Implementation of HL7 FHIR-Based Interoperability Profiles to Manage Care Plans for Multimorbid Patients with Mild Dementia

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Abstract. Management of multimorbidity in patients with mild dementia and mild cognitive impairment introduces additional challenges. The CAREPATH project provides an integrated care platform to assist both healthcare professionals and patients and their informal caregivers in the day-to-day management of care plans for this patient population. This paper introduces an HL7 FHIR-based interoperability approach for exchanging care plan action and goals with the patients and collecting feedback and adherence information from patients. In this way, seamless information exchange between healthcare professionals, patients and their informal care givers is achieved to support patients in their self-care management journey and increase their adherence to their care plans despite the burdens of mild dementia.

Keywords. Interoperability, Profiling, HL7 FHIR, Multimorbidity, Dementia

1. Introduction

Multimorbidity refers to the simultaneous presence of two or more chronic diseases in the same person. It affects more than half of the elderly population, and the number of people experiencing multimorbidity is predicted to increase by >1% per year by 2030 as the population ages [1, 2]. The aging population combined with the increasing burden of multimorbidity poses a challenge to the sustainability of healthcare systems worldwide due to high healthcare costs it causes [3]. Multimorbidity management is a complex process and involves many challenges for both the patient and their caregivers. The situation becomes more complex when multimorbidity is associated with dementia. Multimorbid patients with dementia are at additional risk compared to those without dementia, because multimorbidity can accelerate the progression of dementia and dementia can hinder effective disease management, resulting in worsening of the patient's condition [4]. Therefore, there is a need to develop solutions that addresses the challenges of multimorbidity and dementia. To address these challenges, the CAREPATH project proposes a patient-centered approach by developing a flexible and

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modular Integrated Care Platform consisting of several components that provide enhanced healthcare interventions for the management of multimorbidity in elderly patients living with mild cognitive impairment and mild dementia [5]. The Home and Health Monitoring Platform (HHMP) provides sensors and medical devices to continuously collect real time data of patients for monitoring their physiological and functional status. The Advanced Early Warning Smart Decision Tools (AEWSDT) processes the data gathered by the HHMP and detects declines before a clinical or functional threshold is reached. The Adaptive Integrated Care Platform (AICP) enables implementation of personalized care plans for managing multimorbidity and dementia with the help of patient's Electronic Health Records (EHRs), patient's most recent context from the HHMP, the early onset triggers delivered by the AEWSDT, and the Clinical Decision Support Services (CDSS) based on evidence based clinical guidelines. The Patient Empowerment Platform (PEP) provides personalized assistance and guidance to patients by presenting care plan activities as daily tasks to patients and collecting feedback from them for monitoring their adherence to the care plan [6]. All the data collected from the health devices, EHRs, AEWSDT, CDSS, AICP and PEP are stored in a secure Patient Data Store in HL7 FHIR format.

The Fast Healthcare Interoperability Resources (FHIR) is a health data content modelling and health data exchange standard released by HL7 to achieve interoperability with a modular approach that represents data as standalone entities called *Resources* instead of the traditional document-centric approaches [7]. It is increasingly adopted by the healthcare industry, thanks to its uncomplicated structure and easy access to resources with HTTP REST API [8]. The use of international standards such as HL7 FHIR is essential to achieve interoperability between various systems in complex architectures such as CAREPATH. However, standards alone may not be sufficient to ensure interoperability, because adaptation to specific context of use may be required depending on different system requirements. Therefore, the concept of profiling is used to add new resource elements, restrict the use of some elements, update element cardinalities, specify the terminologies to be used in specific elements, etc. [9]. Profiling can also include descriptions of choreographies, business rules and constraints, as in Integrating the Healthcare Enterprise (IHE) Profiles [10]. Although profiling is frequently used in applications in healthcare domain [11], it has also been adapted in different domains such as emergency management, disaster management and maritime surveillance [12, 13].

