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The Social Platform: Profiling FHIR to Support Community-Dwelling Older Adults

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Abstract
The care networks of community-dwelling older adults require cooperation between different actors, including health and social caregivers, assistant providers, care receivers, and their informal caregivers (e.g. relatives or friends), across time, space, and organizational boundaries. In this context, the project Social Cooperation for Integrated Assisted Living (SOCIAL) aims at the development of a platform of services to support the care networks of community-dwelling older adults. Therefore, the study reported in this article assess the adequacy of the Fast Healthcare Interoperability Resources (FHIR) to guarantee the interoperability of the relevant information related to the assisted persons of the SOCIAL platform, which are mainly older adults that need care and assistance services.

Keywords Older adults · eHealth · Residential care · Integrated care · FHIR

Introduction

When dealing with older adults, health conditions can be influenced by a wide range of factors which may hinder individual's autonomy and independence [1]. For instance, being unable to perform daily activities or daily instrumental activities usually implies that the individual, who in some circumstances lives alone, is on the verge of dependency and needs help and support [1]. Consequently, care networks for community-dwelling older adults (i.e. care networks

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involving formal caregivers, informal caregivers and assistance providers namely to support domestic activities, personal care, nursing care, administrative tasks or transporting) become increasingly important [2].

To date, usually there are no mechanisms which register, provide access to and share the information required to support the care networks for community-dwelling older adults or, whenever they are in place, they are substantially inferior to those available for healthcare provision. This is also the case with the procedures associated with these care networks, which are substantially less structured than the equivalent healthcare procedures. Moreover, the significant technological differences between the health and social care sectors hinder social care and assistance provider's access to essential information [3]. In sum, bridging the information gap existing in the social sector is both a technological and an organizational challenge.

The Social Cooperation for Integrated Assisted Living (SOCIAL) services platform [4] aims to overcome the so-called health and social care divide [3] by providing information services designed to support the care and assistance provided to community-dwelling older adults. The Fast Healthcare Interoperability Resources (FHIR) of the Health Level Seven (HL7) was thought out to ensure both internal and external interoperability.

In this context, the objective of the research study reported in this article was to assess the adequacy of the FHIR resources to persist the required information entities involved in the social support provided to the assisted persons of the SOCIAL platform, who are mainly older adults in need of care and assistance.

In addition to this introductory section, the present article comprises four more sections: Background, Methods, Results, and Conclusion.

Background

The use of digital applications to mediate the cooperation between the different stakeholders providing a functional healthcare centred on the care receiver serves various purposes. In particular, advances in sensing technology has enabled the development of mobile and wearable personal health devices (PHD), which continuously monitor physiological parameters in out-hospital conditions (e.g. measurement of blood pressure, body temperature, blood glucose level, heart sound, heart rate, respiration, blood oxygen saturation or perspiration) [5, 6]. Furthermore, the monitoring of physiological parameters as well as the monitoring of behaviours and daily activities might help in the process of automating assistance and help prevent the worsening of diseases or accidents as well as improve reaction to emergencies. In this respect, ehealth applications might improve access to care, particularly when time is vital (e.g. in stroke or acute trauma). Furthermore, as falls are one of the main causes of morbidity and mortality in older adults, fall detection is another ehealth application area [5, 7].

The design and development of new applications is an opportunity to promote the evolution from an organization-centred care (i.e. process-controlled or shared care) to a paradigm focused on the needs of the care receivers [8]. From their perspective, one needs integrated care approaches which are not only designed for medical purposes, but also focus on a range of activities which are essential for the maintenance of their quality of life. Therefore, the provision of integrated care and assistance services that support the individual's normal everyday life, as is the case of the care networks for community-dwelling older adults, requires the efficient coordination of professional, organizational and jurisdictional service providers [9].

