# FHIRForm: An Open-Source Framework for the Management of Electronic Forms in Healthcare

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**Abstract.** Electronic Forms (E-Forms) for data capture are vital for most health information systems in public health and clinical research. Standardized electronic forms ensure accurate data collection, consistent form rendering, easy maintainability, and interoperability. Adopting an innovation research method we explore the challenges of standardized data capture in healthcare and offer a pragmatic solution. We appraise existing standards and software to propose the list of requirements for an ideal E-form framework. Our proposed solution leverages FHIR specification and existing open-source software tools. We discuss how our open-source solution can be extended collaboratively and discuss its value using InterRAI instruments as examples.

**Keywords.** E-Form, FHIR, InterRAI

## 1. Introduction

Electronic forms (hereafter E-Forms) remain the standard method to acquire user entered data in health information systems (HIS). E-Forms are vital for clinical research (case report forms) [1], order sets for patient management [2] and public health [3]. It is common for healthcare organizations to realize after expensive HIS installations that a comprehensive system for end-to-end data management from data collection to analytics is challenging to implement. An end-to-end form-based data capture and analytics is important for public health and clinical research organizations that have unique data management requirements. The standardization of the content, structure, and workflow enable effective sharing of E-Form assets between these organizations in a system independent manner.

There is a growing emphasis on deriving knowledge from patient data that requires the application of knowledge management principles and frameworks. In this paper, we apply the innovation action research method [4] to the problem of structured health data

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capture. First, we review some of the commonly used standards and frameworks in this domain. Next, we propose a list of requirements for an ideal E-Form framework.

This is followed by a description of a novel framework and its instantiation using existing standards and open-source tools. Then we describe a potential value of our solution using InterRAI [5] as an example. Finally, we briefly evaluate our solution as a software artifact.

## 2. Existing standards and solutions

There are several standards for semantic data collection in healthcare. The ISO 13606 standard is a two-level modelling approach for semantic interoperability [6]. It segregates information level (represented by the reference model) from the knowledge level, (represented by the archetype model) [7]. The advantages of ISO 13606 include a formal definition of clinical data structure, simplified terminologies and scalability [8]. The openEHR specification [9] is an extension of ISO 13606 with a focus on content. In addition to the reference model and the archetype formalism defined as restrictions on the reference model shared with ISO 13606, openEHR defines an archetype query language, service models, and APIs.

The Multilevel Healthcare Information Modeling (MLHIM) [10] Specifications extends on the multi-level modelling approach introduced by openEHR. In MLHIM, Reference and Data Models are represented in the traditional XML Schema Definition format. Since data models allow the creation of data instances that need to be valid in perpetuity, they are immutable and unique, ensuring data validity of longitudinal records. MLHIM uses RDF within the XML schema in a unique way to define the semantics that provides semantic interoperability [11].

Next, we describe existing software solutions for semantic data capture and manipulation.

The Clinical Knowledge Manager (CKM) is the repository management system for openEHR [12]. It is a Web 2.0 tool that supports the online collaboration of domain experts to create and publish archetypes. The ADL Workbench is a tool for manipulating the archetypes and templates written in the Archetype Definition Language (ADL). It can reference any model such as openEHR and ISO 13606 [13].

Research Electronic Data Capture (REDCap) is a web application for building and managing online surveys and databases mostly for research studies [14]. REDCap supports data entry, data validation and export/import operations, and has a shared repository of data collection forms. Open Data Kit (ODK) is an open-source solution for data collection using mobile platforms. It is designed to be useful in resource-constrained areas with poor connectivity, by saving submissions locally before syncing them with the server [15].

Existing standards focus on structure, content and semantics but not on form presentation and rendering. The lack of a suitable standard made most health information systems rely on proprietary standards for form management. In the next section, we discuss the list of requirements that we consider important for an ideal E-Form framework based on our experience and a review of the above standards.

## 3. Characteristics of an ideal E-Form framework

An ideal E-Form framework should have the following features:

1. A centralized repository is needed for hosting E-Forms. The vendor systemsshould retrieve the forms in real-time from the repository. This would allow Eform maintainers to update forms and push the changes efficiently to downstream systems.
2. The E-Forms should ensure semantic interoperability so that E-Forms can beshared across health service providers (HSP) seamlessly. This will also enhance cooperation between analytic teams.
3. Form elements should be maintained independently and shared across forms forconsistency and ease of maintenance.
4. The forms should be rendered consistently with enough information incorporatedin the E-Form to facilitate accurate rendering.
5. The form submissions should be standardized so that the information can be submitted to various systems simultaneously. This would ensure accurate data collection at various levels.
6. The E-Forms should support procedural logic so that the rendering system canperform calculations and implement hide/show of elements.
7. The E-Forms should ensure patient safety.
8. The rendering engine should be generic enough to be easily incorporated into anyHIS.

In the next section, we describe how we used existing standards and open-source tools to propose a software instantiation.

## 4. Approach

We adopted Fast Healthcare Interoperability Resources (FHIR) as the standard for representing form structure and content. FHIR resources were chosen based on their support for 80% of common use cases. Extensions can be used to bridge the gap for the remaining 20%. FHIR has been successfully used for a variety of use cases outside of conventional interoperability such as exchange of clinical study data [16].

We propose a software framework for E-Form management, using FHIR specification and open-source tools for editing, serving and rendering E-Forms. *FHIRForm* is an FHIR Questionnaire including extensions for managing form related procedural logic. The E-Form components are independently managed as FHIR DataElements that are injected into the Questionnaire. The FHIRForm framework (Figure 1) is a software stack for managing E-Form workflow with the following components.