When it comes to multimorbidity with dementia, the care plan should focus not only on multimorbidity management, but also on tailoring it to dementia-specific needs. In addition, monitoring compliance with the care plan in dementia patients is important for managing multimorbidity effectively. In this paper, we present the implementation of HL7 FHIR-based interoperability profiles for effective management of personalized care plans in multimorbid patients living with dementia.

2. Methods

In CAREPATH, care plan management of multimorbid patients with dementia is mainly handled by two components: AICP and PEP. AICP is a web-based platform that allows creation and sharing of personalized care plans across multi-disciplinary care teams, including health and social care providers. In the management of multimorbidity, it is of utmost importance for patients to take health measurements at home, take their medications as prescribed on time, follow lifestyle recommendations, and have regular

follow-up visits. In this regard, a personalized care plan is created by the care team of the patient based on patient's available health records such as diseases, symptoms, drugs, vital signs, recent lab results, family history etc. in the FHIR repository, which was already retrieved from underlying EHR systems or generated by the CAREPATH components. In the care plan, each item that patient needs to perform is defined as an "activity". In addition, targets such as weight or blood pressure can also be defined and added to the care plan as "goals".

The medical data of patients are accessed via the *Condition, Observation, MedicationStatement* and *FamilyHistory* FHIR resources. Care plan of a patient is stored in the *CarePlan* resource. In *CarePlan*, the goals are modelled with *Goal* resource, while activities are defined in *ServiceRequest*, *MedicationRequest*, and *Appointment* resources. *ServiceRequest* is used for self-measurements of vital signs and lifestyle recommendations. The medications that the patient will start/stop using or the dosage changes in already used medications are specified in *MedicationRequest*. *Appointment* is used for setting a follow-up appointment. However, considering the fact that patients living with dementia often battle memory problems and have difficulty in performing daily activities due to cognitive decline, it would not be sufficient to list the activities to be done in the care plan alone. Therefore, several interoperability profiles are defined with *ServiceRequest* resource, in which the exact time or period in a day should be specified in one of the "occurencePeriod" or "occurenceTiming" elements. In addition, these patients need to take a lot of medications during the day due to their multimorbidity, but it is not practical to list these one by one in the care plan. Instead, it is more practical to divide the day into parts and ask patients to take their medication with the pill box method, e.g., "take your medication before breakfast". Therefore, in the *CarePlan* profile, the *MedicationRequest*s are encapsulated in *ServiceRequest* objects and shown in the care plan as medication intake activity. Furthermore, to aid patients with dementia for remembering daily activities outside the care plan such as meeting with a friend, a custom task interoperability profile is defined with *ServiceRequest* resource.

In the management of multimorbidity in patients living with dementia, it is also important to follow patient's adherence to the care plan activities. In this regard, a mobile application called PEP is provided both to the patients and their informal caregivers. In PEP, patients display the daily activities they need to perform in a day with time and other useful information that can help them to perform corresponding activity. Then, either the patients or their informal caregivers provide feedback on whether the activities are performed or not. These feedbacks are stored in an *Observation* FHIR resource based on the activity feedback profile. The CAREPATH interoperability profiles are presented and explained in detail in the next section.

3. Results

Figure 1 shows the overview of the FHIR resources and references for CAREPATH interoperability profiles. In the figure, only the extensions to the original FHIR resources, cardinality updates and restrictions on the terminology systems and values are presented. Other elements in a resource can still be used as defined in its FHIR documentation.

As shown in the figure, at the heart of the CAREPATH interoperability profiles is the *CarePlan* profile. A care plan is created by a team of caregivers for a specific patient. For these, *CareTeam* and *Patient* FHIR resources are used without any modification. The "intent" element in the *CarePlan* is always set as "plan" and goals are stored in *Goal*