Due to the difference in nature of the various services, several factors (e.g. organizational or cultural factors) hamper the integrated work between different care and assistance services [9, 10], thus leading to what scientific literature calls the health and social care divide [3]. While healthcare is usually centralized in health facilities for several reasons, social care is provided in the individual's home or in nearby facilities. Indeed, in many countries, local authorities are those responsible for the management of social care [11, 12]. Furthermore, the provision of social care and assistance is fragmented due to its nature and special attention must be paid to informal caregivers.

Considering the availability and diversity of ehealth applications, a considerable effort is being made to promote their integration in interoperable platforms. Therefore, several platforms address both patients and healthcare provider's needs [13–15]. Nevertheless, existing open platforms [16], such as the Substitutable Medical Applications and the Reusable Technologies (SMART) [17] aiming to provide the agile development of new applications, target electronic health records (EHR) and, therefore, do not take into consideration the specificities of the information required for the provision of social care (i.e. electronic social records - ESR [3]).

As many information systems created to support social care, have been designed to merely serve bureaucratic interests rather than support the professional practice or improve the services provided to the public [18], information management between health and social care still relies heavily on paper or word of mouth, and current healthcare standards and terminologies do not yet ensure the interoperability of the information regarding social care and the provision of assistance [11]. In fact, the main focus has been on the standardization of clinical content models [11]. Thus, despite the amount of scientific

literature reporting interoperability between information systems that support clinical practice, there is little research reporting interoperability between healthcare and social care records: interoperability standards have been taken into consideration by the Old@Home project [19, 20], which developed a virtual health record to provide integrated views of information stored in different health information systems [19], and shared care plans to support nurses and social workers in the provision of home care services [20]. These shared care plans conform to the European Standard EN 13940–1 for continuity of care, and the Old@Home promoters showed interest in evaluating the HL7 standards as a viable alternative [20].

In this respect, FHIR developed by HL7 is an excellent standard for intermediate communication in terms of the complete communication chain ranging from the PHD to complex ehealth infrastructures such as hospital information systems or EHR. This is present in the initiatives of the Personal Connected Health Alliance (PCHA) [21] and the Integrating the Healthcare Enterprises (IHE). Both are making considerable efforts to include FHIR in their specifications for data exchange in healthcare information systems. PCHA uses FHIR to share PHD data from mobile devices such as smartphones, tablets or laptops with telehealth service centres. From there, based on IHE specifications and initiatives, FHIR can be used with the XDSonFHIR option shown in the Mobile Access to Health Documents (MHD) integration profile [22]. This enables the seamless integration of FHIR resources into a Cross Enterprise Document Sharing (XDS)-based EHR using HL7 Clinical Document Architecture (CDA) for the sharing of clinical documents.

Methods

The SOCIAL platform has a set of structural components which enable the development of innovative information services to empower community-dwelling older adults and their caregivers. Considering the architecture that has been implemented, the SOCIAL platform comprises three layers [4]: application, business and data.

The application layer allows for the integration of a broad range of applications. The business layer is responsible for all the logic underlying the interactions between the different applications and the data persisted in the platform (e.g. authorization, authentication, auditing or complex event processing for the management of PHD) and presents a set of interfaces that enable communication with the applications using established standards: i) FHIR interface for the exchange of interoperable information about the assisted persons; ii) Representational State Transfer (REST) interface for requests concerning user authentication, secondary use of information, or workflow management; and iii) Advanced Message Queuing Protocol (AMQP) interface for asynchronous processing of messages generated by PHD. Finally, the data layer ensures the persistence of all information processed by the remaining layers.

For the purpose of the study reported in the present article, to evaluate the adequacy of the FHIR resources to persist social care information, one took into consideration the applications developed to support the services provided by local authorities with regard to the management of assistance requests or the management of different types of activities aiming to promote the quality of life of older adults living independently (e.g. physical activity such as swimming or trekking, or sociocultural activities, such as theatre, dance, or trips to religious sites, among others).