1. A FHIR server.
2. A FHIR resource editor.
3. A FHIR client that can render the FHIR Questionnaire as a web form.
4. FHIR Extensions and other resources.

The FHIR server is a Spring-Boot application based on University Health Network's HAPI-FHIR Server, available as open-source[17]. The FHIR resource editor (FRED)

[18] is an open source web application that enables users to edit JSON FHIR resources and FHIR bundles. We have improvised and integrated it into the FHIR server so that FRED is served by the same server instance and can directly edit FHIR resources on the
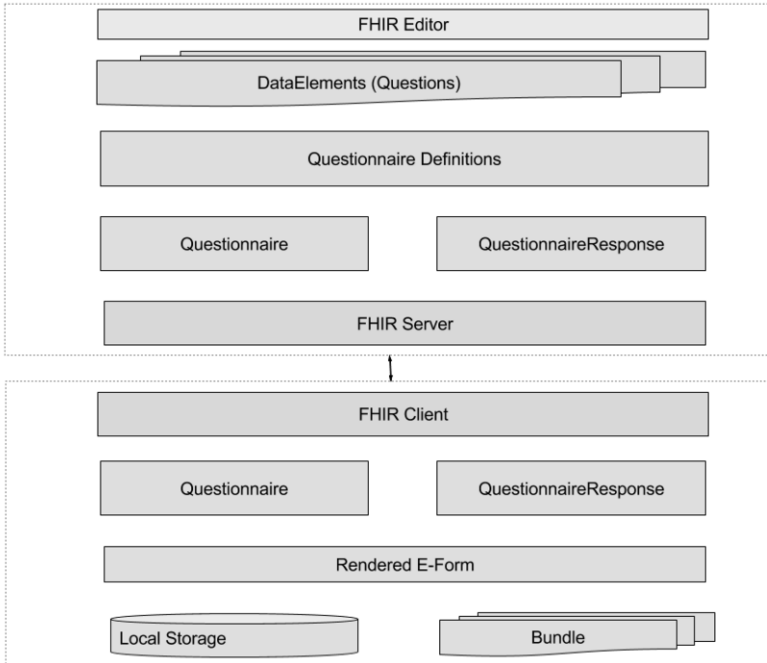


Figure 1. FHIRForm Framework

server. The FHIR client application is a generic rendering engine that can be incorporated into other web frameworks [19].

The FHIRForm framework is open-source for collaborative development [20]. In the next section, we describe a typical use case of our FHIRForm framework.

## 5. Use case

InterRAI [5] is an international collaboration of researchers that strives to standardize the collection and interpretation of high-quality health data. In addition to data collection forms, InterRAI instruments have outcome measures, assessment protocols, casemix algorithms, and quality indicators. Though InterRAI does not propose a well-defined content representation and presentation standard, its forms have a consistent organization. Each data point is defined separately and incorporated into semantic blocks that are shared across forms. InterRAI tests and certifies vendor implementations of data collection software. Unfortunately, its overlap with other assessment and registration forms such as patient demographic data leads to double data entry [21].

The FHIRForm framework would enable InterRAI to improve the maintainability of their instruments and to make the testing of tools more efficient. The individual items in each instrument could be maintained as FHIR DataElements that can be injected into an E-Form at the time of the request. The paper forms could be discontinued, and the vendors with credentials could access the instruments from the server. The data collected

can be submitted to any FHIR compliant system as a QuestionnaireResponse resource. InterRAI has scales and algorithms associated with its instruments that require specific handling [22]. Customized FHIR extensions may be necessary to handle the specialized rendering of scales and algorithms.

## 6. Discussion

End to end solutions for E-Form management do not exist, leading to different standards and proprietary frameworks that cause interoperability problems. Data collection forms in healthcare may require embedded procedural logic [23] for functions such as hiding, disabling or showing parts of a form based on the response received for a previous field, calculating scores based on responses, and displaying alerts. The XML and JSON used in a FHIR resource can be used to define procedural logics with extensions. The two commonly used procedural logic used in healthcare forms are the *IF..THEN..ELSE* logic. This requires logical gates such as *OR* and *AND* and operators such as *'Equals'*, *'Lesser than'* and *'Greater than'* as described by Bethke et al [24].

The transformation of data-centric decision making to knowledge-centric decision making requires a common data model (CDM) for data aggregation. We are currently working towards adopting The Observational Medical Outcomes Partnership (OMOP) CDM for data persistence. The OMOP CDM is supported by observational health data sciences and informatics (OHDSI) with a set of data visualization and analytics tools [25].

Finally, we use Hevner's design science research guidelines [26] for the preliminary assessment of the software artifact that we created. The outcome of our research is a prototype software stack for E-Form management (design as an artifact) to mitigate current inefficiencies (problem relevance). Design evaluation is based on structural and functional testing of our software according to a typical use case. Our predominant research contributions are requirements analysis of the ideal E-Form framework and the linking of existing open-source software into a framework. Our design involved searching the existing standards and software systems to ensure research rigor. Communication of research is important in Hevner's guidelines and innovation action research [4]. Our results are relevant to both clinical-oriented and technology-oriented audiences.

We propose a pragmatic framework for the end to end management of electronic forms in healthcare. The framework leverages existing open-source software and standards to realize a cost-effective and efficient solution to create, maintain and share forms. Data collected using this framework ensures semantic aggregation and sharing at various levels. The work on the rendering engine is still in progress, and we seek help and guidance on this topic from the open-source community.

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