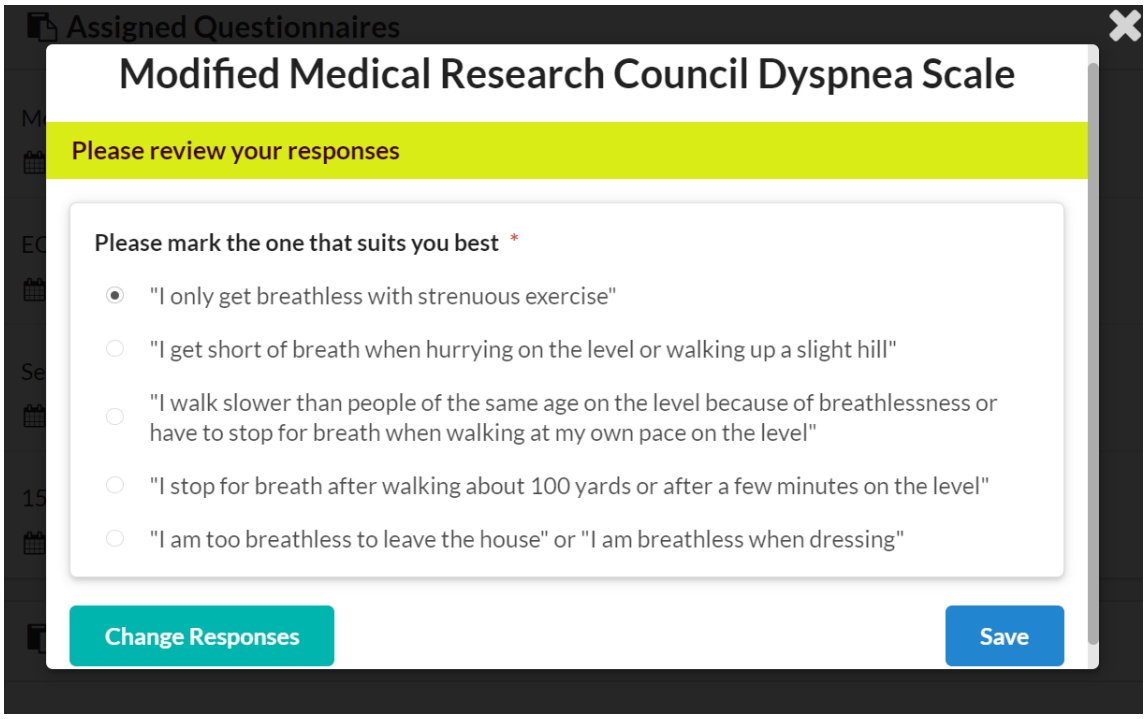

Figure 27 Popup for reviewing, changing or saving the responses

In adaptive questionnaires, questions are shown one by one. The user should answer the question and click the "Next" button to proceed to next questions. The next question can vary according to previous responses of the patient which make these questionnaires "adaptive". Unlike a non-adaptive questionnaire, a suggestion/intervention might be shown to the user while proceeding to next steps. When the questionnaire ends, the user save their answer using the "Finalize" button.

The user can see previous responses of a questionnaire as described previously. Responses shown on a read-only popup as shown in Figure 28.

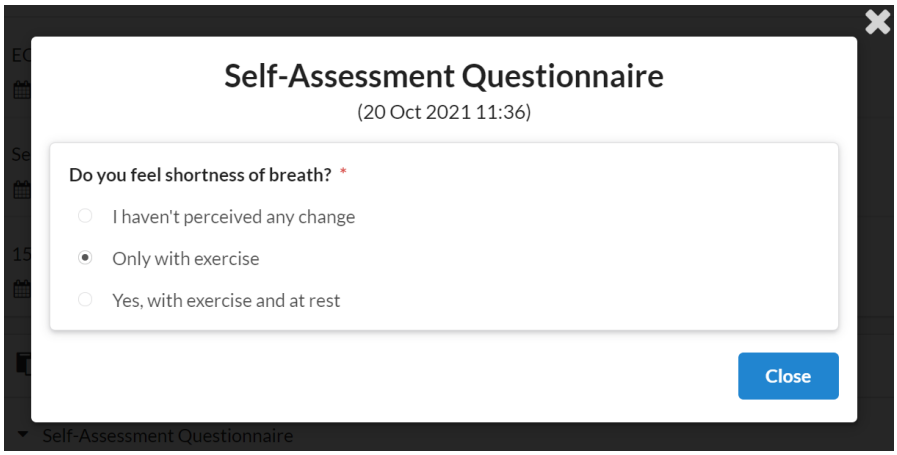

Figure 28 Read-only questionnaire response review popup for previously filled questionnaires

3.5.5. Education Materials Catalogue

The ADLIFE pilot sites have contributed to a list of materials considered relevant for ADLIFE patient groups which categorized under various topics. Healthcare professionals can assign some educational materials to a patient in accordance with the patient's care plan through PCPMP. This allows clinicians to tailor the type and topics of materials for each patient while maintaining consistency across a wide range of patients. Training materials can also be suggested to the clinician by clinical decision support systems during the care plan definition process. After the training materials are added to the care plan, the training materials are presented to patients in the PEP as seen in Figure 29. The user can access the online education materials (Figure 30) or download the ones which are provided as documents easily by clicking on the education material items listed in the care plan.

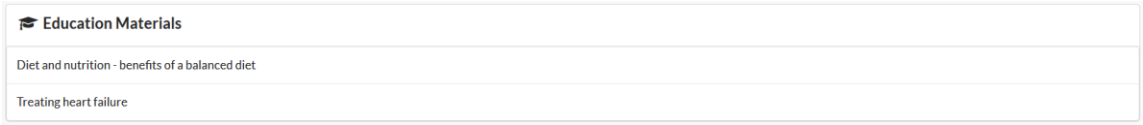

Figure 29 Education Materials section of Care Plan page

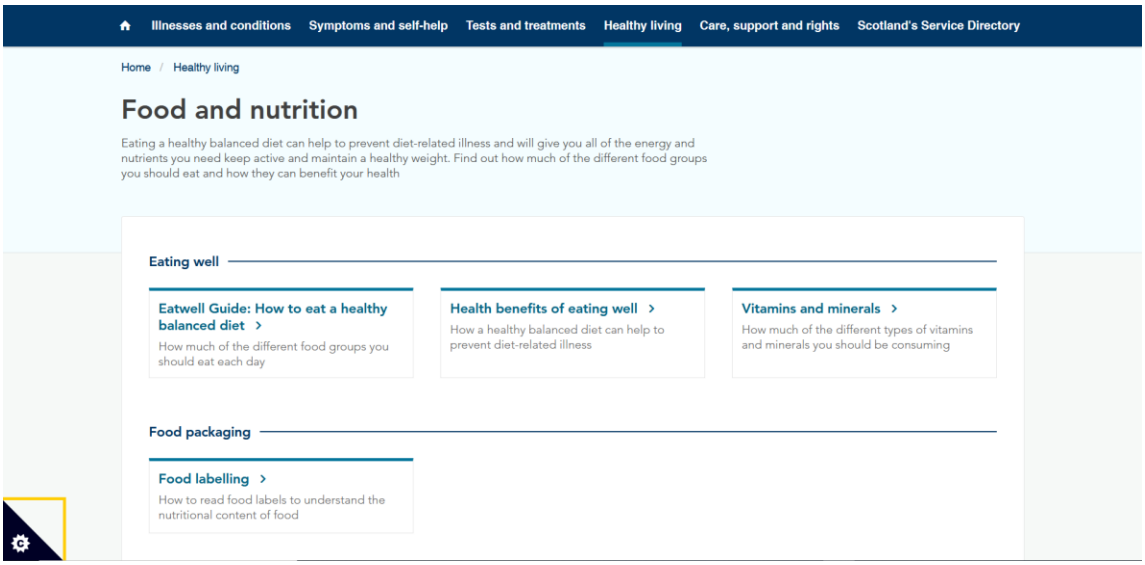

Figure 30 Example education material (web page)

PEP also includes a catalogue of educational materials. The user can navigate to the Education Materials catalogue via the “Education Material” item on the side menu (Figure 31). In this catalogue, all educational materials on the system are presented to the patient with their content types, categories, title and URL. Categories contain related morbidities and topics of the materials. In the catalogue, patients can list all the items identified by their pilot sites. The catalogue also provides filtering based on categories and search functionality by titles.