Figure 1 illustrates the sequence of methods used. Following a review of the literature, a comprehensive specification process was conducted. Initial meetings were held in eleven institutions and relevant people (i.e. formal careers and experts in social care and assistance services) were identified with the help of the involved formal care organizations, namely city councils, parish councils, and social care institutions.

The interviews were conducted face-to-face using a semi-structured interview guide. Once all the data from the interviews were gathered, personas and scenarios were developed to highlight [23]: i) individual's functioning, health condition, personal factors, daily routines, activities and participation; ii) problems to be solved; and iii) a wide range of requirements, namely information, interaction or quality requirements, among others. Once the personas and scenarios were outlined, they were validated by a focus group involving formal careers and experts in social care and assistance services, different from the ones who had participated in the interviews.

Although the data collected during the interviews and from the focus group were not sensitive, the principles underlying the Helsinki Declaration were taken into consideration [24]: all the necessary authorizations were requested and all participants in the interviews and focus group signed an informed consent prior to data collection.

Afterwards, the defined personas and scenarios [25] were the basis for the definition of the assisted person's information model and an analysis was performed to assess the adequacy of the FHIR resources to persist the identified information entities.

Additionally, a technical proof of concept was conducted. It included the implementation of an example, the Assessment entity (e.g. Observation resource) to validate the use of the original FHIR specification (i.e. STU 4.0.0) in this work. Furthermore, the Activity entity (i.e. a FHIR extension) was created, which included the schema definition, its integration into FHIR specification and an implementation example. Regarding technical validation, the official FHIR validator

