FHIR for Research Capacity Building – IDeA-CTR Site Survey

Background

NIH is interested in understanding how IDeA-CTR sites like yours might be using Fast Healthcare Interoperability Resources (FHIR, pronounced "fire") for research, and how NIH can assist sites in increasing sites' capacity to use it.

FHIR is a widely used standard that enables portability and accessibility of clinical data across institutions and applications. FHIR is designed to enable health data, including clinical and administrative data, to be quickly and efficiently exchanged.

FHIR may be useful across many types of research involving clinical data, including research that requires direct/real time access to clinical data stored in EHRs, spans multiple data sources that can benefit from a common FHIR data model and interface, or integrates directly with an EHR (e.g., clinical decision support; clinical trial matching/registration).

More information on FHIR: https://bit.ly/2021-fhir-fact-sheet.

The purpose of this survey is to help our team understand how your CTR has used FHIR previously, especially for research, and what kinds of FHIR/research-related resources and tools your site would benefit from.

Section 1: Current use of FHIR and future plans

1.a) Are you currently using FHIR for research? If so, please describe.

(Replace with your CTR's response)

1.b) Is your CTR currently considering FHIR for any new research uses, and if so, can you briefly describe these use cases?

(Replace with your CTR's response)

1.c) What is the most significant obstacle for your CTR to utilize FHIR for research? For example: access to FHIR APIs, difficulty in approval process, staff knowledge of FHIR, EHR capabilities, etc.

(Replace with your CTR's response)

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1.d) Do you have any other initiatives using FHIR that have built technology, infrastructure, or staff skills that may be applicable to research? If so, please describe.

(Replace with your CTR's response)

Section 2: EHRs and common data models

2.a) What EHR vendor(s) are used by the sites in your CTR (please list each hospital/health system, and the corresponding EHR)?

Health system/hospital	EHR vendor (e.g., Cerner, Epic, etc.)
(Please fill with your response, and add rows as necessary…)	

2.b) How do researchers in your CTR currently access **deidentified** clinical data, and what is the typical deidentification process?

E.g., do you have an existing common data model, do one-off data pulls, use a data lake provided by your EHR vendor, and/or etc.?

(Replace with your CTR's response)

2.c) How do researchers in your CTR currently access **identified** clinical data?

E.g., do you have an existing common data model, do one-off data pulls, use a data lake provided by your EHR vendor, and/or etc.?

(Replace with your CTR's response)

2.d) Do you use any common data models that are not mentioned in (2.b) or (2.c)?

(Replace with your CTR's response)

Section 3: Use cases

3.a) We are interested in assessing interest in training around FHIR for research use cases we have identified so far, and in identifying any additional use cases of interest to your CTR. To this end, please fill in the following table for your CTR:

Use case	Which role(s) may be interested in this use case? (e.g., PIs, core facility staff, clinical researchers, graduate students, etc.)	Rough number of people in each role at your CTR (e.g., 5, 10, 20, 50, etc.)
Introductory overview on FHIR and its potential uses for research	*Example:* *Graduate students* *Early career investigators*	*50* *10*
Extracting data from EHRs, or other FHIR-enabled systems		
Building cohorts consisting of patients among multiple medical centers		
Create patient-facing FHIR applications for communication or education		
Practice-based research with practitioners (e.g., clinical decision support)		
Access particular parts of patients' EHRs records		
Convert FHIR resources into tabular data for analysis in R or Python		
…add rows for any additional use cases of interest for your CTR…		

Section 4: Organizational structure

4.a) Who in your organization can describe existing data flows related research? (i.e., how data gets from EHRs into the hands of researchers)
(Replace with your CTR's response)

4.b) Who else should we talk to at your CTR to learn more about FHIR for research needs or existing professional development efforts related to FHIR?
(Replace with your CTR's response)

4.c) Are there people/groups at your CTR who have hands-on experience with using FHIR in a research context, and would be willing to provide additional input to the MITRE team over the coming months? If so, please list their contact information.
(Replace with your CTR's response)

4.d) What else do you want us to know about your CTR?
(Replace with your CTR's response)

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