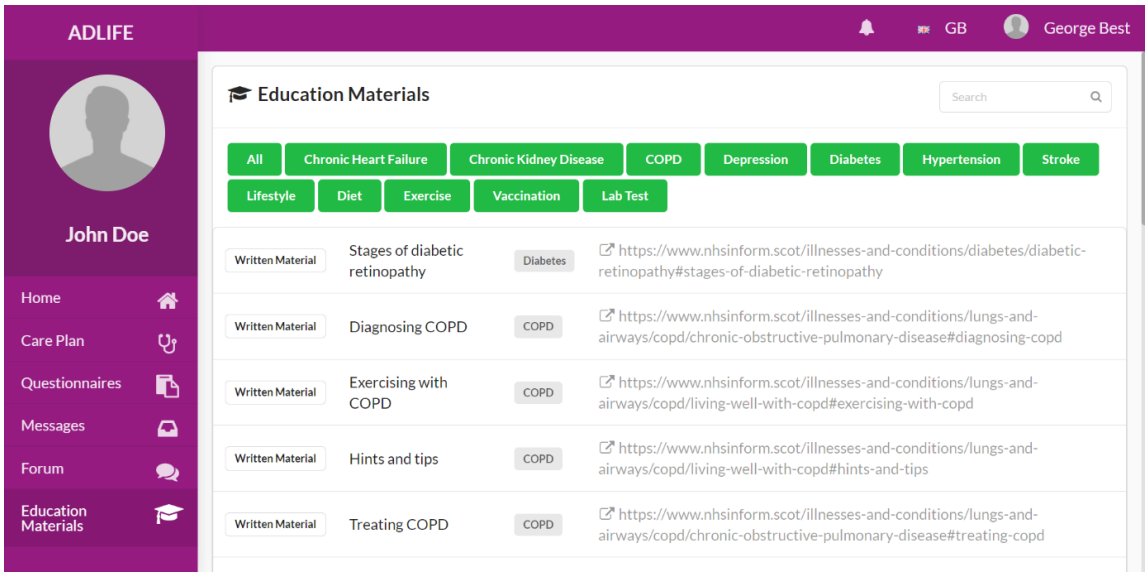

Figure 31 Education Materials page of PEP

3.5.6. Messaging

In order to enable direct communication between the care team members and the patients, we have implemented an asynchronous messaging module. PCPMP and PEP shares these messages over FHIR repository and notified using the subscription mechanism provided by onFHIR. The PEP user can send messages to care team members or other practitioners to share information, or to ask questions. Please note that the users are notified that this module shall not be used in case of emergencies, and the healthcare professionals may not be checking these messages instantaneously.

The user can navigate to the Messages screen by clicking the “Messages” item on the side menu. The user can see the messages they received or sent on the related message boxes as Inbox, Sent, Drafts and Trash which are available in the side menu. The user can filter messages by text search or according to senders, recipients, etc. Messages can also be removed, marked as read/unread using the top menu. The user can see the messages belongs to the same conversation as threads. The messages can be sorted according to title, sender/recipient or date by clicking the related column header.

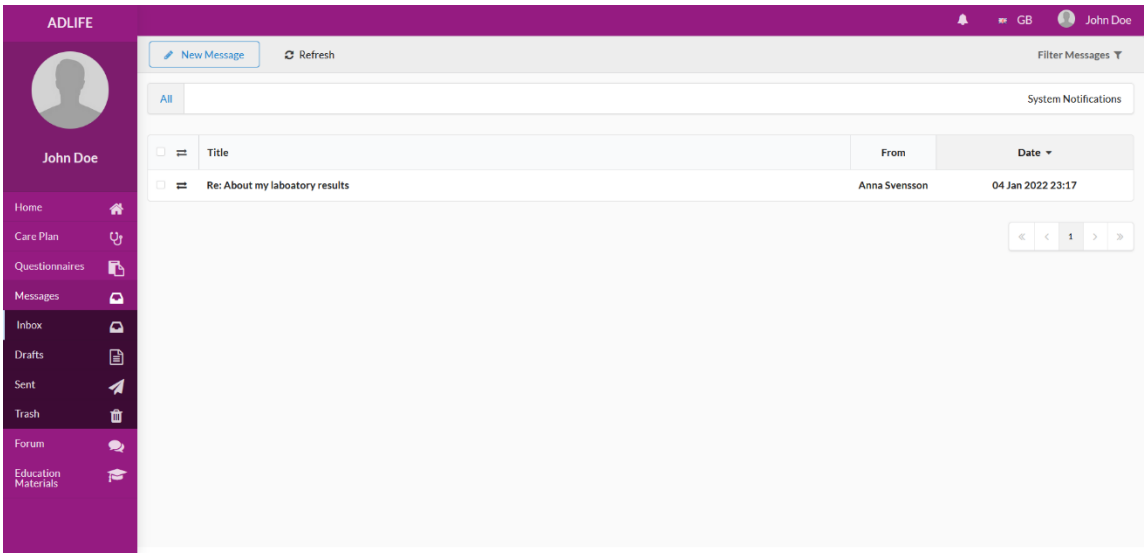

Figure 32 Inbox

After opening a message by clicking on its title, the user sees the message content and the related conversation. The user can reply to, forward or remove the message through the top menu (Figure 33).

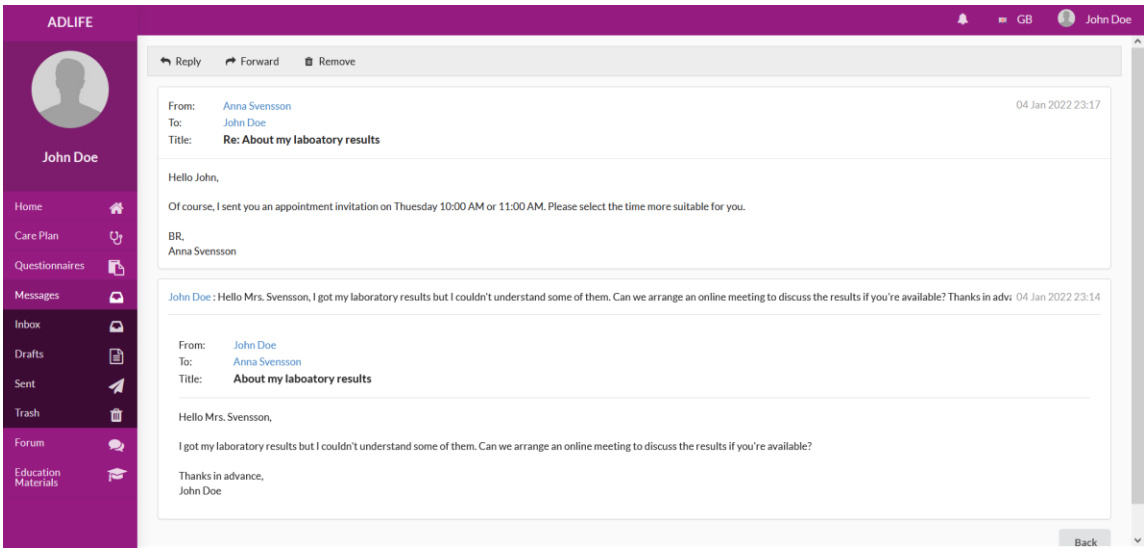

Figure 33 Reading messages

The user can send a message to one or more practitioners or directly to the care team. Also, attachments are available in messages to share images, lab results or any other useful data between users. The user can send the message with the “Send” that will be active after filling all fields. The user may want to write a message and send it later. Written messages can be saved as draft with the “Save” button and edited any time. These messages can be found under the “Drafts” section.