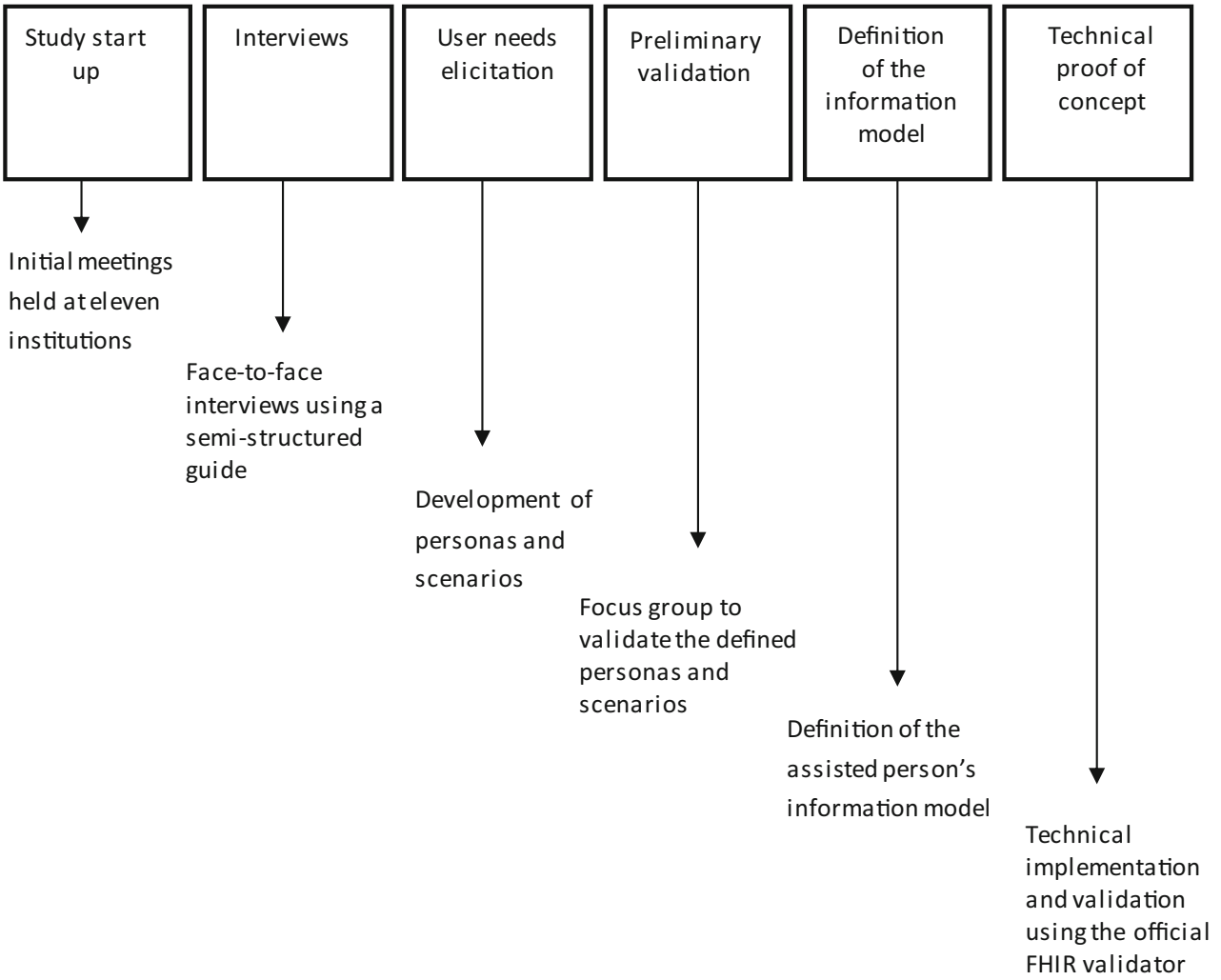

Fig. 1 Methods

was used to test compliance of the two entities to the FHIR specification.

Finally, a pilot will start in the first semester of 2019 and will take place for several months. Observations and questionnaires (e.g. Unified Theory of Acceptance and Use of Technology [26, 27]) will be used to assess the suitability and perceived usefulness of the developed applications, their adjustment to the needs and duties of the care networks for community-dwelling older adults, and their ability to be used in everyday activities to manage the information about care receivers.

Results

In the context of the SOCIAL project, assisted persons might be active older adults who need the provision of periodic assistance services to extremely vulnerable individuals, with a low level of autonomy and independence:

- The fulfilment of autonomous and independent older adult's needs without regular contact with formal caregivers can be achieved by using applications with self-management mechanisms or other mechanisms which promote the participation in active aging programs.
- For extremely vulnerable older adults, with a low level of autonomy and independence, and who have regular contact with formal providers of one or more organizations, there is a need for a wide range of functions, such as the sharing of relevant information between different caregivers or of the data gathered with monitoring devices (i.e. PHD).

As an example, Table 1 presents the description of an active elderly persona and the respective scenario [25]. In this description, the individual's functioning, health condition, personal factors, daily routines, activities and participation, problems to be solved and a range of requirements (e.g. functional requirements, data requirements, interaction requirements or business requirements) were highlighted.

