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Interoperability Architecture of the ADLIFE Patient Empowerment Platform

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Abstract. Chronic diseases introduce challenges for the patients to manage the changing requirements of the disease. Patient empowerment activities are a critical component to assist patients in their long-term care journey. In order to be effective, patient empowerment tools need to be well-integrated with the chronic disease management tools used at the clinical sites. This paper explores and analyzes the exploitation of HL7 FHIR to design and implement an interoperable patient empowerment platform that can be seamlessly integrated with external chronic disease management and Electronic Health Record (EHR) systems

Keywords. Patient Empowerment, Interoperability, HL7 FHIR, Chronic Disease Management

1. Introduction

As the prevalence of chronic diseases continuously increases, so does the burden of management of these long-term conditions on healthcare services. Chronic diseases are reported as major causes of disability and mortality and are associated to significant healthcare costs and, often, inadequate access to care services [1]. Chronic diseases introduce demanding challenges for the patients as well [2]. Long-term conditions necessitate continuous and complex management, disease and treatment requirements change over time requiring continuous decision making and adjustments at the patient side as well. One of the key features of health policies addressing the needs of chronic diseases is cited as exploitation of patient empowerment tools in integrated care. Empirical evidence of a positive relationship between patient empowerment and better healthcare outcomes has been reported such as increased satisfaction of patients and health professionals and better adherence to treatment activities [3,4].

In order to be effective, patient empowerment tools need to be well-integrated with the chronic disease management tools used at the clinical sites. Continuous two-way information exchange is essential to convey the care plan in clear terms to the patients and their informal care givers, to encourage them to adhere to their care plan, be in

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constant communication with the patient to collect and process preferences, feedback, symptoms and patient recorded data. This introduces an interoperability challenge, and results in development of custom patient empowerment tools that are tightly integrated with the chronic disease management systems mostly via proprietary interfaces, which diminishes re-usability across sites. This paper explores and analyzes the exploitation of HL7 FHIR to design and implement an interoperable patient empowerment platform that can be seamlessly integrated with external chronic disease management systems and Electronic Health Record (EHR) systems.

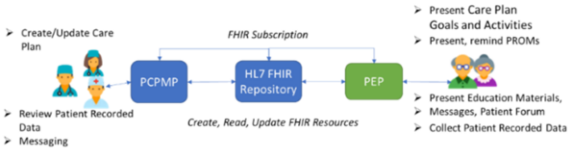

Figure 1. Using HL7 FHIR as a means of interoperability between ADLIFE PEP and PCPMP

This work is being carried out within the scope of ADLIFE Project, (H2020, SC1-DTH-11-2019, 875209) [1] which 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, heart failure and COPD. The technical solution is composed of a Personalized Care Plan Management Platform (PCPMP), 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. This paper focuses on interoperability architecture between PCPMP and PEP to seamlessly share care plan and related artifacts enabling integrated supportive care.

2. Methods

We have positioned an open source HL7 FHIR Repository[6] as the common data repository that enables seamless data exchange between local EHRs, chronic disease management platforms such as PCPMP and the PEP. In the following sections we present how we have represented core data items for patient empowerment and how we have enabled exchange of these data between PCPMP and PEP.

Exchanging Care plans and patient feedback

Shared care plans are an indispensable component of an integrated care environment for long-term care of chronic disease patients, presenting clear measurable goals, as well as treatment activities jointly agreed across multi-disciplinary care team members. Sharing care plans with patients and informal care givers empowers them to be actively involved in their treatment journey.

In our architecture, care plans are represented as HL7 FHIR *CarePlan Resource* [7]. Within the care plan, the care team members are clearly described via a reference to *CareTeam Resource.* Each care plan is composed of a set of goals represented via *Goal Resource* where the desired target health state, such as ‘Keeping the blood pressure (BP) measurements below 140/80 mmHg in the next 3 months' is defined, and a set of planned activities within the scope of the care plan. These activities can be: prescriptions represented as *MedicationRequest Resource;* control appointments represented as *Appointment Resource;* medical device assignments as *DeviceRequest Resource*; referrals to specialists, lab orders, diagnostic tests and patient activities (such as symptom reporting, diet and exercise regiments, patient-reported outcome measure questionnaires and self-blood glucose/BP measurements) represented as *ServiceRequest Resources. CommunicationRequest Resource* is used to represent education materials assigned to patients as a part of their care plan. For each activity, the planned period, timing or frequency upon which the described activity is aimed to be fulfilled and also the assigned performer such as a specific Practitioner, Patient or Informal Care Giver are specified.

PEP is subscribed to the FHIR Repository which supports FHIR subscription protocol [8], to be informed whenever a new care plan is created for the specified patients or whenever existing care plans are updated. In this way, PEP is automatically informed about new and updated care plans and care plan retrieval is triggered via standard based HL7 FHIR RESTful API. Once the machine-processable care plan content is retrieved from the common repository, it is displayed to the patient in a patient-friendly manner. Patients are enabled to provide feedback about care plan goals and activities. They can mark the activities as achieved/not achieved, select emojis to present whether they are comfortable with carrying out activities and also provide free text comments. These are noted as *Annotation Resources* linked to care plan activities and goals. Through the subscription mechanism, the subscribed platforms are informed about patient feedback to be notified to practitioners in the care team. Practitioners review this feedback in the next care plan review meeting and update the care plan accordingly.