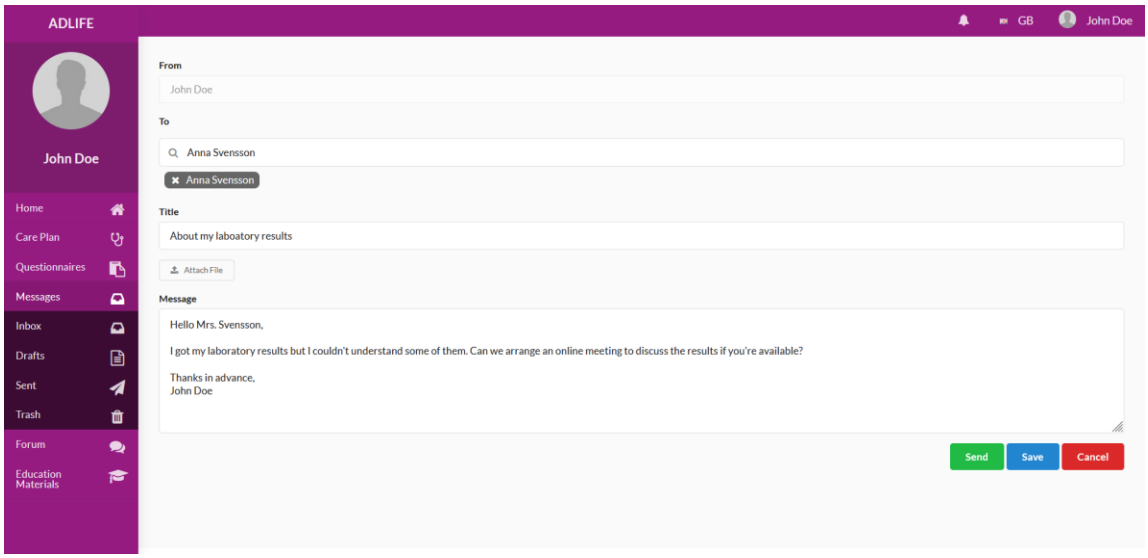

Figure 34 Write new message

3.5.7. Patient Forum

We have implemented a forum module enabling the patients to initiate discussion topics to ask questions about their disease or share their experiences with other patients. The user can navigate to the Forum screen by clicking the “Forum” item on the side menu. The topics are listed according to related disease categories in the Forum screen (Figure 35). The topics which the user is subscribed are filtered in the “Watch” tab and the topics that are opened by the user are listed under “My Posts” tab.

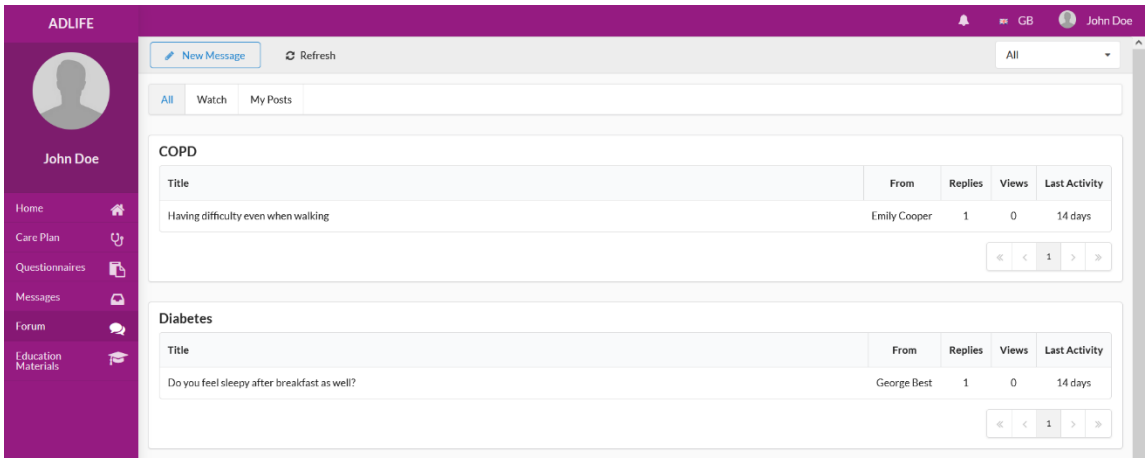

Figure 35 Patient Forum

The user can see the entries as in Figure 36 about a topic by clicking on the topic title. In this screen, the user can see first entry and replies, subscribe to the topics with the “Watch” button or reply to the topic with the “Reply” button.

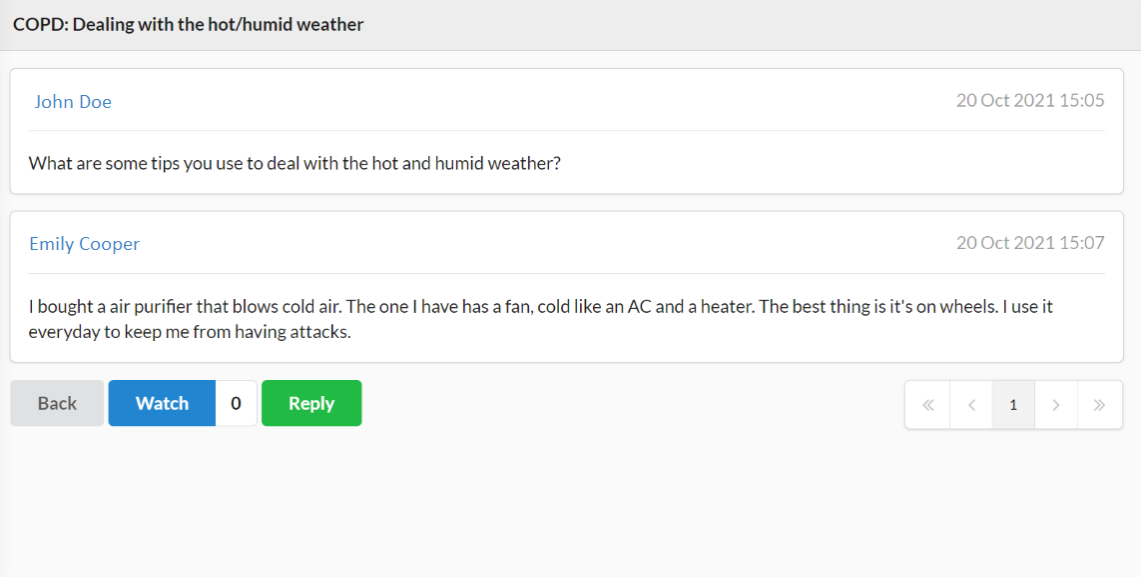

Figure 36 Example topic and related entries

The user can open a new forum topic by clicking on “New Message” button on the Forum page. The user will be navigated to the message form where the title, related category/disease and the content is asked (Figure 37). The user is also able to provide documents as attachments by clicking the “Attach File” button. The topic will be created after the user fills all required fields and clicks the “Send” button.

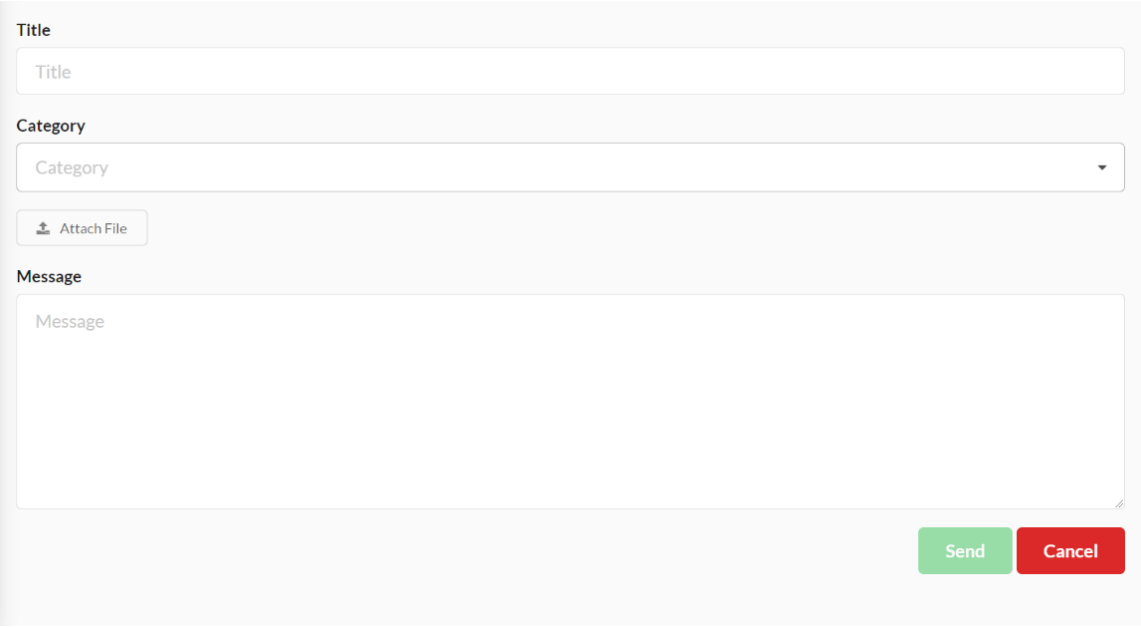

Figure 37 Adding new topic

CHAPTER 4

CONCLUSION

In this thesis, the concepts of integrated care and patient empowerment are discussed in the context of the ADLIFE project. An overall structure of the architecture around ADLIFE's two core components for patient-centered care planning, the Personal Care Plan Management Platform and the Patient Empowerment Platform (PEP), and the FHIR standard-based integrations between the components are illustrated. The research-proven patient empowerment tools used in PEP to enable more consistent care are mentioned, such as:

- Patient education
- Patient-reported outcome measures
- Just-in-time adaptive interventions

The technologies and standards used in implementation are briefly described while supported by integration examples. The profiling and designing stages are demonstrated, and some example FHIR resources are given in appendices. Lastly, the functionalities of PEP are shown with screenshots of related pages.