Table 1 Active elderly persona and scenario

Active elderly – Carlos Mendes	
Persona	Name: Carlos Mendes [Personal factor].
	Age: 66 years old [Personal factor].
	Carlos lives in Ílhavo with his wife Sofia. He's a retired bank clerk [Personal factor].
	Carlos shows good technological literacy and knows very well how to work with electronic devices [Personal factor], especially his smartphone, which he uses to read digital newspapers and play Sudoku [Daily routine].
	He has heart problems and his health condition requires regular monitoring and daily medication [Health condition], which Carlos controls himself. He has weekly surveillance appointments in his local healthcare centre [Daily routine].
	Due to his health condition, Carlos has the habit of going for long walks every morning. Sometimes, Sofia goes with him [Daily routine].
	At weekends, whenever it is possible, he goes out for a bike ride with his son [Participation type].
	Maria, Carlos's daughter, is living in Rio de Janeiro with her husband and her two children. Carlos normally calls his daughter, but the phone calls are very expensive [Participation type].
	Carlos would like to buy equipment which eases contact with his daughter and he heard that there are some applications which facilitate the control of medication and the monitoring of physical activities [Activity type].
Scenario	During his last walk, Carlos fell [Problem scenario] and hurt his arm [Interaction requirement]. It wasn't a big problem, but he was alone and now his family is concerned about his daily routine [Problem scenario]. The family doctor told him to write a diary with his heart rate and every time he goes for a walk or cycling he has to monitor his heart rate and physical activity (distance and velocity) [Functional requirement]. Carlos doesn't want to stop only because his arm is in pain and he prefers to use an application which automatically monitors these signals [Data and functional requirement]. He also wants something which will help keep his family calm while he is doing these activities and enables him to send the results to his doctor [Functional requirement].
	His daughter Maria was very concerned about the accident, especially because she is so far away and with the time zone difference it is difficult to talk with her father [Problem scenario]. Carlos would like an application to share photographs and videos with Maria and his grandchildren [Functional requirement], but something cheaper than phone calls [Business requirement].
	Due to his accident, Carlos has some limitations in moving his arm [Problem scenario]. Recently he installed an application in his smartphone, but he would prefer if the interaction could be done through voice [Interaction requirement].

The assisted person's information record, in addition to the demographic data, should contain different types of assessment: i) various types of information, including, for instance, the description of the support networks or requests for assistance (i.e. the possibility for the caregiver or the assisted person to create attendance or occurrence requests for specific needs or to report an anomalous situation); ii) evaluations using specific assessment instruments; iii) PHD data; iv) an individual plan with personal tasks and tasks that involve care and assistance providers of one or more organizations; and v) additional information such as Programs and Activities. In this respect, Programs are initiatives promoted by local and regional organizations with the aim of improving the quality of life of people in a given area allowing them to participate in different types of Activities (e.g. physical activity or sociocultural activities).

The first step to profile FHIR to the assisted person's information model was to identify, for every entity of the information model, the most suitable FHIR resource. Then, extensions were defined to address aspects not covered by the standard FHIR resources.

Figure 2 presents a simplified model of information entities related to the assisted person. On the top right corner the legend clarifies that the fire-symbol identifies the original FHIR entities involved and the fire-plus-symbol indicates the FHIR extensions developed.

According to the research done, some of the entities of the assisted person's information model can be directly mapped to FHIR resources:

- Assisted Person - Patient resource: demographics and other administrative information about an individual receiving care or assistance services.
- Care or assistance provider - Practitioner resource: a person who is directly or indirectly involved in the provision of care and assistance.
- Role - Practitioner Role resource: specific set of roles, locations, specialties or services that a care or assistance provider may perform at an organization for a certain period of time.
- Organization - Organization resource: a formally or informally recognized group of people or organizations created