Patient-Reported Outcome Measures (PROMs) as scored questionnaires

To assess the care delivered to the patients via ADLIFE integrated care approach from the patient perspective and to measure the patients' perceptions of their own health status and quality of life, our clinical reference group has identified several Patient-Reported Outcome Measures (PROMs) questionnaires. Some examples are, CAT (COPD Assessment Test) and HADS (Hospital Anxiety and Depression Scale). In ADLIFE architecture, we have followed the FHIR Patient-Reported Outcomes Implementation Guide [9] and PROMs are represented as HL7 FHIR *Questionnaire*. PROMs are assigned to the patient via *ServiceRequests* as a part of their care plan to be carried out by patients periodically as defined in the care plan. The PROM assignments are presented to the patient and rendered as user-friendly web-based surveys, enabling the patient to easily fill them out. The responses are recorded as FHIR *QuestionnaireResponse Resources* and saved back to the FHIR Repository. When the PROM includes a scored assessment, the resulting score is represented as an *Observation* Resource that is linked with the PROM. The chronic-disease management solutions subscribed to receive notifications are informed, and the responses are made available to the practitioners.

Collection of Patient-Recorded Observations and Medical Device Data

In ADLIFE, as a part of the care plan, patients can be requested to regularly report self-measurements of clinical parameters and vital signs such as blood pressure (BP) measurements, pulse, oxygen saturation, weight. These self-measurement activities are assigned to the care plan of the patient as *ServiceRequests*, medical device assignments are also recorded in the care plan as *DeviceRequests.*

ADLIFE PEP implements the Personal Connected Health Alliance (PCHAlliance) Continua Design Guidelines (CDG) [10], to enable seamless integration with medical devices in order to automatically gather device readings from assigned devices and to record them as patient observations. The 'Personal Health Devices Interface' defined in CDG is implemented between the medical sensors (BP measurement Device, Weight scale, pulse oximeter) and ADLIFE PEP Mobile application that functions as a mobile gateway to collect device readings via Bluetooth communications. The CDG 'Services Interface' is implemented between mobile app and the common FHIR repository to store device readings via FHIR RESTful API. As guided by CDG, we have followed the FHIR Personal Health Device Implementation Guide (IG) [11], to represent patient-recorded measurements: *Observation Resource* is used to represent values of measured clinical parameters, and when received from a medical device via 'Personal Health Devices Interface', *Device Resource* is used to record the device parameters linked with the *Observation Resource*. ADLIFE PEP also allows the patient to manually record measured parameters via Web and mobile interfaces that are recorded via *Observation Resource,* without the link to the *Device Resource*.

Once these patient-recorded data are saved to common FHIR repository, the subscribed clients are informed, and the measurements are made available to the practitioners. Another client app that can be subscribed to receive these patient-recorded observations is Early Warning Clinical Decision Support Services. This enables to proactively check deterioration in the patient's clinical condition, and based on pre-defined thresholds, can initiate alert messages to the respective pre-assigned care givers such as nurses, practitioners and informal care givers.

Symptom Reporting

Based on the analysis of the clinical guidelines addressing the needs of the targeted diseases, several symptoms are identified to be closely monitored by our clinical reference group, such as *cough, shortness of breath, sputum, dyspnea.* Patients are assigned activities to periodically report these symptoms as a part of their care plan. As a result of requirement analysis studies, we have discovered that instead of a plain screen for asking the existence of these symptoms to the patient, it is more effective to ask the existence and details of these symptoms via dynamic, interactive surveys. Based on the patient's answers, the next question to be asked may dynamically change by adding more detailed questions if needed. For example, if the patient answers that he is coughing more mucus than usual, he is then asked more detailed questions about the color, quantity, and viscosity of the mucus. In our architecture, this kind of dynamic questionnaires are represented in *Adaptive Forms* as defined by FHIR Structured Data Capture (SDC) Implementation Guide[12]. SDC has extended *FHIR Questionnaire Resource* to make it possible to represent adaptive questionnaires where the questionnaire is dynamically developed based on previous answers to questions chosen from a set of questions.

Asynchronous Messaging between care team members and Patient Forum

As part of our integrated supportive care approach, we enable asynchronous messaging between practitioners and patients and informal care givers. The FHIR repository is used to enable exchange of asynchronous messages. We represent messages through

Communication Resource, where the sender and receiver parties are clearly marked, and the message can be linked with the *CarePlan, Observation, Condition or DiagnosticReport instances.* The PEP and also the chronic disease management systems are subscribed to be notified whenever a new message is received for the practitioner or the patient. The patients are reminded that emergency situations should not be communicated via asynchronous messages, and practitioners will be able to check their messages at regular intervals. The *Communication Resource* is also used to represent the messages exchanged between the patients in the implementation of the Patient Forum. The Patient Forum enables the patients to create virtual communities involving patients suffering from similar conditions to share their experiences and coping strategies.

3. Discussion and Conclusion

In this paper, we have presented the HL7 FHIR based interoperability architecture we have designed and implemented for seamlessly integrating patient empowerment platforms with the underlying care systems used at clinical sites. Within the scope of the ADLIFE project, the system and its integration with care planning systems will be validated in seven pilot sites involving 577 healthcare professionals from 75 different hospitals, clinics, and primary care services. The effectiveness of the system will be evaluated with 882 patients and 1243 caregivers.

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