My contribution to the project was mostly on the development of PCPMP and PEP web applications and some of the underlying FHIR services.

4.1. Future Work

As the ADLIFE project is still ongoing, the pilot studies are not conducted yet. Before the pilot study starts, a pre-deployment usability study will be carried out with a group of patients, caregivers and clinicians. The participants will be attending online training sessions and user manuals will be provided to them to explain the functionalities of PCPMP and PEP platforms and how to access these platforms. The participants will be encouraged to use the system for a couple of weeks and finally they will be asked to fill a QUIS usability survey as in APPENDIX C.

The pilot application is planned to be done in 7 sites with the participation of 577 healthcare professionals and nearly 1000 patients. User interfaces are continuously enhanced with the feedbacks from health professionals and patients, and they will be enhanced according to outcomes of the pre-deployment usability study as well.

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APPENDIX A

FHIR Resource Examples

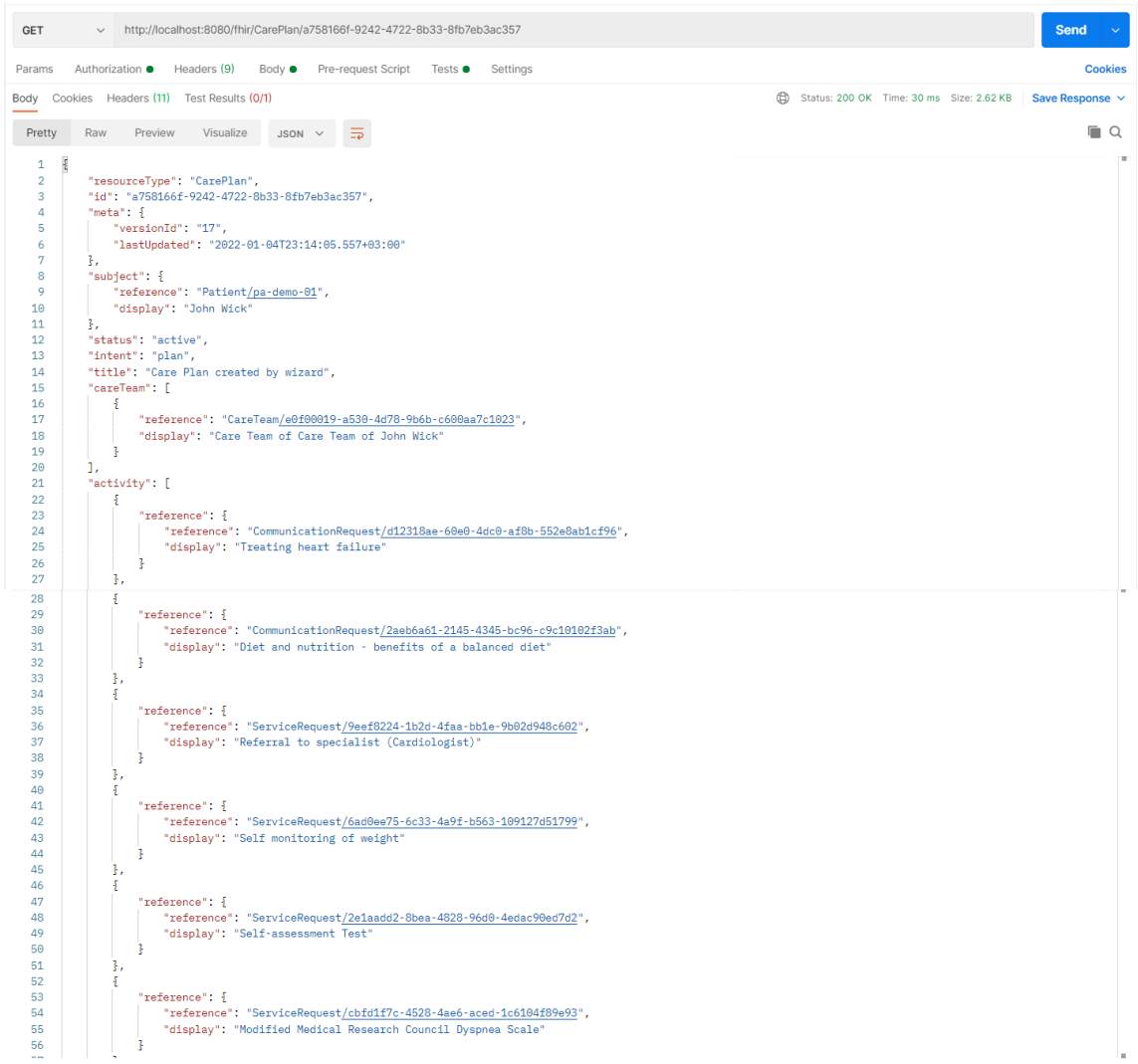

Figure A- 1 FHIR CarePlan

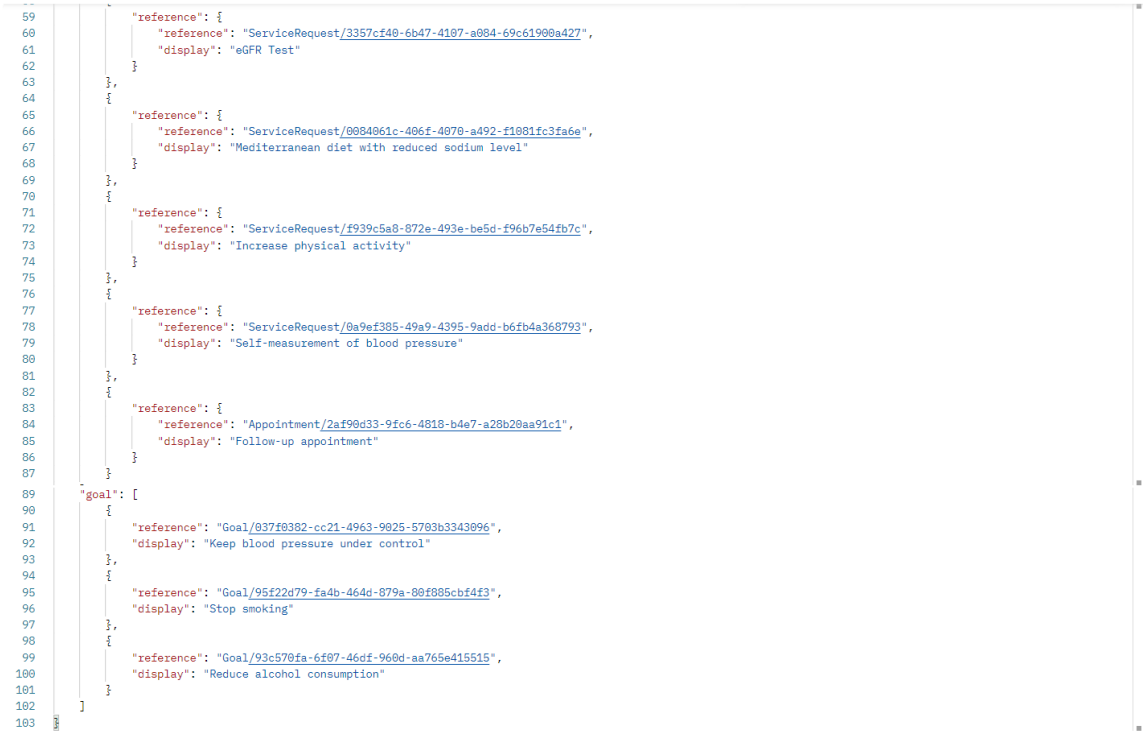

Figure A-1 FHIR CarePlan (continued)