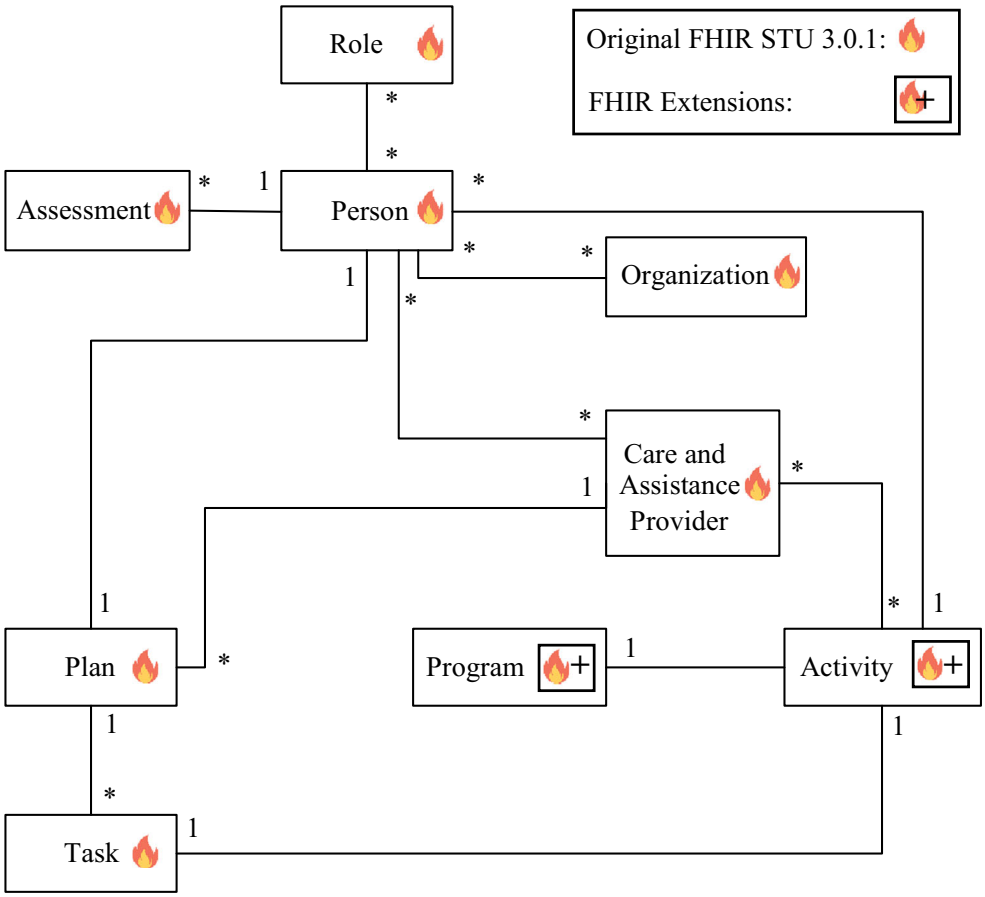

Fig. 2 Assisted person's information model

for the purpose of achieving some form of collective action.

- Plans - Care Plan resource: description of how one or more care or assistance providers intend to provide care to a particular assisted person, group or community for a given period of time, possibly in need of care for a specific condition or a set of conditions.
- Tasks - Task resource: a task to be performed.

Furthermore, different types of assessment can be covered via the development of the following FHIR resources:

- Questionnaire Response resource: a structured set of questions and their answers. The questions are organised and grouped into coherent subsets.
- Observation resource: measurements and simple assertions made about an assisted person, device or other subject.

Observation enables the collection of different types of information (e.g. the description of the support networks or requests for assistance), while the Questionnaire Response resource enables the persistence of data resulting from the application of a wide range of assessment instruments.

By using FHIR it is possible to organize the data shared by home monitoring devices such as blood pressure monitors or puls oximeters in Observations. Observations can be used to monitor progress or to determine baselines and patterns.

An Observation record cannot directly contain multiple values, which might lead to a large number of individual resource values. A similar issue arises when several assessment instruments (e.g. several Questionnaire Responses) need to be aggregated or summarized. However, FHIR provides resources such as Bundle or List to help organize the uploading of multiple resources.

Since no FHIR resources were found to map Programs and Activities, two extensions were developed for:

- Program (extension of Care Plan resource) to persist initiatives promoted by local and regional institutions with the aim of improving the quality of life of people in a given area. Each program is made up of a set of activities that are usually entertaining and intend to promote healthy lifestyles (e.g. physical activity or sociocultural activities). The Program can be built to run throughout a predefined period of time, with different Activities.
- Activity (extension of Task resource): Activities aiming to promote and improve the population's quality of life, such as physical activity or sociocultural activities.

```
1  <Patient xmlns="http://hl7.org/fhir">
2      <id value="2"/>
3      <extension url="http://healthyio.technikum-wien.at/oid/sa-extension">
4       <extension url="activityId">
5        <valueIdentifier>
6         <value value="1.2.40.0.29.99.99.1"/>
7        </valueIdentifier>
8       </extension>
9       <extension url="actName">
10       <valueString value="Annual trip to Fatima (Portugal)"/>
11      </extension>
12      <extension url="actAims">
13       <valueString value="Promote prayer, leisure and socializing moments"/>
14      </extension>
15      <extension url="actLocation">
16       <valueReference>
17         <reference value="http://www.hl7.org/fhir/location-example.xml"/>
18       </valueReference>
19      </extension>
20      <extension url="actIcon">
21       <valueReference>
22         <reference value="https://www.freepik.com/free-icon/man-practicing-exercise_721379.htm"/>
23       </valueReference>
24      </extension>
25      <extension url="actParticipantLimit">
26       <valueInteger value="25"/>
27      </extension>
```