resource as it is defined in FHIR. For *Conditions* and *MedicationStatements*, ICD-10 and ATC international coding systems are used, respectively. In *Observation*, LOINC is used for laboratory results, while SNOMED-CT is used for lifestyle parameters.
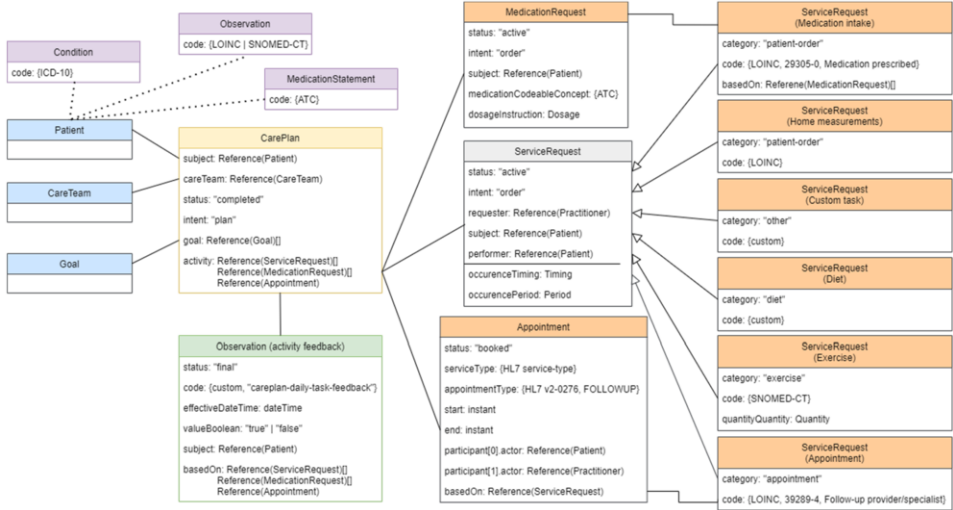

Figure 1. Overview of the FHIR resources and references for CAREPATH interoperability profiles.

For the *ServiceRequest* activities in the care plan, 6 profiles are defined. These profiles extend the base *ServiceRequest* profile shown in grey in the figure. The most important customization in the base profile is that at least one of the "occurenceTiming" and "occurencePeriod" elements are mandatory. If the "occurenceTiming" is used, then the "frequency", "period", "periodUnit", and "when" elements in it must be provided. The medication intake *ServiceRequest* profile is used for indicating when a box of medication is to be taken in a day as described before. The LOINC code of "29305-0" is used and the list of medications are referenced in "code" and "basedOn" elements, respectively. The details of medications are provided in *MedicationRequest* with ATC code and dosage information as defined in *MedicationRequest* profile. The home measurement *ServiceRequest* profile requires the use of a LOINC code in the "code" field (such as "29463-7" for body weight), whereas the custom task and diet *ServiceRequest* profiles requires the use of some custom codes, because there is no standard code system available for custom tasks or dietary recommendations. In the exercise *ServiceRequest* profile, SNOMED-CT code system is used for the "code" element, and information like duration and repetition are provided in "quantityQuantity". In the care plan, follow-up appointments are stored in *Appointment* FHIR resource as shown in the figure, but to show these appointments in the daily activities of patients and collect feedback about them, an appointment *ServiceRequest* profile is defined and linked to corresponding *Appointment* as in the case of medications. In this profile, the LOINC code of "39289-4" is used to indicate follow-up appointment. The types of activities in *ServiceRequest* are specific in the "category" element, such as "patient-order", "diet" and "exercise". Finally, for the feedbacks of the patients and/or their informal caregivers on performance of daily activities, activity feedback *Observation* profile is defined, where the "valueBoolean" is used to indicate whether task is performed and "basedOn" is used to refer corresponding activity.

4. Discussion and Conclusion

In this paper, the implementation of HL7 FHIR-based interoperability profiles for effective management of personalized care plans in multimorbid patients living with mild dementia is presented. We chose to base our interoperability architecture on the HL7 FHIR, a widely accepted international standard in healthcare domain, to increase its future exploitation in integration with existing health IT systems at care sites. We will conduct a Technical Validation and Usability (TVU) study and Clinical Investigation (CI) at four different pilot sites in Europe to demonstrate the effectiveness of the CAREPATH interoperability profiles presented in this paper in real life care settings.

Acknowledgements

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