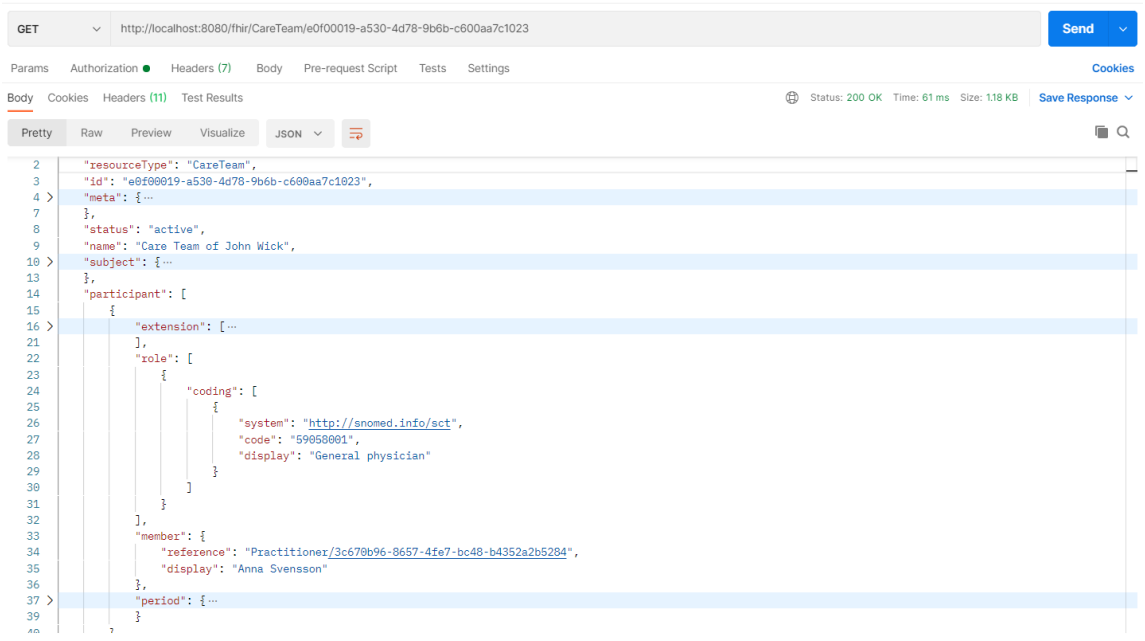

Figure A- 2 FHIR CareTeam

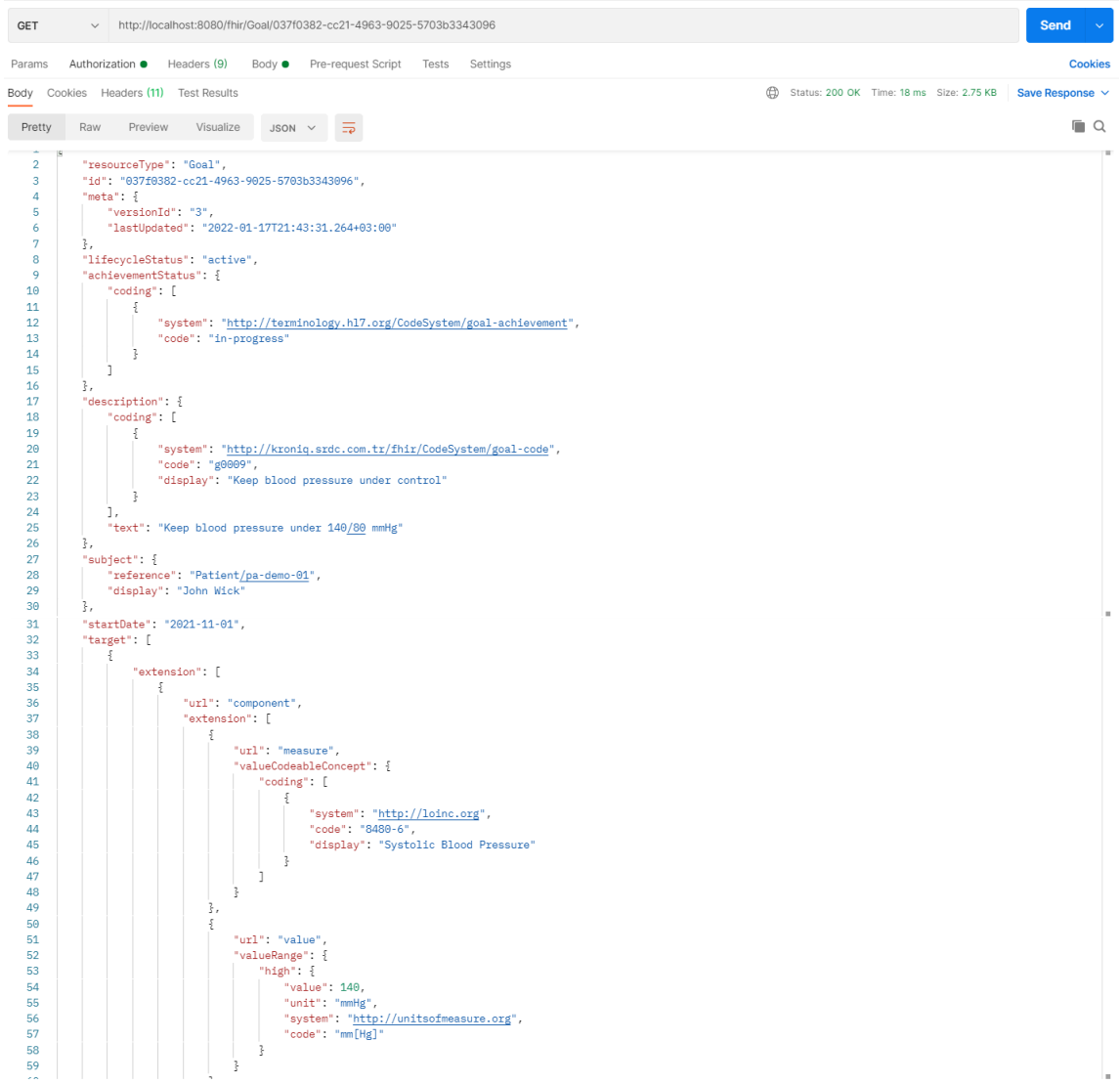

Figure A- 3 FHIR Goal

```
            {
                "url": "component",
                "extension": [
                    {
                        "url": "measure",
                        "valueCodeableConcept": {
                            "coding": [
                                {
                                    "system": "http://loinc.org",
                                    "code": "8462-4",
                                    "display": "Diastolic Blood Pressure"
                                }
                            ]
                        }
                    },
                    {
                        "url": "value",
                        "valueRange": {
                            "high": {
                                "value": 80,
                                "unit": "mmHg",
                                "system": "http://unitsofmeasure.org",
                                "code": "mm[Hg]"
                            }
                        }
                    }
                ]
            }
        ],
        "dueDate": "2022-05-01"
    }
],
"statusDate": "2022-01-04",
"expressedBy": {
    "reference": "Practitioner/3c670b96-8657-4fe7-bc48-b4352a2b5284",
    "display": "Anna Svensson"
},
"note": [...
],
"extension": [
    {
        "url": "http://kroniq.srdc.com.tr/fhir/StructureDefinition/title",
        "valueString": "Keep blood pressure under control"
    },
    {
        "url": "http://kroniq.srdc.com.tr/fhir/StructureDefinition/visible-to-patient",
        "valueBoolean": true
    }
]
```


Figure A- 3 FHIR Goal (continued)