Fig. 3 Activity entity – FHIR extension implementation example

Finally, to codify the different data values, a code set was especially defined to codify attributes of the assisted person which cannot be classified by existing terminologies, such as International Classification of Diseases.

The following link provides access to the resulting development package of the technical proof of concept: http://healthyio.technikum-wien.at/oid/SA_FHIR_DevPack_v0.2.rar. It includes the official FHIR Validator and the adapted STU 4.0.0 specification of the Activity entity, an example of a FHIR extension, which is linked to the Patient resource. This example includes the schema definition of the Activity entity, named sa-extension. The example also shows an inline definition of an instantiation of a Patient resource to prove its connection with a FHIR resource. Furthermore, another example was included, the Assessment entity, in the form of an Observation resource to store heart rate measurement data measured with a fingertip puls-oximeter (Nonin Onyx Vantage 9590).

Figure 3 shows a snippet of the first lines of the Activity FHIR extension example in XML format (included in the development package). The first two lines show the start of the Patient resource and the fictive patient's identifier. In line 3 the Activity FHIR inline definition starts, showing a link to the schema definition developed and integrated in the FHIR specification. The Activity is identified by a test Object Identifier (OID according to ISO/IEC 9834–1) and has a name which is shown in the sub-extension element at line 9–11. This shows that it is about an annual trip to Fátima, a religious site in Portugal. In the lines 12–14 the objectives of the Activity are shown. Subsequently an externally defined FHIR location resource is referenced, which shows location information (in this prototype an existing test location resource was linked). Finally, the example shows the integration of an icon or image to describe the theme of the Activity (line 20–24) and the maximum number of participants, limited to 25 individuals (line 25–27). However, the complete examples and data fields can be downloaded from the provided link.

Both examples were successfully validated with the included a FHIR Validator and therefore it can be assumed that technical proof of concept was successfully shown and FHIR is a valuable standard for the assisted person's information model.

Conclusion

Given the need to guarantee the interoperability of the information to support the care and assistance provided to community-dwelling older adults, the study referenced in this article aimed to assess the adequacy of FHIR resources to this application domain. In conclusion, the study shows that several entities of the assisted person's information model can be directly mapped to standard FHIR resources, which are in line with other studies related to the profiling of FHIR to specific application domains (e.g. [28]). However, specific entities related to the promotion of active and healthy lifestyles (i.e. Programs and Activities) do need the definition of extensions to the standard FHIR resources. Moreover, two infrastructure resources were used: Bundle and List, respectively, to gather a collection of resources into a single example, and to provide a set of information summarized from a

list of other resources. Therefore, FHIR might promote EHR and ESR interoperability, which is an essential requirement of the care integration.

Nevertheless, only the first steps in the direction of a practical application were taken. Presently, there are ongoing efforts to validate and achieve the complete implementation of the created profile in real cases, which will be evaluated in a real pilot study, scheduled to start during the first semester of 2019.

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Compliance with ethical standards All procedures performed in this study involving human participants (i.e. a set of participants were interviewed, and a focus group was created) were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments. All the necessary authorizations were obtained, the study had the approval of an Ethical Committee, and all participants signed an informed consent document prior to data collection.

Conflict of interests All the authors declare that they have no conflict of interest.

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