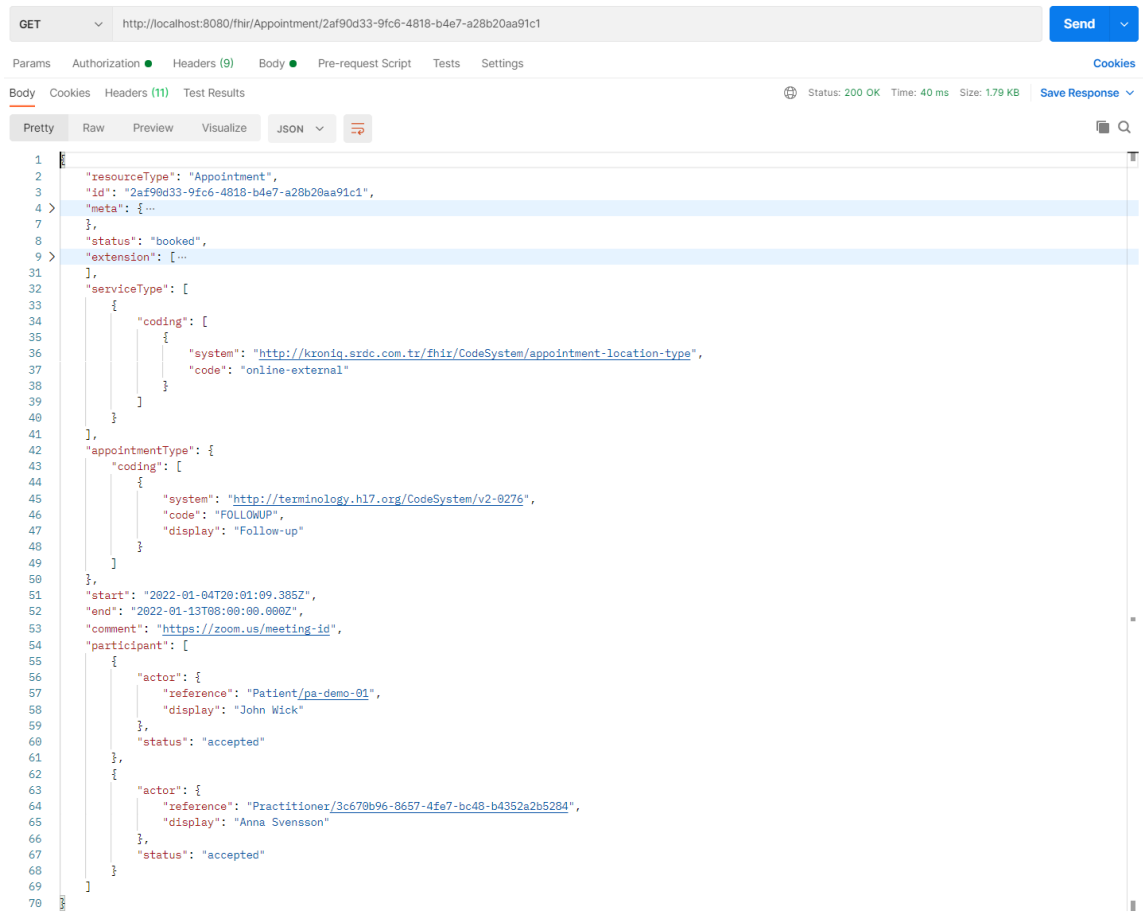

Figure A- 4 FHIR Appointment

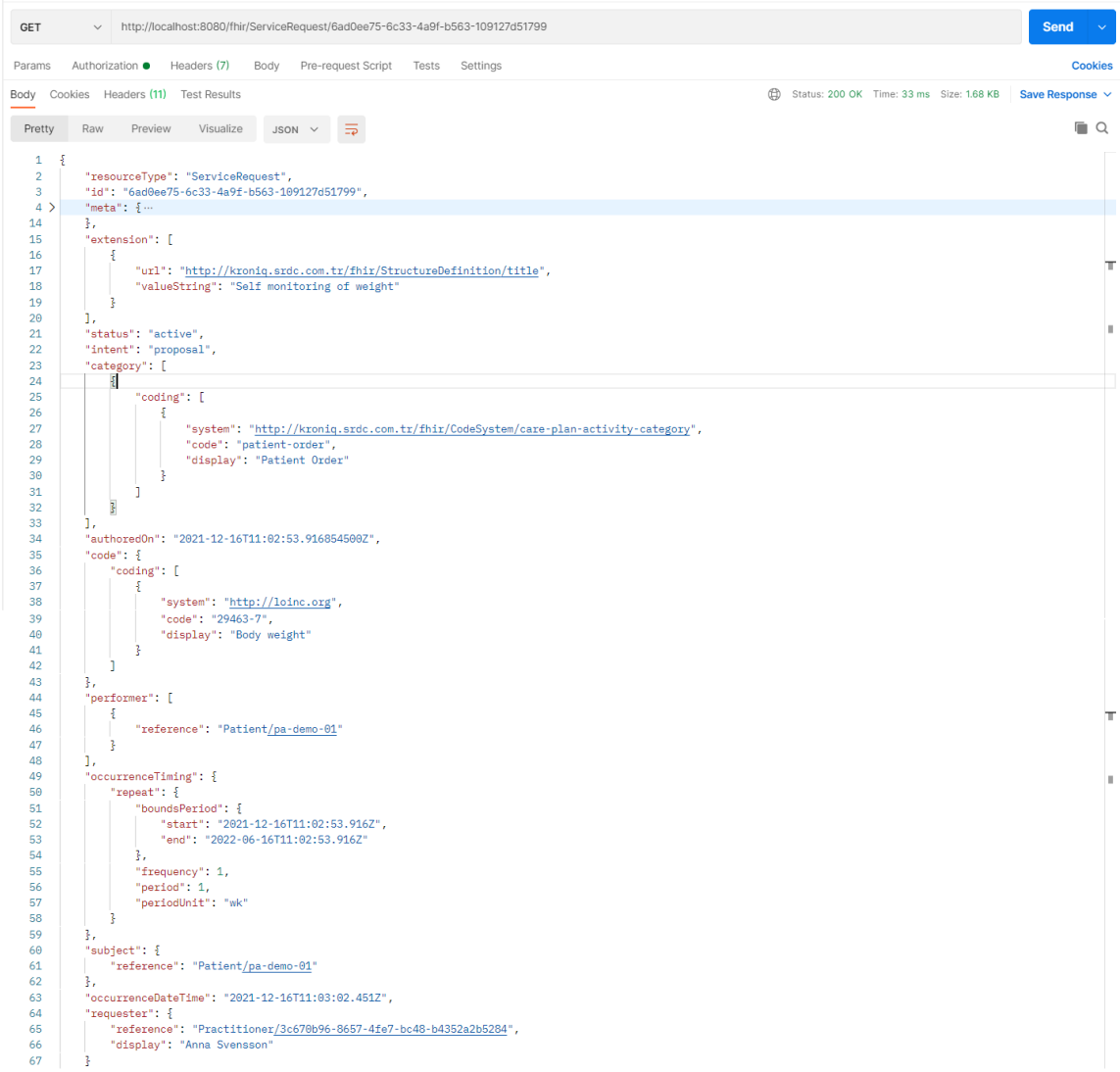

Figure A- 5 FHIR Service Request (Patient Order Activity)

APPENDIX B

Patient Reported Outcome Measure (PROM) Examples

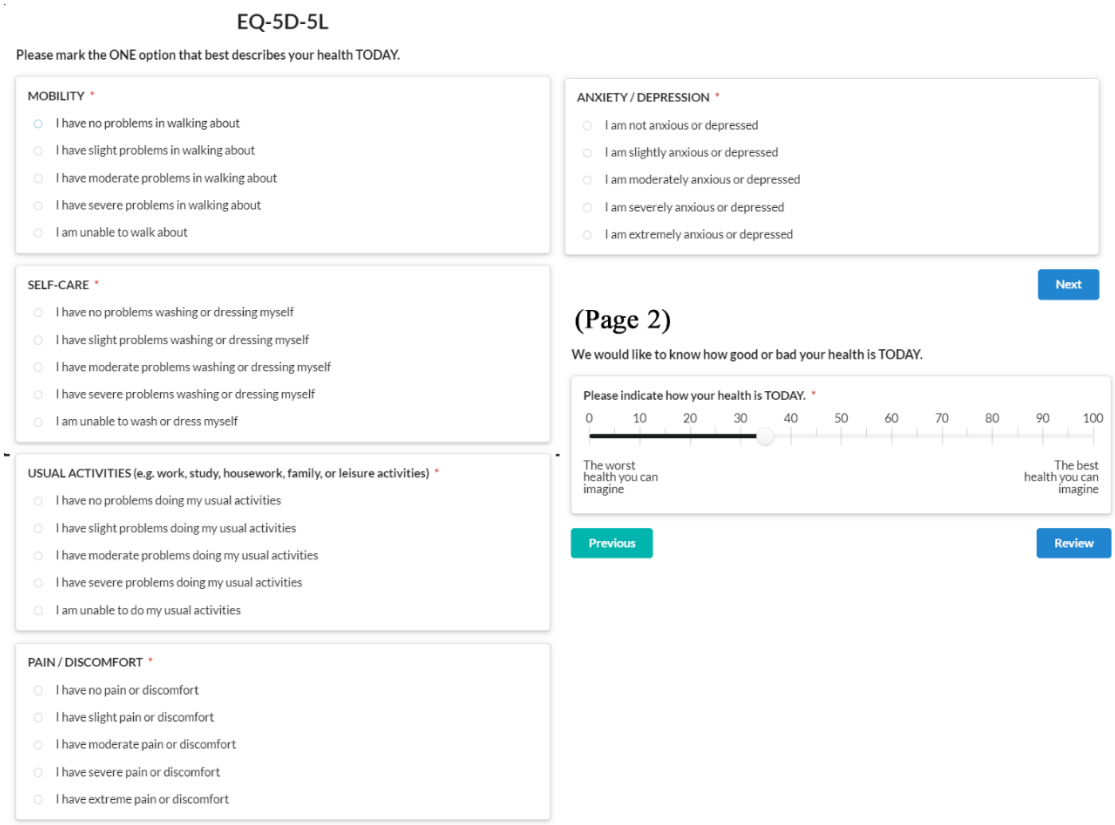

Figure B- 1 EQ-5D-5L Questionnaire

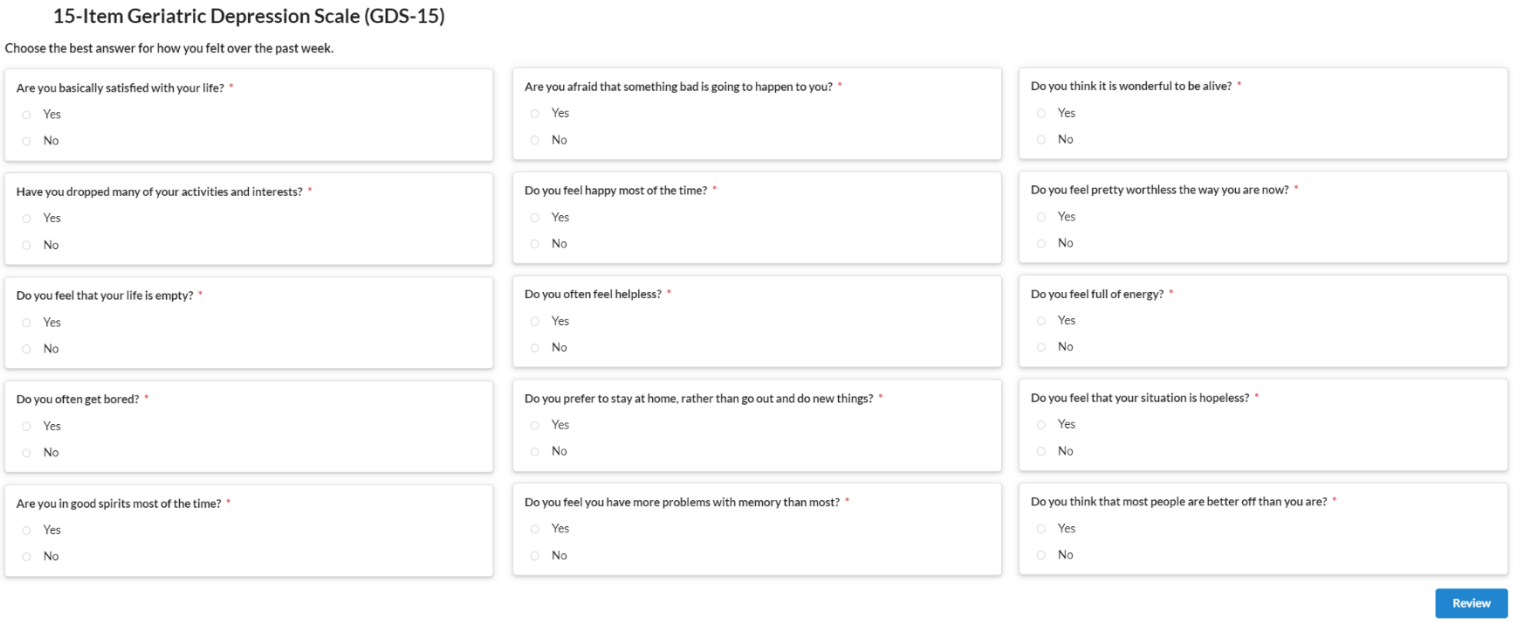

Figure B- 2 GDS-15 Questionnaire

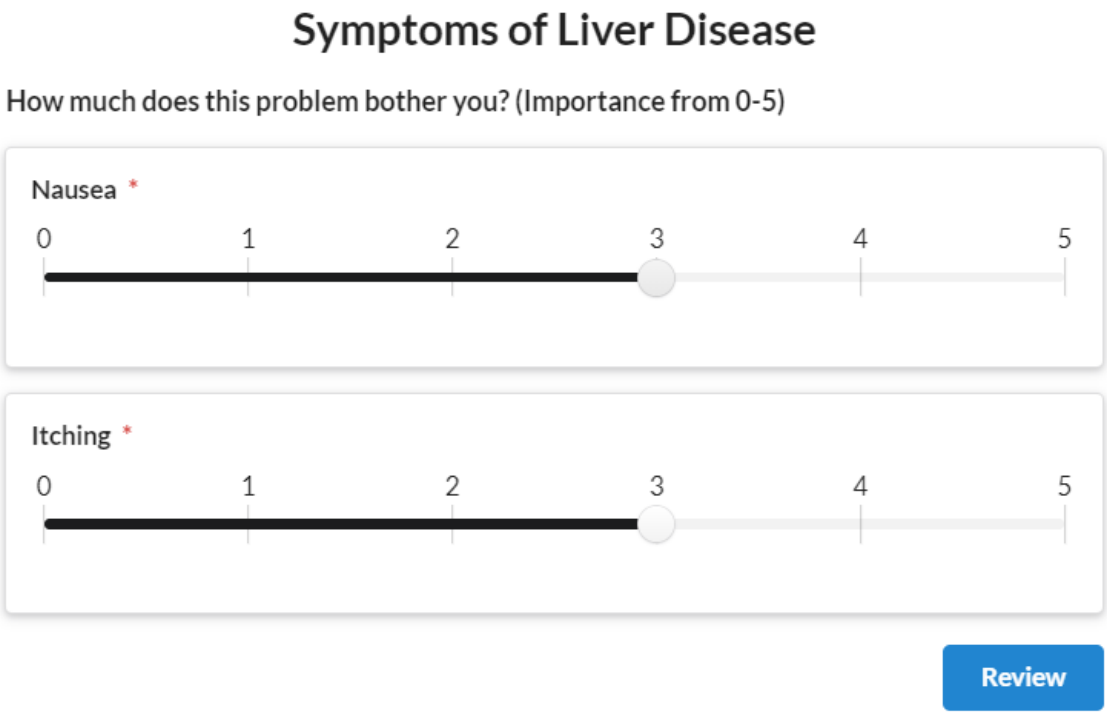

Figure B- 3 Liver Disease Symptoms Questionnaire

APPENDIX C

Usability Testing Questionnaire

Dear participant,

Your feedback is very valuable to us and we appreciate your participation in this demonstration session. In the following 10 minutes we kindly ask you fill in the “QUIS”-questionnaire.

The QUIS (Questionnaire for User Interaction Satisfaction) is a tool to assess your personal satisfaction with how the ADLIFE software is presented to you.

The questionnaire asks for your feedback on your overall satisfaction with the ADLIFE software. It does that along several topics, including: your overall reaction to the software; the screen; the terminology used; learning factors, the capabilities of the software and how you experienced them, the user manuals that you saw. You can save your progress anytime during the survey and resume it later by clicking the button on the upper right-hand corner of the page and then by following the process. Thank you very much in advance.

Overall Reaction to the ADLIFE Patient Empowerment Platform

Please select the number per question, which most appropriately reflects your impression about using the ADLIFE software.

If you prefer not to answer a question, you can leave it unanswered.

1. I find the ADLIFE Patient Empowerment Platform:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Terrible	○	○	○	○	○	○	○	○	○	○	Wonderful

2. I find the ADLIFE Patient Empowerment Platform:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Frustrating	○	○	○	○	○	○	○	○	○	○	Satisfying

3. I find the ADLIFE Patient Empowerment Platform:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Dull	○	○	○	○	○	○	○	○	○	○	Stimulating

4. I find the ADLIFE Patient Empowerment Platform:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Difficult	○	○	○	○	○	○	○	○	○	○	Easy

5. I find the ADLIFE Patient Empowerment Platform having:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Inadequate power	○	○	○	○	○	○	○	○	○	○	Adequate power

6. I find the ADLIFE Patient Empowerment Platform:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Rigid	○	○	○	○	○	○	○	○	○	○	Flexible

The Screen

Please select the number per question, which most appropriately reflects your impression about using the ADLIFE software.

If you prefer not to answer a question, you can leave it unanswered.

7. Characters on the computer screen are:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Hard to read	○	○	○	○	○	○	○	○	○	○	Easy to read

8. The image of characters are:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Fuzzy	○	○	○	○	○	○	○	○	○	○	Sharp

9. The highlighting on the screen is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Unhelpful	○	○	○	○	○	○	○	○	○	○	Very helpful

10. **The use of bolding is:**

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Unhelpful	○	○	○	○	○	○	○	○	○	○	Very helpful

11. The screen layouts were helpful:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Never	○	○	○	○	○	○	○	○	○	○	Always

12. The amount of information that can be displayed on the screen is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Inadequate	○	○	○	○	○	○	○	○	○	○	Adequate

13. The arrangement of information on screen is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Illogical	○	○	○	○	○	○	○	○	○	○	Logical

14. **The sequence of screens is:**

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Confusing	○	○	○	○	○	○	○	○	○	○	Clear

15. **The next screen in a sequence is:**

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Unpredictable	○	○	○	○	○	○	○	○	○	○	Predictable

0 1 2 3 4 5 6 7 8 9

16. Going back to the previous screen is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Impossible	○	○	○	○	○	○	○	○	○	○	Easy

17. Progression of work-related tasks is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Confusing	○	○	○	○	○	○	○	○	○	○	Clearly marked

Terminology and System Information

Please select the number per question, which most appropriately reflects your impression about using the ADLIFE software.

If you prefer not to answer a question, you can leave it unanswered.

18. The use of terminology throughout system is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Inconsistent	○	○	○	○	○	○	○	○	○	○	Consistent

19. The terminology relates well to the activities I am doing:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Never	○	○	○	○	○	○	○	○	○	○	Always

20. Computer terminology is used:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Too frequently	○	○	○	○	○	○	○	○	○	○	Appropriately

21. Terminology on the screen is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Ambiguous	○	○	○	○	○	○	○	○	○	○	Precise

22. Messages that appear on the screen are:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Inconsistent	○	○	○	○	○	○	○	○	○	○	Consistent

23. The position of instructions on the screen is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Inconsistent	○	○	○	○	○	○	○	○	○	○	Consistent

24. Messages that appear on the screen are:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Confusing	○	○	○	○	○	○	○	○	○	○	Clear

25. Instructions for commands or functions are:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Confusing	○	○	○	○	○	○	○	○	○	○	Clear

26. Instructions for correcting errors are:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Confusing	○	○	○	○	○	○	○	○	○	○	Clear

27. The computer keeps me informed about what it is doing:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Never	○	○	○	○	○	○	○	○	○	○	Always

28. Animated cursors keep me informed:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Never	○	○	○	○	○	○	○	○	○	○	Always

29. Performing an operation leads to a predictable result:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Never	○	○	○	○	○	○	○	○	○	○	Always

30. Controlling the amount of feedback is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Impossible	○	○	○	○	○	○	○	○	○	○	Easy

31. The length of delay between operations is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Unacceptable	○	○	○	○	○	○	○	○	○	○	Acceptable

32. Error messages are:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Unhelpful	○	○	○	○	○	○	○	○	○	○	Helpful

33. Error messages clarify the problem:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Never	○	○	○	○	○	○	○	○	○	○	Always

34. Phrasing of error messages are:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Unpleasant	○	○	○	○	○	○	○	○	○	○	Pleasant

Learning

Please select the number per question, which most appropriately reflects your impression about using the ADLIFE software.

If you prefer not to answer a question, you can leave it unanswered.

35. Learning to operate the system is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Difficult	○	○	○	○	○	○	○	○	○	○	Easy

36. Getting started is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Difficult	○	○	○	○	○	○	○	○	○	○	Easy

37. Time to learn to use the system is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Slow	○	○	○	○	○	○	○	○	○	○	Fast

38. Exploration of features by trial and error is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Discouraging	○	○	○	○	○	○	○	○	○	○	Encouraging

39. Number of steps per task are:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Too many	○	○	○	○	○	○	○	○	○	○	Just right

40. Feedback on the completion of a sequence of steps is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Unclear	○	○	○	○	○	○	○	○	○	○	Clear

Multimedia

Please select the number per question, which most appropriately reflects your impression about using the ADLIFE software.

If you prefer not to answer a question, you can leave it unanswered.

41. Quality of still pictures/photographs was:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Bad	○	○	○	○	○	○	○	○	○	○	Good

42. Pictures/Photos were:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Fuzzy	○	○	○	○	○	○	○	○	○	○	Clear

43. Picture/Photo brightness was:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Dim	○	○	○	○	○	○	○	○	○	○	Bright

44. Colours used are:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Unnatural	○	○	○	○	○	○	○	○	○	○	Natural

45. Amount of colours available is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Inadequate	○	○	○	○	○	○	○	○	○	○	Adequate

Tutorials

Please select the number per question, which most appropriately reflects your impression about using the ADLIFE software.

If you prefer not to answer a question, you can leave it unanswered.

46. The training workshop was:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Useless	○	○	○	○	○	○	○	○	○	○	Helpful

User Manuals

Please select the number per question, which most appropriately reflects your impression about using the ADLIFE software.

If you prefer not to answer a question, you can leave it unanswered.

47. The terminology used in the manuals is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Confusing	○	○	○	○	○	○	○	○	○	○	Clear

48. The information from the manual is easily understood:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Never	○	○	○	○	○	○	○	○	○	○	Always

49. Finding a solution to a problem using the manual is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Impossible	○	○	○	○	○	○	○	○	○	○	Easy

50. Amount of help given is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Inadequate	○	○	○	○	○	○	○	○	○	○	Adequate

51. Placement of help messages on the screen is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Confusing	○	○	○	○	○	○	○	○	○	○	Clear

52. Accessing help messages is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Difficult	○	○	○	○	○	○	○	○	○	○	Easy

System Capabilities

Please select the number per question, which most appropriately reflects your impression about using the ADLIFE software.

If you prefer not to answer a question, you can leave it unanswered.

53. System speed is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Too slow	○	○	○	○	○	○	○	○	○	○	Fast enough

54. Response time for most operations is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Too slow	○	○	○	○	○	○	○	○	○	○	Fast enough

55. **The system is reliable:**

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Never	○	○	○	○	○	○	○	○	○	○	Always

56. **Operations are:**

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Undependable	○	○	○	○	○	○	○	○	○	○	Dependable

57. System failures occur:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Frequently	○	○	○	○	○	○	○	○	○	○	Seldom

58. The system warns me about potential problems:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Never	○	○	○	○	○	○	○	○	○	○	Always

59. Correcting my mistakes is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Difficult	○	○	○	○	○	○	○	○	○	○	Easy

60. Correcting typos is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Complex	○	○	○	○	○	○	○	○	○	○	Simple

61. The ability to undo operations is:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Inadequate	○	○	○	○	○	○	○	○	○	○	Adequate

62. The ease of operation depends on my level of experience:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
Never	○	○	○	○	○	○	○	○	○	○	Always

63. I can accomplish tasks knowing only a few commands:

Please choose the appropriate response for each item:

	0	1	2	3	4	5	6	7	8	9	
With difficulty	○	○	○	○	○	○	○	○	○	○	Easily

64. Do you have any additional comments?

Please write your answer here: